

Chapter 10

HEALTH & SOCIAL WELFARE

Themes in this chapter

- Interpretation and translation
- Training and information resources
- Medical/diagnostic/assessment tools
- Supporting Black, Minority Ethnic and Foreign National Staff
- Working with other services
- Partnership working between race equality and health services
- Social welfare

Listening to Health Staff

In this chapter we look at health issues and the role that Health and Social Services have to play in addressing race equality and reducing isolation. During the research, we worked with a wide range of professionals from service-providing organisations to look at their ability to address race equality.

In particular, we worked with 32 community health workers: among them Consultants, Midwives, GPs, Health Visitors, Reablement Nurses, Heads of Hospital Services, Team Managers, School Nurses. 11 of them were Black and Minority Ethnic staff. We focussed on three lines of enquiry:

- We heard from Black and Minority Ethnic staff about their personal experience and about their professional observations about race equality within the Health Service
- We heard from community health workers about their concerns for Black and Minority Ethnic patients with whom they'd worked
- We explored the role and readiness of the Health Service to address rural Black and Minority Health needs and to provide a link to other services.

The importance of the Health Services in addressing race equality was illustrated by one participant who reflected, as a patient, that health workers among all the supporting agencies have a particular opportunity to support the needs of Black and Minority Ethnic people. This is her story:

Case study:

A young black woman was suffering severe depression, a few weeks after having given birth. The only contact she had with supportive agencies were her visits from midwives and health visitors and to the doctor. They assumed she was suffering post-natal depression. They failed to notice that she was being beaten by her partner on a regular basis and was in fact covered in bruises, and that this was the cause of her depression, and that she and her child were at risk. The woman does not know if the bruising on her face was not noticed for lack of training or because of a fear on the part of staff about how to raise the question with a Black person. The woman was too depressed and vulnerable to open up herself without encouragement. The consequence of the violent abuse has been mental health problems, relationship difficulties with her daughter and later, homelessness. All of these consequences could have been addressed by referral to other services, had the issues been uncovered by health workers when they had the opportunity.

Nearly everyone will use the health services, and often at the time of greatest need in their lives. Health staff have a unique position of trust, and opportunity of confidential time with patients, in which to encourage them to open up, and can provide access to relevant services when there is a need. The woman reflected that health service workers provide a window into the outside world for vulnerable, isolated people. When vulnerability and isolation is experienced by Black and Minority Ethnic people it is a double disadvantage. When it is experienced by women it is a multiple disadvantage. (For multiple isolation indices see chapter 5.) However not all health workers recognise how crucial and singular a role they can play in uncovering and addressing need and in providing access to wider support for Black and Minority Ethnic patients. Many staff need support to deliver this role in a way which addresses inequality in access to services, removes discrimination and builds good race relations.

The research work with health staff was carried out through questionnaires, workshops and interviews. A number of concerns were raised, but many *ideas* were generated for practical action which would help in shaping Trusts' Race Equality Scheme Action Plans and that could be undertaken by Trusts to support staff.

Interpretation & translation

Aspects of concern:

The issue of Interpretation and Translation emerged as a major concern for health staff – for themselves and on the behalf of many of their Black and Minority Ethnic patients. The following comments from the research workshops illustrate the depth of concern:

☞ *Because of **language barriers**, it's difficult to give the same quality of care. In fact sometimes it means that despite our best intentions, patients get an appalling service. Patients and parents can't pick up the phone and ask for help or get access to services like other patients can. Patients also just don't get the same level of information as English speakers. For example they don't get information on immunisation and contraception. There are life and health consequences of this e.g. un-immunised children at school, birth control problems, vulnerability during health interventions e.g. childbirth. One couple with little English went back to Northern Ireland to deliver their baby because they knew they'd get a better service there. They were even given the child's Red-book in Chinese.*

☞ *We usually rely on **family members to translate**. But you just can't be sure that they're translating what you, or your patient is saying. We're also putting people in embarrassing and inappropriate situations – for example children used as interpreters for all kinds of medical topics. There was one case of a very embarrassed daughter, expected by the family, to act as translator when her father needed a catheter fitted.*

☞ *We're also making **decisions** about people's lives that **they don't understand**: In one case, a family's decision to look after their disabled children at home without access to education was considered by Social Services to be child abuse. The Mum, who had very little English, had to attend a child protection meeting on her own with no interpreter. Also, in many cases, women are being given information in English about antenatal screening, and we have no idea if they really understand the decisions they're being asked to make.'*

And as one Minority Ethnic doctor summed it up

☞ *'BME patients are more vulnerable in Devon than elsewhere because there are less resources for interpreters'.*

The situation described by health staff called for a number of responses:

- It's important that Trusts act to ensure that language services are in place so that family members are *not* used as interpreters – whether on home visits, at the GP surgery, or for hospital in- and out-patients.
- Women should be given language support so that they can communicate fully with midwives. Staff shouldn't be in danger of mis-diagnosis in the absence of information: one hospital case was reported in which a patient was admitted who spoke no English. Reports from third parties were leading health staff in the direction of a very serious diagnosis and intervention, until a member of staff was found to interpret who revealed that the condition was not serious at all.
- Staff wanted Trusts to support their access to interpreters and language services by ensuring:
 - ➔ that staff are fully aware of language services
 - ➔ that the services available address combinations of language skills and can cope with dialects
 - ➔ that services are quickly and readily accessible to all health delivery settings, including those in the community.

The Health staff described how their problem wasn't that language services are non-existent among Trusts, but far more to do with awareness of what is available (for example Language Line, and staff with Language skills), and with difficulties in accessing it. Aspects of their current service which staff felt also needed to addressed included:

- ➔ Skill banks and in-house interpretation
- ➔ Matching language need with language resource
- ➔ Ability to assess language needs
- ➔ Ability of the language service to respond fast enough

Skill banks and in-house interpretation

- For example, some staff in one Trust were aware that a register existed of colleagues with language skills, who could be called upon for interpretation. However they noted that as the list was 10 years out of date, success in using it was limited, time consuming and frustrating. They also complained that using the in-house list depended entirely on a colleague's availability and that this led to delays and future reluctance to use the service. These health workers also noted that the in-house service depends on staff having independent transport to get to a patient, which isn't always the case. The overall feeling was that staff needed interpretation services to be quickly and readily accessible to all health delivery settings, including those in the community.

Matching language need with language resource


- Staff also pointed out that matching interpreter skills or translated resources with patients' needs is often a complex business: For example a patient may speak in Gujarati as his first language but be illiterate in it, and have basic literacy in Urdu but not able to speak it fluently. Staff also talked about difficulties in accessing interpreters for speakers of minority dialects. These complexities also mean that the interpretation and translation facilities provided must be flexible, appropriate and comprehensive.

Ability to assess language needs

- Not all staff are aware that they need to consider these complexities when asking patients about language - a problem that needed to be overcome with training and with carefully designed patient assessment processes.

Ability of the language service to respond fast enough

- Staff described how in many situations it would take too long to arrange for available services to attend a patient case:

 *The huge time commitment involved in bringing in interpreters is a deterrent for doing so. It slows down the whole process...*

This is particularly the case in emergency settings, but also because assessment of patient needs is not done until a patient is booked in on admission.

Staff suggestions for improving language support

Staff had a number of suggestions for improving the problems of meeting language needs:

- ➔ **Clarity about access to Language Line**
- ➔ **Up to date in-house language audit registers**
- ➔ **Community Midwifery/Health Attendants**
- ➔ **Provision of a single *accessible* portal through Intra-net for downloadable translated information**

Clarity about access to Language Line

- Staff were very uncertain about the availability of Language Line to them. Some didn't know about it at all, some thought it had been deemed too expensive for the budget. Staff wanted to be made fully

aware of the service that their Trust wants them to use, the extent to which it can be used, and how to use it. They indicated that low use of existing services shouldn't be taken as an indication of lack of need, but rather of the problems associated in using them. They pointed out that to generate good use of language services, a staff member's first use of the service has to be an experience of accessibility and success in order to breed confidence and sustain take up.

Up to date in-house language audit registers

- Staff were also keen to see better use made of in-house language skills, but felt both that they needed to be kept up to date and that participating staff needed to be supported so that their involvement in the scheme could be effective.

Community Midwifery/Health Attendants

- The idea also emerged for the training and employment of Black and Minority Ethnic women who have language skills and traveller women as Community Midwifery Attendants to work alongside Midwives. (This has a precedent in primary health care in developing countries). Attendants could be trained to understand the medical and care concepts involved in Midwifery, race equality and cultural awareness good practice, and in the protocols of the Attendant role, and then used as translators. Staff noted however that Attendants would need to be police checked and commented on the length of time police checking involves at present. Midwives also noted the importance of overcoming the obstacle of women not wanting someone they do not know involved. A benefit of the Attendant idea is that women could get to know Attendants just as they get to know their Midwives. Attendants could also help women develop birth plans, covering cultural and religious needs, naming issues and family involvement issues. Conceivably, Attendants could also be used to support the Health Visitor service to provide continuity.

Provision of a single *accessible* portal through Intra-net for downloadable translated information

- Staff also made a plea that accessing information in appropriate languages must be simple and not time-consuming. They wanted a single reference point for information and to be appraised of what's available– they didn't want to have to hunt. (Some staff reported having to ask friends in other parts of the UK to find them information.) The health workers suggested that translated leaflets should be

available from the Intranet, in *all* languages and on all topics. However, whilst accessing information from the Intra-net was considered a good idea in principle, in practice access to computer terminals was currently a real problem for many staff. Many have to share terminals with others or have no access at all and, where staff had to go through an administrator to use Intranet, there was insufficient admin time available. Other Intra-net access deterrents include navigation and search problems, lack of time to use the terminals and lack of GP surgery connection to the Intra-net.

Training and information resources

Training and information resources were another key area of concern for the Health Staff participants.

The staff described their level of appraisal of race equality issues: Only 2 of the 32 health workers had received training in cultural awareness or promotion of race equality. One staff member reported getting knocked back from trying to get involved with race equality when she was told at a national conference workshop on race equality issues that she was not welcome as she was White and ‘wouldn’t understand the issues’. Another health worker raised the concern that, whilst she felt Nurses were more likely to ask for advice if they have gaps in their knowledge, Doctors would be less likely to expose information gaps, and that training for them should also be a priority. Another staff member said that all training in her Trust had stopped because of lack of funds.


Only 1 staff member of the 32 had read a Policy. And only a further 2 were aware that a Policy of some sort existed. The research workshop with Heads of Service found that none of them were aware of their Trust’s Race Equality Scheme. One staff member reported asking her Trust if there was any form of anti-discrimination policy governing staff and patient relations. She was told that “*no policy existed because there was no problem here*”.


In particular, staff identified the need for training on racism, institutional racism and tackling racism, in addition to cultural awareness. Many staff were uncertain about the concept of institutional racism, and were concerned about the concept of ‘unwitting institutional racism’. They pointed out that ‘you don’t know what you don’t know’ and felt that training was needed for many colleagues to alert them to what they need to know about. Staff confided that they often don’t know *when* to ask patients about pertinent issues or *what* to ask, or *how* to ask questions. They also

warned that if Trusts were to take the initiative of providing staff with more race equality support services, staff might not take these services up because of lack of awareness that such support *should* be accessed in the first place.


In addition and by contrast to their acknowledgement that they were poorly briefed on matters of race equality in institutional terms, staff were acutely aware of their training needs in relation to cultural awareness.

Based on the difficulties they had experienced in providing care to Black and Minority Ethnic patients, this was an area about which staff were much clearer in their ideas about the knowledge gaps that affected their patient care and about the training and information they needed. Their list included:

Training needs analysis – cultural awareness	
Country- and ethnicity-specific information	Staff wanted training to begin with better cultural awareness and understanding cultural norms. They were insistent that information needs to be country specific, rather than broad continental generalisations, to be practically useful in health care delivery.
Childcare and protection	Staff wanted more information to help them appraise what is ‘normal’ childcare in different countries. They wanted to be better equipped to identify what is and isn’t child abuse and to define acceptable boundaries between discipline and abuse. In particular they needed advice on how to overcome difficulties in communication about child protection issues and decision-making and help in making sure that decisions and communication are properly understood. One staff member produced a copy of the child protection handbook her team used which had only two pages on Black and Minority Ethnic issues. She felt this was inadequate. Staff in one workshop confided that due to lack of knowledge and training.....  <i>Health Visitors may feel less confident about involving Social Services if an abuse or social problem is suspected, for fear of being accused of discrimination.</i>
Integration	Staff also expressed worries about knowing when it is appropriate to “ <i>push integration</i> ” as they put it. They reported helping people to use services e.g. family

	support and services for Mums, but felt worried about the intrusion and push to integrate that this involves.
Food	<p>A big issues was the need for better knowledge about the culture of food with respect to four things:</p> <p>I) knowing the nutritional value of different food styles. Most nutrition guidance staff use is based on traditional English ‘cuisine’.</p> <p>II) knowing about different cultural approaches to weaning and how to give the best advice that will synthesise standard good practice and different cultural traditions.</p> <p>III) knowing about cultural rules around food and health, especially at key points of intervention e.g. after childbirth, and knowledge about how to deal with conflicts between standard medical advice and customs and to discuss the issues with patients.</p> <p>IV) More awareness in hospitals about religious food requirements. Staff cited an example in which a Muslim Doctor was offered ham during Ramadan. Another reported that....</p> <p> <i>Food is always a problem, but families overcome it by bringing their own food in for the patient.</i></p>
Sleep	Staff wanted better knowledge about culture around sleep and sleeping arrangements, especially with respect to advice for parents of young children.
Pain management	They raised the need for better understanding of cultural concepts around pain management. For example the different cultural attitudes to experience of pain in childbirth and expectations about the way pain should be managed.
Contraception	Training is needed regarding how to approach issues of contraception. Staff also found this especially difficult where language barrier exists.
Women’s Health	Similarly staff need information to know how to deal with issues of women’s health – what can and cannot be mentioned.
Gender issues	In the same way, Health workers described difficulties around knowing the protocols of who may and may not speak with whom. Knowing what to speak about to whom (e.g. midwives and doctors talking about whether

	<p>a baby's testicles have descended and taboos about discussing this with Mums). Knowing whose permission in a family is necessary for what. How to work with women patients when men in the family interfere or bar access. (One staff member reported a case where it seemed that a woman was unable to communicate in English and that all discussion was done through the husband. It later transpired that the woman spoke English fluently but was not permitted to speak by her husband). School nurses wanted to know how to advise Asian girls at school e.g. about what to wear for Physical Education.</p>
Privacy	<p>Staff felt that colleagues needed training on making sure that appropriate respect is paid to cultural and religious needs regarding personal privacy. An example was given of an Arab woman feeling angry, exposed and vulnerable when the curtain around her bed was consistently drawn back by hospital staff, especially when men were present on the ward.</p>
Religious dates	<p>Staff noted that provision of basic resources like a yearly directory of important religious dates would be helpful. (E.g. SHAP calendar)</p>
Family involvement	<p>Staff wanted training about cultural attitudes to family involvement in health care and how to manage this in terms of family involvement on hospital wards, in terms of self-help at home and in terms of decision making about the care plan for a patient.</p>
Language & communication training	<p>Staff wanted this aspect of training and information to cover:</p> <ul style="list-style-type: none"> ➤ Basic words in other languages ➤ Using the right race equality terminology in culturally sensitive communication. ➤ Knowing how to get people to open up. Getting over language and cultural and family barriers so that real dialogue can take place and issues can be properly discussed. ➤ Knowing <i>how</i> to ask questions and which questions to ask - They suggested a checklist of race equality and cultural issues to be alert to. <p>As one Minority Ethnic doctor described her experience of work in the community:</p>

	 <i>BME women patients especially won't tell you they're unhappy. They need you to ask the questions.</i>
Names and valuing identity	A senior hospital staff member reported that Black and Minority Ethnic Staff (and patients) often find that they are given or have to adopt Anglicised names because other staff and patients find names difficult to pronounce. The senior staff member worried that her staff may be giving the impression that patients' and colleagues' identity is not valued.
Traveller health	Staff identified the need for better preparation for working with Traveller families and patients, coping with cross-cultural suspicion, and protocols for working on Traveller sites. Midwives gave the example of cross-cultural suspicion when working with Traveller communities resulting in very limited communication between patient and Midwife, added to which is the difficulty of Midwives finding they are often unable to work in pairs in caravans. In the course of the research we also came across a case of abuse in which a Traveller family described how one health professional had been a life-line of support whilst another had been sucked into a local campaign of intimidation against the family including a pregnant Mum, with a mental health impact on the patient.

Staff also had some practical suggestions about the way training and information should be provided for best results, which covered:

- **Cross-cultural experience**
 - ➔ Secondment/visits
 - ➔ Buddy systems
- **Training delivery settings**
 - ➔ Statutory training through Team Meetings
 - ➔ Community Professional Forums - non NHS nursing
 - ➔ Patient Management Teams

- **On the job training and advice**
 - ➔ External community reference workers
 - ➔ Internal sharing of good practice through Teams and Learning Sets
 - ➔ Up to date in-house cross-cultural medicine audit registers

- For **cross-cultural experience**, staff suggested short (maybe week-long) secondment to areas of the UK where staff can get practical experience of diversity. They also favoured the idea of Buddy systems with professionals in urban, diverse areas, through which staff could contact their Buddy on the phone for advice.

- **Training delivery settings**
 - Staff felt that training on race and equalities policies should form part of their *statutory* training. They also felt that training would be better delivered by specialist Trainers coming to scheduled *Team* meetings rather than staff having to go away on study days. They felt that training at Team meetings was the best way to ensure maximum coverage and to get messages conveyed. They also recommended that comprehensive access to Teams could be facilitated systematically by a person in a Trust who knows about all the Teams in existence.
 - One staff member also suggested that *the Community Professional Forum* in her area should also be a training route as it involves nursing services delivered in nursing homes. Staff were particularly concerned about the provision of care to Black and Minority Ethnic patients in nursing care settings for the elderly.
 - Another staff member suggested that in hospitals, *the patient management teams* should be the priority for receiving training, and that they should be supplied with a detailed trans-cultural medicine resource. The PMT could then support relevant staff on particular patient cases and could also supply relevant information to all staff via email.

- **On the job training and advice**
 - Staff advocated the need for an identified race equality/ cultural diversity specialist or cultural access unit to refer to – either on the phone or someone who can come on joint community visits or meet staff on the ward. This reference person does not necessarily have to be a health professional but does need to be a specialist diversity and equality community worker. This person would:

- Provide advice and information on culture/language/religious points, pertinent to a particular patient's care, where necessary
 - Work jointly with staff and with other services to help bring about or negotiate intervention/change where health assessment identifies it's needed
- Staff also suggested having a system through which they can access good practice information via annual Team sessions. Staff suggested that a Trust cascade system should be organised to feed external information and good practice examples from other Teams into each other so that information can be shared about:
- Knowledge and experience from within the Team gained during the course of the year
 - Good practice information collated from external sources
 - Staff also suggested that new Learning Sets are currently being introduced in Trust localities for Health Visitors, School Nurses and Students could be an opportunity for sharing and learning best practice
- Similarly staff wanted to have better use made of in-house knowledge through:
- the creation or updating of lists of colleagues with experience of cross-cultural practice who could be referred to for advice. Staff suggested such a list could be communicated through Trust magazines and Intranet. This list could be compiled along-side a list of staff with language skills. We noted that in carrying out a skills audit to compile such lists Trusts would also do well to check other useful skills such as mentoring, coaching, leadership and staff development skills and qualifications. These could be useful in setting up any Black and Minority Ethnic staff peer support systems.

Medical/diagnostic/assessment tools

Staff also had a number of suggestions about appropriate medical/diagnostic/assessment tools that could help to address a number of

the factors that impede equality of service delivery to Black and Minority Ethnic patients.

Among these ideas were:

- Admissions assessment/ booking-in/ transfer-in and CARDEX
- Ethnicity record keeping - self identification
- Country-sensitive growth charts
- Tropical disease and disease/ethnicity prevalence
- Birth plans


Assessment tools

- Staff identified the need to develop and devise an assessment process so that patients needs are appropriately discussed and assessed, and so that arrangements for meeting needs are agreed once and not over and over again. As mentioned before staff wanted help in asking open questions and eliciting information. A Reablement Nurse suggested that there could be much to learn from the rehabilitation initial assessment interview which takes approx. 1 hour but is time well spent in saving time later in the process - this reablement system could be used to inform the development of a Black and Minority Ethnic patient-needs assessment process.

Another staff member suggested that in hospitals, the cultural- and faith-needs assessment process should be done by the admissions medical assessment unit and that the CARDEX system should be developed to encompass this, so that the information would be easily passed on to all other staff interacting with the patient. A similar process could be applied to booking-in of Midwifery patients. Introduction of such systems, staff advised, would need to be accompanied by staff training, to make sure they are properly introduced and sustained in use.

Ethnicity Record Keeping

- Staff suggested that the assessment process should also enable patients to self-identify ethnicity so that it is specific enough to be useful. As one midwife put it:

 *it's the complexity of each person's identity that affects the values, morals and culture around birth with which you have to work....*

It was suggested that ethnicity monitoring could be addressed at the booking-in or admissions assessment points. However some staff suggested it would be better if ethnicity was addressed when patients register with a GP and that this information should then be forwarded with patient records for all professionals dealing with a patient. Certainly, primary level ethnicity monitoring would transform the way that demographic planning on race equality issues could be informed, and provide much-needed data in between Census intervals. Hence this suggestion has benefits not only for individual health cases but for wider Healthier Communities planning.

Country-sensitive growth charts and disease information

- Staff also identified needs for such items as generation-linked growth charts relevant to different country-origins, and staff reported the need for better training in the diagnosis of tropical and other illnesses. A case was reported in which Bilharzia went undiagnosed in a woman throughout her pregnancy. Her son also had the infestation and was not diagnosed. Staff also wanted better awareness of illnesses associated with different ethnic groups. e.g. blood pressure, diabetes, sickle cell anaemia, thalassaemia etc... and easy access to information about them.

Birth plans

- It was also suggested that Minority Ethnic women could be given more power over their care during pregnancy and child-birth, and more information could be made available to staff if language workers (such as the Attendants mentioned earlier) or specialist community development workers could help Mothers develop bi-lingual birth plans.

Supporting Black and Minority Ethnic Staff

Particular points of concern were raised regarding support for Black and Minority Ethnic and Foreign National Staff regarding:

- **Certification/validation**
- **Ethnicity record keeping - self identification**
- **Co-ethnic patient/staff expectations**
- **Foreign national staff and families**
- **Experience of racism**

Certification/validation


- One staff member pointed out that whilst Trusts depend on a significant foreign national workforce, there are heavy costs and bureaucratic difficulties incurred upon individuals in the recruitment process: applicants have to get qualifications, certificates, and papers and CVs translated into English and recognised by the English system employers. The staff member suggested that the speed and ease of the process could be improved if Trusts could help with certification/validation of translated certificates and the costs involved.

Ethnicity record keeping - self identification

- Staff also suggested that workforce Ethnicity record-keeping needs to allow for people to self-identify. It was suggested that individuals could tick a general heading and then write a more specific definition under it. Identity is specific to the individual, and general continental headings were seen as too broad. Staff also felt this should apply to ERKM of patients. Specific information would also help with in-house language and cultural skills audits.

Co-ethnic patient/staff expectations

- One Minority Ethnic staff member also highlighted the burden that can be felt by staff when co-ethnic patients place too high expectations on them.


 *There is a danger that co-ethnic patient expectations can be too high and that family members can expect too much attention.*

Foreign national staff & families

- Health staff confided that they were often especially unable to provide health service to those foreign national doctors' wives who speak little English because they rely on the husbands for interpretation who are not available because of their long working hours as doctors. Colleagues were worried about poor standards and size of housing for families, and the isolation of women, often with children, who rarely see their husbands because of working hours and who have little social contact outside the house. Colleagues observed that foreign national staff are often in posts short-term, and hence families move frequently without opportunity to develop networks and roots in the community. Staff also raised concerns about the lack of play space for children in NHS-provided accommodation.

Experience of racism

- Staff also had concern about the way that Black and Minority Ethnic colleagues might feel about racism, but were on the whole unsure about what their experience might be. One Minority Ethnic staff member however illustrated the effects of little incidents which in themselves probably went unnoticed by others but, for her, amounted to a wearing-down form of prejudice:

 *People here have very little tolerance of staff with accents. They make lots of jokes about pronunciation and spelling which is silly. They don't understand that we're trying. How many Brits speak another language? I cope with it by making a joke of it but it can really get to me. I have several thousand people to co-ordinate. If there are several comments a day it can really bring a person down.*

Working with other agencies & services

During the work with health providers we also looked at how staff were able to address Black and Minority Ethnic patients' needs by working with other agencies and services. The key issues that arose concerned


- Referral systems: navigation for staff and patients
- Mental health services

Referral systems

- Most staff expressed a lack of knowledge about who to turn to if families need extra support. To make referral possible, staff felt there should be one place to go to find out what support services might be available to a patient: another agency or voluntary sector organisations for non-medical advice; patient groups; race relations organisations and cultural support opportunities. Staff also felt that there was a need for specialist race equality community workers to help facilitate referral and provide continuity.
- Similarly, staff identified the need for specialist workers to whom they could turn for advice about rights to benefits and services depending on a patient's immigration status etc.
- Very few staff knew whether other agencies were being accessed by their patients, and only a few had provided links to non-health service support – usually language classes. Only the Re-hab service was referring on, by virtue of its nature. Lack of confidence in other

services to address Black and Minority Ethnic patients' needs was also noted as a problem in referral. One example was given of an Asian woman who needed co-ethnic social-work support - or at least the support of a worker who understood Asian culture. The health professional was unable to arrange such a referral.

- Staff also raised the problem that they did not know how, or where, to refer on specialist needs – for example, at present there is no point of referral in Devon for circumcision.
- Health workers also noted that their inability to access referral services was all the more serious, because of many Black and Minority Ethnic patients' inability to access services for themselves.
- In particular, staff were especially concerned for many immigrants who do not understand how the health/social service and benefits systems work. Participants described how patients frequently do not know their rights, what services are available to them in the first place, what to expect from a service, how to navigate it and its systems, and the struggle with form filling. Staff noted that some families are not registering with GPs and that there is a preference among many families to try and deal with health problems within the family and without medical help. There's also a lack of understanding about the different roles and services in the system – e.g. Health Visitors, Midwives. A foreign national health professional told us of the difficulties that *even she* experienced in trying to understand what the system provided and how to access it:

 *At home we don't have health visitors etc.. Everything here is different and you're not told what's what, and if you ask people they don't know – they're born into the system*

This participant suggested that there should be a Welcome Pack when a person arrives in the UK or in an area explaining how to register with, and use, services and benefits.

Mental health services

- Staff also reported difficulties in dealing with depression and working with the mental health services. They had particular concerns about cases of women in unhappy or abusive relationships. In the course of the research a number of Black and Minority Ethnic participants, especially women, also described the impact of depression in their lives. We were concerned for the usually un-appraised mental health impact on children of cases of racism experienced by families.

- Within the discussion with health workers, staff raised concerns about not knowing how to deal with depression in the context of different cultural understandings of the illness.
- They reported that they had been unable to refer cases of vulnerable isolated women to mental health services if the illness or depression-state did not involve psychosis.
- Staff also reported that GP waiting lists for GP-sourced counselling were so long, and availability so thinly spread that they were effectively unable to refer women for counselling support. Nurses and GPs alike complained about this problem.
- A re-ablement nurse raised serious concerns about the impact of un-addressed depression on general health status and patient recovery after illness. The re-ablement service, being very person-centred, has the capacity to spend sufficient time with patients to pick up on wider and attendant social, psychological and health problems. Other health workers complained that they can not afford the contact time to build up trust and identify underlying and aggravating problems with patients.

Partnership working between race equality and health services

The key outcomes from this element of the research demonstrated the need for a specialist race equality organisation to which people can turn for support. We heard how both Black and Minority Ethnic employees and patients need someone to turn to when they experience inequality; and we heard how professionals needed a source from which to seek general and case-by-case advice on the best way to support patients.

The support functions required of a race equality service by health providers broke down into the following areas:

- **Specialist advice**
- **Referral support**
- **Consultation**
- **Staff & Patient complainant aid**
- **Policy advice**
- **Training**

In addition, our wider research also demonstrated the need for a single consultation portal, through which the Black and Minority Ethnic

population could continue to raise issues of concern on an ongoing basis, and feed them into the relevant service-provider and partnership organisations for action. 61% of Black and Minority Ethnic participants expressed an interest in having future involvement and voice on race equality issues. Many of them identified specific areas of interest and expertise where they were keen to help shape services. At the same time, the demand from the huge number of service-providing agencies and forums threatened to overwhelm the willingness of individuals to contribute. Hence it became clear that agencies' consultation needs, and the willingness of Black and Minority Ethnic people to participate, needed to be co-ordinated and facilitated in a manner that provided individuals with protection from consultation overload. Moreover, whilst this research has shown that its participants were clear about what mattered to them and what they wanted to discuss, service providers wanted to consult on a plethora of issues. It was recognised that, by networking of Black and Minority Ethnic people in their localities, individuals could themselves rationalise the consultation priorities, thereby setting them from a user (rather than provider) perspective. It was also clear that the status quo for consultation relied on unreasonable expectations upon a few known Black and Minority Ethnic individuals to speak on the behalf of the Black and Minority Ethnic population in all its diversity. Networking was recognised as a means for bringing many more voices together to raise concerns and feed them forward.

In chapter 12 we see that networks were put forward by Black and Minority Ethnic participants as a key recommendation. The primary function of these networks would be to provide an opportunity for celebrating culture, drawing peer support and accessing information. However, with the high interest expressed in having a voice, these networks could also provide the safe, facilitated and informal space in which to raise issues and make them available to service planners.

With all the above in mind, the Devon & Exeter Racial Equality Council therefore proposed work in rural areas which would, among its functions, offer (subject to funding) five key support functions to health staff and patients:

Support functions	
Consultation	A single consultation portal, facilitated by community development workers with various sectoral specialisms, including health, who could provide a permanent, efficient interface between Black and Minority Ethnic staff, BME patients and the Trusts. The consultation gateway would allow Trusts and other service-providing organisations to access a breadth and depth of local information hitherto unobtainable.
Policy advice	This consultation data would be available through the staff of the Racial Equality Council (REC) and through 'community contributors' as policy advice to strategic forums, and as a policy development (Race Equality Scheme) consultancy service to individual organisations. This advice would also help Trusts keep one step ahead of Audit and Inspectorate requirements and to meet their legal duties.
Staff & Patient complainant aid Policy advice	The advice that would be provided would also be informed by monitoring the case-loads coming through the REC's independent complainant aid service. This service supports individuals in resolving cases of discrimination, and the learning from this work also provides intelligence through which the REC can help Health Care Trusts to take action to prevent repetition or escalation of complaints.
Specialist advice Referral support	The proposed community development workers would also be available to provide a reference service for staff and their patients when external advice is needed on dealing with cases where cultural and referral issues needed to be addressed.
Training	The REC also has a training service through which bespoke training is available to Trusts to raise in-house competency to deal with race equality in service provision and employment.

The Racial Equality Council's proposals are designed to address the needs raised by participants in the research, and to provide optimum benefit for Black and Minority Ethnic Patients and Staff, and for the Trusts and agencies who need help to meet their race equality duties. The proposals form part of the REC's Business and Service Plan which was put forward to Devon's Health Trusts with a request for funding, in spring 2003.

Social welfare

In addition to health issues, the research also picked up on a few other areas of concern relating to social welfare, in particular:

- **Growing older**
- **Children's services**
- **Welfare systems administration**

Growing older


Issues concerning old age were raised by a number of the Black and Minority Ethnic participants in the research (see chapter 9). Their concerns reflected the in-migrant status of most of the participants who still had family links overseas. The concern divided into two areas.

On the one hand, younger middle-aged participants had concerns for their parents overseas, some of whom had consequently come to the UK (or moved from elsewhere in the UK) to join them. (12% of our sample had come to Devon to be nearer family.)

 *My [Asian] in-laws came [here] from Nairobi because of the increase in violence and their own children had left the country.*

On the other hand, older middle-aged participants raised concerns about whether rural Devon would be a suitable place for them in old age. Factors influencing these concerns included:

- Worry about whether care for the elderly would be culturally sensitive
- Health concerns and the hope that overseas climates would provide a better environment
- The need to have cultural and family support in old age

 *My Dad is back in Bangladesh to be with the family for retirement. I don't know where the family will settle when we retire. We might go to London where the family are or similarly Exeter - I have a business there and my wife likes it because there are more other Asian women and it's a bigger city and there's better education for the kids. The dampness in winter is one of the worst things about life here. This is why my parents went home because of the arthritis.*

- ☞ *A person's origins become more significant as a person becomes older and age raises issues of identity once again.*
- ☞ *Are dietary needs met for older people? Is it offered? - surely to do so would be common courtesy*
- ☞ *You very seldom have elderly in restaurants. Elderly go back to Malaysia to be with relatives and for warm weather. Traditionally young people look after the elderly. If they can't the young people will find you for help. I think the Chinese Housing Association idea is a good one. But when I am old I would prefer to be on my own or with English people.*
- ☞ *I wouldn't stay here if I retired. It's a nice place but not near enough to family. We would need support and understanding of culture.*

In chapter 8 the issue of learning support needs, in particular English language support, are also considered as a need for ageing generations of restaurant workers.

Children and services

We heard of four cases of problematic trans-racial adoption/fostering in the course of the research. Aspects of concern described among these cases included:

- Placement of children in families that were unprepared to deal with a child's ethnic identity
- Placement of children in unstable or un-supportive environments
- In three of the cases, the issue of adoption was considered a root factor in adult mental health problems, destructive life-choices, or anti-social behaviour.

Whilst this research did not pursue investigation issues of trans-racial adoption/fostering specifically with social service providers, it has been recognised by Racial Equality Council workers and by the Exeter based project Planet Rainbow as an important issue needing further work. Taking the isolation indices described in chapter 5 into account, the placement of Black and Minority Ethnic Children in White families in predominantly White areas, without reference to ethnic roots, raises further need for research on this topic.

☞ *White people should not foster Black kids. I hated big family gatherings - I was very quiet and didn't say how I felt because they said I was making a fuss over nothing. So I couldn't join in and felt like a spectator. I felt anger towards my biological parents who had 5 kids, because they had 2 kids after who got kept together and adopted by a Black family and the third child got taken on by my Mother's family. It made me feel I was the only one who had no contact with the family..... I don't understand why my [adoptive] parents had me..... I can't remember ever being cuddled. Now I feel my own 7 year old is too old to be cuddled and it's difficult for me to show affection..... I have sickle cell trait and have problems with my eyes. It made me scared. I told Mum who told me not to whinge, but as soon as Dad appeared she got more sympathetic. He cuddles me and Mum hates it. She won't touch me even if I'm crying. It really annoys me. Now I don't trust anyone at all and certainly not with my feelings....the social workers just reported on me being very quiet. They didn't understand why I was unhappy. I haven't got any trust in them. They talked about everything else with my family but me. I just used to sit and spectate. They didn't try to get to the bottom of things..... they didn't interact with me or try to work at the problems with my Mum.....*

We also noted that in many cases of racial abuse covered during the research, that the impact of cases on children were not fully assessed or identified. In some cases, the reporting of incidents touched on the situation of children caught up in abuse directly or indirectly, but that children's issues often became lost beneath other issues of concern raised by adults about the way that other agencies were failing to respond to incidents. The point flagged up by this observation, and by the issues discussed in chapters 6 & 8 (about children's experience of racist bullying), is that any case in which children are involved or connected in any way should prompt service providers to conduct specific investigations on the impact upon children.

However, as one Minority Ethnic social worker indicated, welfare agency staff do not receive sufficient training or information to examine the levels of vulnerability of Black and Minority Ethnic children:

☞ *Social workers are not geared up to mixed race issues. They need briefings in what's on offer to help them - not just a list of telephone numbers.*

Another Minority Ethnic welfare worker also raised concern in this area, which was flagged up for him by the case of a White child whose social service assessment was poorly handled:

☞ *There's the example of a Social Services case locally where a girl who had sought CAB support was asked by Social Workers in front of her parents what her family grievance was – this lack of good sense and poor communication is exactly what sent the African 8 year old [Victoria Climbié] in London to her death.*

Welfare systems administration

A number of participants shared their views about the way in which benefits are administered, in terms of

- staff attitudes
- form filling
- reservations about taking up benefits

In a few of the cases reported, participants described their perceptions that staff were unresponsive to their needs and insensitive or insulting in their attitude to their clients. Often the cases involved more than one agency, with poor performance on the part of one service, leading to a general breakdown in trust between the client and the welfare services, between whom clients made little distinction.

Two cases illustrate participants' concern about insensitivity and negative attitudes.


Case study 1:

A couple with mental health and other social exclusion difficulties complained of consistently unhelpful, confusing, inconsistent and punitive action by the social services and benefits agencies. The couple's complaints of poor professionalism on the part of service-providing staff included an incident in which a member of staff wrongly alleged that the White female of the couple was not the mother of their Mixed Heritage child and should not be eligible for benefits. They also described another incident in which a staff member was reported to have threatened 'I'll get you'. The case involved a spiral of deteriorating relations between service staff and the couple, which the couple felt was motivated by racist discrimination. They described their frustrations in not being able to evidence racial prejudice, which they felt was indicated by comparison with similarly circumstanced friends who did not receive the same

treatment, and by comparison with the White partner's relatively good experience of services up until she met her Black partner.


Case study 2:

A health professional described how on returning to the UK with her British husband and child, she experienced real difficulties, not in getting work, but in finding her way through the administration necessary to be allowed to work. To add to the difficulty in navigating her way through an unfamiliar process, she experienced intimidating behaviour from administrative staff:


 *To get my national insurance number I had to go through an interview in the Benefit office. They asked me everything including how I met my husband. I felt insulted especially as I come from the EU. They treated me like a refugee with no passport - it was very intimidating. It was insulting as I'm not asking for citizenship, I'm asking to be an asset, to work for the population and pay tax.*

The health professional's experience of finding welfare and other administrative systems unfamiliar and complicated was echoed by several other participants. This was raised as a particular concern for people who spoke limited English. In chapter 8 we examine how English as an Additional Language tutors have found themselves acting as informal welfare workers, helping students cope with form filling, and other Black and Minority Ethnic participants described fulfilling the same role for peers with less English than themselves. Some participants described how some forms – such as Working Families Tax Credit applications – were even beyond strong English speakers, and how others – such as Child Benefit forms - were easier but only if you had fairly good English. In chapter 8 we look at suggestions for improving support in accessing welfare administration, including multi-lingual Welcome Packs, provision of information through the English as an Additional Language Service, and information and support provided through rural Minority Ethnic networks.

However, a couple of points were made by participants about reluctance to take up benefits, that information and help with form-filling alone would not address. One professionally qualified Asian single parent described how he had finally succumbed to encouragement to accessing benefits once he had run out of savings. He had held out hope that he would remain financially independent through work, and was disappointed that the employment service hadn't been more active in supporting him in his desire to find work. A Chinese waitress observed that her low-income peers in the restaurant industry were also unlikely to take up benefit entitlements:

 *Chinese don't like to use benefits - prefer to earn money - there's 'no face' in benefits - especially men like to feel they can earn own money.*

Reluctance to use benefits born of the feeling that self-sufficiency is a marker of personal dignity was also raised by the Asylum Seeker participants in this research. For them, the bar on working once they arrived in the UK and their dependency on the state was a matter of real frustration. Their need to be seen to be financially self-sufficient was made further acute by their awareness of the belief among members of the public that they were here for financial benefit. Moreover, with many people coming from countries which do not have welfare state systems, the notion of benefits is an alien one, and with which many people are unlikely to identify personally. These experiences indicate that several barriers exist between welfare resources and many low-income families to whom they are eligible.

This handbook and supporting tools  can be accessed at www.DevonREC.org