JML TRAINING & CONSULTANCY

Responding to the Needs of Minority Ethnic Carers Summary - September 2001

Summary

The research has found that few services are making specific provision within mainstream services to respond to the specific needs of minority ethnic communities. To describe the services as being guilty of institutional racism is provocative but no amount of literature that talks about the need to ensure that services are provided in an ethnically sensitive way is having any significant impact.

Carers appeared confused about what services were available. Some expressed reluctance to access mainstream health and social care services and voluntary services. The services are seen as inappropriate and bureaucratic. The latter is not peculiar to minority ethnic communities, but the language, religious, gender and cultural barriers they meet make access especially difficult.

A fundamental issue that impacts on the use of services is the ability of staff to respond to diversity, without constantly measuring the minority community with the majority community.

There are resource implications for services. To date, the needs of minority ethnic communities have not been properly met within mainstream services. Those mainstream budgets have been historically allocated and appear frozen. Yet there is no extra money forthcoming.

This is a conundrum, which severely challenges the ability of services to act within the confines of the Amended Race Relations Act (2000) This is now enforceable legislation, which will be used by the Audit Commission and the Social Services Inspectorate when monitoring performance. At some stage, representation may well be made under the Act to the Commission for Racial Equality. Enforcement action could be taken if organisations are not meeting their responsibilities within the General Duty to promote racial equality.

The NHS Plan now recognises that we live in a diverse multi-cultural society (para 2.11). It also states that people from minority ethnic communities are less likely to receive the services they need (para13.8). The latter point has been borne out by the findings of this work.

Services will need to be flexible and prepared to adapt their way of working and current provision to meet the need of this minority ethnic group. The New Carers and Disabled Children's Act could provide the incentive to begin this process, as local authorities are required to reconsider the needs and services to carers in their own right.

'If we can get it right for one individual, we can get it right for the majority' - Tameside Social Services

1. Introduction

This summary presents the findings of research undertaken to map the current provision of services for carers of people from the Pakistani population in south Buckinghamshire. In order to understand the needs of carers it was essential to review the provision of health and social care services and how they responded specifically to the needs of a minority ethnic population.

The summary presents the following information:

- Issues relating to the provision of services to a minority ethnic population.
- The professionals' perspective of the carers needs.
- The carer's perspective of their needs.

The report then makes a series of recommendations for improving access to and appropriateness of services.

A key principle of the NHS Plan is that 'the NHS has to be redesigned around the needs of the patient'. The work of the US/UK Collaboration for addressing inequalities in minority ethnic health has shown that a service that starts from a perspective of addressing the needs of its minority groups will move easily to addressing the needs of the majority. Working the other way round, from the majority to the minority, leads to marginalisation and ghettoisation.

A key objective within the research was to identify good service provision and explore what it is that makes that service acceptable. Examples of national good practice where a project has been responsive to the needs of an individual patient or carer have been included in the main report, but not in this summary.

2. Main Findings

2.1 Key Factors Relating to Services

This section of the report outlines a number of common factors that emerged from the interviews with service providers. It is suggested that all these issues have negatively impacted on service provision for minority ethnic populations.

- Current funding constraints are being blamed for a lack of service development, although staff reported little investment over the years.

- Whilst there is an awareness that the needs of dependants and their carers from minority ethnic communities need to be addressed, the response is reactive rather than proactive. The pursuit of diversity and equal opportunities does not rest with other priorities on the agenda. There are no coherent organisational strategies for improving services to people from minority ethnic communities. Improvements in service provision appear dependant on concerned managers within a service taking the initiative.

- Despite numerous reports, from different agencies over time highlighting unmet needs and recommendations for action, some service planners still seem unaware of what is deemed as appropriate service provision or unconfident in their ability to develop services for minority ethnic people in the planning process.

- Information about ethnicity is not collected at present in many organisations. In some instances where data is collected it is not of a sufficient quality to inform service planning.

- There is a sense that the user / carer will have to adapt to fit the service, despite the rhetoric to develop patient oriented services or person centred planning, because of a lack of funding.

- Some providers feel that they are making efforts to adapt to meet different community needs, but that there is no reciprocal response from the communities. This can develop into 'they ought to be grateful, look what we are doing' mind set which can permeate a service or organisation. Thus minority ethnic people are labelled as deviant, as their behaviour does not fit in with the accepted way of 'doing things'.

- Staff shortages, due to recruitment and retention problems, are critical in some organisations, and the demands on individuals remaining are considerable. This impacts on service planning for minority ethnic needs as this area is seen as problematic and difficult to tackle.

- Organisations feel frustrated by the limited success of their efforts to recruit Asian people into health and social care posts.

- Constant reorganisation within the statutory services undermines the development of services; initiatives are delayed as staff wait for reconfiguration exercise to be completed. For example changes within the Social Services Department and within the NHS.

- Experience, information and good practice in the provision of service to minority ethnic groups is not commonly shared between departments in an organisation or between organisations.

- Where changes are being made to services, their impact for minority ethnic carers needs to be considered. For example, it is increasingly common for carers of patients with diabetes to be asked to give them their insulin. Some minority ethnic carers are not comfortable with this, they are concerned that should the patient die, the carer (his wife) will carry a stigma in the community "she didn't want to look after him".

- There are positive and negative findings relating to interpreting services.

The provision of a professional training for interpreters has improved the quality of the formal interpreter services. Carers using interpreters now feel much more confident about confidentiality.

Staff reported feeling more confident and able to offer a better quality service when they worked with a professional interpreter, as the threat of a professional mistake caused by a language error was eliminated.

However, professionals still act as gatekeepers to the interpreter services. The services, where they exist, are not directly accessible by an individual carer.

- The use of bilingual staff, pulled away from their work to translate for patients was reported. Assessments, which are done in this way, cannot be comprehensive nor can they provide the dependant and carer with the service they are entitled to.

- Link workers are frequently used for form filling by clients using services that do not provide their own interpreter.

- There is no current mechanism for minority ethnic user/carer comments to feed into service development. The Race Equality Council is sometimes used as the only route by some statutory sector agencies to consult on the community's needs. The Council will have an informed view on many of these issues however; they are not sole representative of the communities.

2.2 The Professional's Perspective of the Carer's Concerns and Needs.

Some professionals demonstrated considerable understanding of the issues facing people from the Pakistani population using services. But, in the main the following information came from workers who were working very closely with the communities.

- Communication still remains a key factor underlying disadvantage in access to services. Some command of English will not be sufficient when carers have to deal with medical and social care jargon. Many carers feel too embarrassed or lack the self-confidence to say they have a problem understanding the conversation.

- A mistrust of health and social care professionals is common. This appears to have developed through: - A lack of understanding of the myriad of roles and tittles that proliferate. - Breakdowns in confidentiality and misunderstandings caused by language barriers. - Expectations that are often unrealistic and attached to the wrong people or wrong service.

- It was reported that many Asian people like to tell people what they like to hear not what is really happening. If staff are not aware of this a consultation or professional visit could clearly be ineffective. This cultural perspective highlights a number of points: -the need for staff time to develop a relationship with and understanding of clients and carers -the need for the use of an interpreter when necessary -the importance of training for staff using interpreters and the importance of only using trained interpreters.

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- Many people do not feel welcome when using services. They describe it as experiencing a 'sense of isolation', this feeling will be exacerbated if the person does not speak English very well.

- Carers feel that hospital staff assume they will not understand what is happening to the patient and consequently do not relate to carers on an equal basis.

- The professional model adapted by health and social care services is a client centred model of care. This may create a cultural clash where families operate within a family model.

- Reported changes in family structures and lifestyles would indicate that it is no longer the case that there are always relatives to provide support and care. This challenges the still widely held stereotypical perception that 'Asian families look after their own'. Parents of children with disabilities are expressing concern about what will happen to their children after they die if relatives do not want them.

- The responsibility of caring for frail elderly or disabled adults lies almost always with the women in a family and often the daughter-in-law. The difficulties of this situation can be compounded by the insensitivity of male members of the family to the needs of the women carers.

- Many Asian people do not perceive themselves as "carers" in the Western meaning of the word. As far as they are concerned, they are just looking after a family member. They can therefore lose out on welfare benefits and support, if a welfare assessment is not provided by a well trained professional who is aware of this difference in cultural perspective.

- Workers report that there is little flexibility in the way current services are provided, so families who do not "like to make a fuss" may well decide to do with out.

- Some families on low incomes where there is only one earner and many dependants see benefits as an income and are not in a position to use this 'extra money' for 'comforts' i.e. paid practical help within the home.

- The concept of day care is not acceptable to some people from the Pakistani community. It is perceived as abdicating "responsibility " to someone else.

- The role of day care is a misnomer to some people in the Pakistani community, as it is perceived neither to educate nor rehabilitate.

- Some people feel there is a stigma associated with attending a day centre. Families feel this may label them negatively within their community.

- However, some carers who would otherwise use day care services were disinclined because the service would not be able to provide for the dietary, cultural and linguistic needs of a family member.

- Fear of racial discrimination from staff or other users of a day care facility was also expressed as a reason for not using a service.

- Respite care usually includes an overnight or weekend stay away from the family to give the carer a break. But for the communities in Wycombe and Chesham, their preference is for help within the home, within the structure of the family.

- Some carers of children with disability have expressed anxiety about the safety of their child in a day care situation. Anxiety about sexual abuse is not uncommon.

2.3 The Carers Perspective of their Situation

Carers from the Asian community like carers from the majority population experience many difficulties as carers, such as recognition, respite and the need for flexible services. But in addition, they also have to face difficulty accessing existing services, have little choice in the services that are available, they frequently have language difference and often have little information about what help is available. All the carers spoken to were women, and for most English was not their preferred language. Loneliness, isolation and stress were all reported by carers. It was quite significant that these women were able to express these views to a 'stranger' and demonstrates the strength of feeling and perhaps despair amongst carers.

- Some people are using services as they are currently provided, although they are not always satisfied with the provision.

- Carers reported that the difficulties of caring were exacerbated by the lack of interpreters available in the different services. Difficulties accessing interpreter services at Wycombe and Amersham Hospital and some GP practices were specified.

- Carers did not always understand which services they were using; this would suggest that the communication between them and the service provider was limited.

- Some carers would seek more help if the services could be provided in a more acceptable way to the family.

- Negative past experiences have left carers with a lack of confidence in the ability of the services to provide for them.

- The responsibility of care seemed mainly to lie with one individual in a family, mostly the woman.

- Carers expressed the need for someone to talk to outside the family, to off load their anxieties, stress and frustrations.

- Practical assistance within the home was identified as a key need; this would allow more time for the carer to concentrate on the frail person or on their own needs. 'You feel you have not got any life' one carer said.

- Some of the carers, particularly those who were less educated, felt very guilty about accepting external help with the caring role. However, if this help were provided in a more appropriate way it would help to breakdown those barriers.

- In a few instances women carers were providing care for a chronically sick husband and chronically sick children with limited support.

- The appearances of day care centres was criticised, 'they needed to be more home like', one carer described a centre as looking a bit like a prison. This only increased carer's guilt if they used them.

- Most carers appeared to be caring for parents or parents in law in the same household.

- Frustration was expressed about the lack of understanding by the Council regarding the conversion of a dining room into a bedroom for a dependant. This created significant problems for a family where separate rooms are needed for entertaining men and women.

- One young woman with children reported that her mother had a month's stay in Amersham Hospital after a fall. She spent each day there, often till about 10.00pm at night, as there was no one who could communicate with the mother. Regular interpreter provision did not appear to be available

- Access to buildings can be difficult, Social Services in Easton Street is perceived as particularly intimidating for a person with little English.

- There are different views in the Asian community on the employment of Asian women to provide domestic or personal care in the home. Some people felt that neither would be acceptable. Others felt that domestic work was more acceptable. Concern was expressed that problems related to gender were inevitable and women who found themselves in employment of this kind would no longer be seen as respectable.

3. Recommendations

3.1 What will make a difference?

Many of these recommendations relate to issues common to all health, social services and voluntary agencies. Solutions for some issues will require partnership, for example on interpreting services.

Many issues relate to the improvement of practice and will need to be addressed under Quality of Service outcomes and Clinical Governance. All relate in some way to the NHS Plan and reflect the views of the SSI for the development of services for minority ethnic groups. Audit and inspection bodies including the Audit Commission will now be monitoring racial discrimination in public bodies when carrying out any of their functions.

3.2 Responding to Specific Needs

The health and social care system is now required 'to shape its services around the needs and preferences of individual patients, their families and their carers', (The NHS Plan). Local NHS action plans need to reflect action to improve access to services for minority ethnic groups.

If people see the services are there for them they will more likely use them and apply for jobs in them. In order to achieve this services need to acknowledge and be sensitive to different needs.

The specific requirements of minority ethnic groups need to be understood and addressed as part of routine service design. Providers need to recognise what makes a service successful. Carers are only using services, which they can easily access and that are flexible in their approach. Other services need to take on the challenge of change and be more flexible. The following issues would help to make the difference.

- Home respite would appear to be the most popular choice of support. All respite schemes need to be able to respond to the specific lifestyle needs of the minority ethnic carer

- Home sitter services where the sitter spoke the same language as the dependant.

- The gender of the sitter or home carer must match that of the cared for person.
- Residential care, which meets the religious, cultural and dietary, needs and there must also be other people of the same ethnicity and language around.
- Residential care needs to be geographically close and support family involvement.
- All services should be able to offer access to interpreter provision. Clients should be able to directly access the interpreter services. Arrangements need to be in place for 'out of hours' cover. This is a key issue, as many of the problems that arise appear to be associated with poor communication.
- Services need to set targets to increase the numbers of people using services.
- Where possible employ workers from the same cultural background and who speak the patient's language.
- Relationship building between professionals and carers. This would help carers to feel more welcomed into a service and less like a 'problem'
- Carers would appreciate information about the illness, what to expect, what to do, and what to look for and information about the medication. This, it was felt, would help to reduce the sense of powerlessness experienced by some carers.
- Targeted appointment systems with an interpreter available
- Clearer communication to carers of what a service can/cannot provide
- Greater flexibility in the use of the Disabled Facilities Grant acknowledging the cultural needs of Asian families

3.3 Developing Community Capacity

Organisations that attract minority ethnic users in to their services stress the need for greater visibility of staff from minority ethnic groups as this increases the confidence of potential users.

Recruiting staff from the Pakistani community to work as care workers is not an easily achievable task. Nationally, this has been a challenge for many organisations. The successful organisations, mainly those in the Voluntary Sector, have been flexible in the work arrangements (dealing with gender related issues), recruit by word of mouth, and provide support and training for their workers who may previously not have been in paid employment.

With leadership from the public sector there is opportunity to initiate dialogue with members of the Pakistani community to explore partnership opportunities to tackle some of the current barriers in meeting needs eg employment.

There is a need to challenge the traditional orthodoxy evidenced amongst this population. Whilst there is some resistance to change, this is often only the view of male or older members in the community. But if the statutory sector can provide a more flexible service it will help to change this conservative orthodoxy and improve the quality of care. This is a challenging position agencies can find themselves in but the benefits would be significant.

The provision of information via an ongoing and visible outreach programme will help to promote the concept of a 'Carer' to the Mirpuri community. It will also highlight their rights to be supported and the existence of services. By not using services carers and the cared for may be denied rights and choices they are entitled to. This is a challenging task for agencies but a key issue if services are seeking to tackle health and social care needs.

There is a need to support the development of a voluntary sector within this population. Experience from other areas suggests that, with support, a voluntary organisation can become an ideal provider of services. Locally, the Domestic Work Initiative funded by the Carers Special Grant and operated by South Buckinghamshire Carers Centre has demonstrated this.

The concept of volunteering is not a common function in the community. A number of historical factors have been suggested to account for this. A lack of community security and a responsibility to establish financial roots to support families back home. Language difficulties and a lack of understanding of the indigenous community can also account for a reluctance to volunteer one's services. But as the Asian community is undergoing change a middle class community is emerging with potential to take on this role. This is work that could be undertaken in partnership with the REC's and with support from organisations like The Afiya Trust.

3.4 Ensuring Equal Opportunities

There is a need to ensure that all providers have an equal opportunities policy in place that covers service provision as well as employment, and are prepared to tackle discrimination in either employment or service delivery. The Race Relations (Amendment) Act 2000 gives statutory force to the imperative of tackling institutional racism. Within the amendment authorities are now required under a new General Statutory Duty to eliminate unlawful discrimination and promote equality of opportunity and good race relations in carrying out their functions. More specific duties, outlining additional requirements will be published shortly.

Addressing the needs of ethnic minorities and responding to current inequalities will require rigorous compliance with equal opportunities policies in contracts with providers.

Purchasers of services need to undertake direct work with independent and private sector providers to develop their capacity to provide ethno sensitive services. There is considerable experience amongst providers in other areas and opportunity to learn from their ongoing experience. (Further details on this can be found at the end of the report.)

Contracts with providers (statutory, independent and voluntary sector) should require them to demonstrate a commitment to provide for all people in the community equitably, and the mechanism by which this will be put into operation. Basic service standards should include standards for cultural competence. Under the new legislation the duty remains with the public body to ensure that the services are being provided in compliance with the Act.

Operational objectives to increase the usage of in-house and contracted out services by minority ethnic carers/users need to be set and monitored. There is a need to introduce some level of personal accountability from Heads of Departments to ensure that diversity objectives are included in business plans with identified monitoring mechanisms.

The Race Relations Act makes it unlawful for public authorities generally to discriminate in the exercise of its function. In order to avoid doing this unintentionally organisations need to understand the culture of the diverse communities, which they serve. This needs to be targeted at executive board members and senior staff first. This should include training, which enables the services to deliver culturally competent services, and training in anti-racist practice. The NHS Human Resource Framework declared that race and equality training was compulsory for NHS Trust Boards by April 2001. It has not yet happened in Buckinghamshire.

Managers need to be equipped to manage inclusion. Management posts should include the need for competencies reflecting a greater emphasis on leadership and on managing people and services for diversity. Candidates for promotion or new posts need to demonstrate how they will achieve this in employment and service provision. Appraisals need to include evidence of how staff are meeting objectives on diversity.

Key staff working with minority ethnic families/carers need to have their development needs recognised and addressed, as staff from minority ethnic backgrounds can be marginalized into a role defined by their ethnicity.

Ongoing work to promote services to people from different minority ethnic backgrounds. Successful providers are those that maintain an ongoing programme to promote their service to the relevant minority ethnic populations.

3.5 Developing Professional Standards

All staff need to be able to demonstrate that they are applying the same professional standards in every situation. Currently, this is not the case, when professional services are being provided without an interpreter, where English is not the preferred language.

This is the sort of issue that will be seen as part of the obligation of an organisation by the CRE. A key strategic objective for the CRE is to work with the public sector to make full use of new powers under the Race Relations (Amendment) Act 2000 as a driver for change. It will shortly be issuing codes of practice for health and local authorities containing such practical guidance as the Commission thinks fit in relation to the performance by persons of duties imposed on them.

Properly trained interpreters should be available for all consultations/meetings with clients where English is not their preferred language. There is an urgent need to support plans to develop the interpreter service across southern Buckinghamshire. It is also important to ensure that current interpreters have access to ongoing professional development training. Staff using interpreters need to be trained to work with them.

The SSI Report *'They Look After Their Own Don't They'* identifies assessors as playing a critical role in ensuring equality of access to services. It urges them to be aware of their own knowledge and skills limitations and where appropriate involve someone else with more specific expertise.

Staff with a flexible attitude could significantly improve the quality of individual patient/client care. Those who are prepared to use their initiative, think about the way a service is currently provided and how it can be improved for individual carers can improve accessibility. Most importantly, they then give clients a sense that the service does welcome them.

Staff need some training to provide appropriate initial information to minority ethnic carers.

There is opportunity to use the expertise of staff working with minority ethnic communities to develop the skills and confidence of all staff. Teams can also share their experiences of good practice thus increasing knowledge of how quality of service can be improved.

Where NHS staff have introduced a more creative approach to appointments, they have identified a drop in DNA's (clients who do not turn up for appointments). Some members of staff use an interpreter to ring their clients on the day or the day before an appointment to remind them to come for appointments. This may initially appear to be a time consuming process but they have found that this has significantly reduced their DNA's. Others organise appointments by the language need of a client and arrange for an interpreter to be available at that time. The concept of patient centred appointment systems is part of the NHS Plan to drive forward quality improvements in patient care.

Ethnic monitoring is an essential process to improve the quality and sensitivity of services to meet the different needs of a multi-ethnic population. All services, statutory, private and voluntary, need to collect service data by ethnicity. Both by overall caseload and by monthly contacts. Services need to be monitored for fairness in service uptake. Data needs to be routinely analysed and circulated so that it is available for use in service planning. This will be a requirement under the Amended Race Relations Act.

Ethnic monitoring needs to be undertaken in primary care and integrated with the development of electronic patient and health records as outlined in the NHS Plan.

As clients and their carers are frequently asked the same questions time and again, services should be encouraged to include information on interpreter need, preferred language and ethnic group within any referral they make to another department / agency.

Staff training in ethnic monitoring will increase understanding and commitment to the process.

3.6 Developing Supportive Relationships

There is a need to ensure that people are consistently offered fair assessment procedures. Assessment procedures are still in use, which disadvantage people from minority ethnic backgrounds. They may be eurocentric and are sometimes undertaken without adequate or no language support for the client or carer.

Whilst there may be a clearly articulated expectation that users and carers are at the centre of the assessment process, it is difficult to see this happening for minority ethnic communities Families need to be involved in the development of the care plan and this needs to be sufficiently flexible for support to be provided in more relevant and appropriate ways.

The family model of care, within which many families operate, may work against the carer and the cared, as it may limit the amount of support accepted by a family. This can place agencies in a very difficult position. Whilst a worker may not feel that the family values are in the best interest of the client, any challenge to this may result in a withdrawal from services. On the other hand the long term interest of the carer and cared may suffer as a consequence of this approach. Agencies need to ensure that appropriate support is available for staff involved in these situations.

There needs to be a constant flow of information out to the community about what services are available and what they can offer. Word of mouth seems to be the preferred option. Primary Care Teams could play a significant role in this area. For example, the Over 75 checks undertaken by district nurses and child development checks carried out by health visitors could be used to increase access to information for carers.

Where a self-referral system is in operation, service providers need to recognise that this process requires self-confidence in order to self-refer. Many people from minority ethnic communities may not have this level of self-confidence, assuming they know the service exists. There is therefore a responsibility on providers to ensure that these barriers are addressed. Within the Health Service this is primarily about improving access to GP's, as most referrals to the Trust come through them.

3.7 Securing Public Involvement / Consultation

Statutory and voluntary sector providers all need to look much more closely at mechanisms for involving users/carers in evaluating services and in the overall quality assurance process. Current mechanisms need also to show how they are getting information from a cross section of the minority communities.

Some professionals perceived that many of those who do decide to use services withdraw after a very short time. This perception needs to be tested out.

A communications strategy between the communities and the public and voluntary services needs to be developed.

User feedback assessments need to demonstrate how the views of minority ethnic groups have been sought.

Informal and more personal methods of consultation are recommended to identify what is good/bad service, and how services should be developed. For example; -

Professionals (particularly link workers and development workers) working closely with minority ethnic communities can play a key role in advising on service development. They have a very full understanding of their clients needs and can act as a proxy for more formal public involvement with communities.

More formal comunication with South Buckinghamshire Carers Centre and other projects successfully providing services to clients and carers will provide a useful source of reliable information.

The Carers Centre can also facilitate direct contact with carers, it is suggested that the process is managed as advised by the Carers Centre.

Individual services could increase contact with parents and carers to get their views and encourage their involvement. This will ensure that carers from minority ethnic groups are not seen as a homogenous group. This will require an appropriate use of interpreters.

Developing the capacity of existing advocacy services (and the proposed PALS Scheme) to advocate on behalf of the minority ethnic population more visibly will provide a mechanism for monitoring the impact of current or proposed policies.

It is anticipated that the monitoring of proposed and existing policies will be required under the specific duties of the Race Relations Act and consultation responses published. These consultations processes will need to be meaningful and effective.