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ORIGINAL ARTICLE

Developing and evaluating a culturally appropriate genetic service for consanguineous South Asian families

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Abstract Blackburn with Darwen Primary Care Trust (PCT) provides services to a substantial Asian population in which the practice of consanguineous marriage is common and there is a high incidence of autosomal recessive disorders. The aim was to provide and evaluate a genetic service accessible to consanguineous families from the South Asian community who had a child affected by an autosomal recessive disorder. Information on genetic risk was provided along with the offer of genetic testing for members of the extended family to identify gene carriers and facilitate informed reproductive choices. An Urdu-speaking health visitor was employed to establish a community-based, hospital-linked genetic service in conjunction with local paediatric and regional genetic services offered to parents who had an affected child and 71 of their relatives. The service was evaluated using a specifically designed questionnaire. There was a high uptake of the service (95% of index parents and 92% of relatives to whom it was offered) and a high uptake of carrier testing (94% of relatives to whom it was offered). Eight requests for prenatal diagnosis were made during the course of the service development. Many individuals stated they would consider genetic risk when making future marriage and reproductive plans. Input from a health care worker from the same ethnic background who provided information in their own language was highly valued. Family orientated genetic services for ethnic groups practicing consanguinity can be acceptable and effective when provided in a culturally appropriate manner.

Keywords Consanguinity · Autosomal recessive disorders · Cascade genetic screening · Carrier testing · Genetic testing · Genetic services

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Introduction

As infant mortality falls due to better health care, congenital and genetic disorders emerge as important causes of early death and chronic disability (WHO 2000). It is recognised, but controversial, that consanguinity has an impact on the occurrence of these types of disorders. Congenital abnormalities have been shown to occur more often in the offspring of consanguineous parents than in the offspring of non-related parents (Terry et al. 1985; Young and Clarke 1987; WHO 1996a, b; Khoury and Massad 2000). There is also an increased prenatal, perinatal and postnatal mortality in children from ethnic groups that practice consanguinity (Bittles et al. 1993; Grant and Bittles 1997), which is largely attributable to an increased incidence of autosomal recessive disorders (Devi et al. 1987; Bundey and Aslam 1993; Stoltenberg et al. 1999; WHO 2000; Tunçbilek 2001;

Mokhtari and Bagga 2003; Bittles 2003; Dawodu et al. 2005). In the general population, the risk of abnormality or death in early childhood is about 2% to 2.5% for non-consanguineous couples compared with 5% for consanguineous couples. It has been suggested by Bittles et al. (1991) that most of this increase occurs in a sub-set of consanguineous families that happen to harbour recessive mutations, suggesting that identification of these high-risk families would provide an opportunity to provide targeted genetic services. Autosomal recessive disorders vary in severity, but many lead to early death or chronic disability and therefore they impose a significant health and economic burden on families and health care services.

Rare autosomal recessive disorders occur more frequently in the offspring of consanguineous parents because of the increased chance that both partners have inherited the same mutant gene from a common ancestor. The genetic implications of consanguineous marriages are determined by the coefficient of consanguinity (F), which describes the proportion of genes that will be shared between individuals because they are inherited from this common ancestor. The closer the relationship, the greater the proportion of genes shared by the couple, the higher the coefficient of consanguinity and the greater the risk that the offspring will be homozygous for the shared gene (Harper 2004). Recurrence risk for other relatives is also greater in families that practice consanguinity. The recurrence risk for any couple who has had a child affected by an autosomal recessive disorder is one in four (25%). The risk of the same autosomal recessive disorder affecting the children of other relatives who marry outside the family is usually small since the general population carrier frequency for most autosomal recessive disorders is low. However, the risk for other relatives who marry within the family is increased because of the greater likelihood of marrying another gene carrier.

Consanguineous marriage is defined as a marriage between close biological kin (Bittles 1998), with “consanguineous” meaning literally “of the same blood”. Consanguineous marriages are practiced widely in many parts of the world, in particular ethnic groups that account for at least 20% of the world's population (WHO 1996a, b). As a consequence, over 8% of all children have parents who were related prior to marriage (Christianson et al. 2006). In the UK, it has been estimated that more than 75% of British Pakistanis are married to a relative, with 55% married to a first cousin (Darr and Modell 1988; Bundey et al. 1990; Modell and Darr 2002; Christianson and Modell 2004).

Despite the increased genetic risk to offspring, there are important social and cultural benefits arising from consanguineous marriages (Modell and Darr 2002). Islamic faith is a common link between many communities practicing consanguinity, but religion is not the prime reason for this preference since marriages between cousins are neither encouraged nor disapproved of by Islam. Marriage within the family strengthens family ties and support systems, maintains a woman's status within the family hierarchy, facilitates the finding of suitable partners for both men and women, and maintains the family lineage. Marriage within the family also preserves culture and traditions that might otherwise be lost by people who no longer live in their native country. In addition, there may be financial benefits since marriage to relatives helps to protect family wealth and property for future generations. Conversely, marriage partners from outside the family may be an unknown quantity in terms of their lineage, upbringing, and values. As a result, consanguineous marriages have generally been more stable than marriages between unrelated partners.

We consider that providing genetic services targeted to the needs of consanguineous families is preferable to making attempts to prevent consanguineous marriage. Members of families in which an autosomal recessive disorder has occurred can be given the information they need to make their own informed choices when planning marriage and reproduction. A family based approach has been explored in families affected with thalassaemia in Pakistan and been found to be an effective strategy for identifying and counselling carriers of recessively inherited disorders (Ahmed et al. 2002). Molecular diagnosis is now available for an increasing number of autosomal recessive disorders and individuals within an extended family can often be offered appropriate carrier testing. This makes it possible to prospectively identify couples where both partners are carriers, who will be at high risk of having affected children. Of equal importance is that couples who are not at risk of passing the condition on to their future children can also be identified, reducing their anxiety and simplifying their reproductive decision making. Prenatal diagnosis can be offered to couples whose pregnancies are at high risk. For a few specific disorders, treatment during pregnancy or in the early newborn period will improve prognosis and knowledge in advance of pregnancy is vital in providing optimal management. Through genetic counselling and carrier testing, individuals who are planning to embark upon a consanguineous union can be fully informed about the risks and options available to them when a specific genetic condition has been identified in another member of the family. Knowing their carrier status before marriage may be beneficial in helping some people choose their marriage partner.

Blackburn with Darwen PCT provides services for a population of 140,900 in which 22% of residents have an Asian background. A preliminary survey in Blackburn determined that the incidence of autosomal recessive disorders in childhood was 12 times greater in the Asian population than in Caucasians (Benson 2005), with 83 different recessive disorders being identified. Where data

was recorded, 95% of Asian parents with an affected child were in a consanguineous marriage.

Another preliminary survey by Benson and Kowariwalla (2002 unpublished) showed that couples with affected children had poor understanding of genetic risks and implications for future pregnancies. Language was consistently highlighted as a barrier to both accessing and understanding genetic information. This survey also found that extended family members of an index case were generally not aware that they were at increased genetic risk of having a child affected by the same genetic disorder.

Genetic clinics based at the local hospital in Blackburn have been provided by the Regional Genetic Service for many years. A review of cases known to the paediatricians showed that less than half of the families who had a child affected by an autosomal recessive disorder had previously been referred to this specialist clinic. Experience from the genetic clinic also indicated that although index couples were told that their relatives could request appointments in the genetic clinic, this was seldom taken up. Genetic services could therefore be improved by being proactively targeted towards those consanguineous families with a child/children affected by a known autosomal recessive disorder, where specific carrier testing to define genetic risk is possible.

A proposal to develop and evaluate a genetic service that addressed these needs of consanguineous Asian families was funded by a service development grant under the DH White Paper initiative "Our Inheritance, Our Future: realising the potential of Genetics in the NHS" (2003) and managed jointly by the Blackburn with Darwen PCT, Royal Blackburn Hospital Paediatric Department and Regional Genetic Service at St. Mary's Hospital, Manchester. A multilingual Asian genetic health visitor was employed and trained in genetic counselling to proactively offer this service.

The aim of the service development was to provide information that would empower families to make autonomous decisions about managing their own genetic risk by cascading genetic information through families that had children affected by autosomal recessive disorders and offering carrier testing to relatives.

Methods

Asian children affected by an autosomal recessive disorder were ascertained from a diagnostic database established by the local paediatricians. The genetic service that was offered focused mainly on conditions amenable to molecular diagnosis for which genetic carrier testing and prenatal diagnosis were available (Table 1). However, some conditions for which genetic testing was limited or not available were also included to determine whether genetic counselling alone would be considered beneficial. Because of the time limit on the project, the aim was to identify between 35 and 45 index cases for initial inclusion in the service development. Families in which the index child had died were only included if the parents had previously been seen by the genetics service and it appeared that they would benefit from further genetic input.

Of the 42 index cases chosen, 23 had not previously been referred to the genetic service. All were living and currently under the care of a paediatrician or other specialist. The remaining 19 index cases had previously been referred to the Regional Genetic Service and seen prior to 2005. According to the accepted practice at the time, the availability of genetic counselling for other family members would have been discussed with the index parents attending the genetic clinic if this was appropriate. In some cases this was specifically mentioned in the summary letter sent to the couple following the consultation. Despite this, there had been no subsequent requests to see relatives from these families so these families were included in the service development.

The parents of affected children were contacted by the consultant paediatrician or geneticist responsible for the child's care by means of a standard letter written in English. This informed them of the availability of the genetic service and indicated that they would be contacted by the genetic health visitor who would explain what this entailed and ask if they wanted to take up the service offered. The health visitor was trained in counselling skills, communicated with the families in their preference of English, Urdu or Punjabi and was experienced in dealing with families who had children with a physical or mental handicap or who had suffered bereavement.

All couples who requested the service (40 of the 42 contacted) subsequently had a formal appointment with the Asian genetic health visitor. Most of these consultations took place in the home and according to their preference, were conducted in the parents' first language or a mixture of their first language and English.

A three generation family pedigree was drawn up from information provided by the index parents. Relationships within the family were often complex, with multiple consanguinity over several generations. From the pedigree, other individuals/couples in the extended family who were at increased genetic risk could be identified. Contact with these relatives was initiated through the index parents. Relatives were given the option of contacting the genetic health visitor directly or having their contact details given to the genetic health visitor for her to arrange an appointment. Relatives who gave their consent were seen by her, again, mostly by visits to the home.

One or more genetic counselling sessions were provided and these included a discussion of the clinical features and

Table 1 Autosomal recessive conditions included in the service development

Categories of genetic disease included in the service development	Conditions	Number of families seen by the service
Mutation analysis available for carrier testing and prenatal diagnosis; prenatal treatment available	Congenital adrenal hyperplasia	10
Mutation analysis available for carrier detection and prenatal diagnosis; early postnatal diagnosis and treatment may improve prognosis	Cystinosis	3
	Haemoglobinopathies	3
Mutation analysis available for carrier testing and prenatal diagnosis; prenatal treatment not available and postnatal treatment not available or only partially effective	Spinal muscular atrophy	8
	Zellweger syndrome	1
	Factor X deficiency	1
	Factor VII deficiency	1
Mutation analysis not available; prenatal diagnosis possible by biochemical analysis	Various inborn errors of metabolism	5
No carrier testing or prenatal diagnosis available at the time	Aicardi-Goutieres syndrome	1
	Bardet–Biedl syndrome	1
	Cohen syndrome	1
	Epidermolysis bullosa	1
	Undefined autosomal recessive disorder	4
Total		40

management of the specific condition as well as an explanation of inheritance pattern, genetic implications within the family, carrier testing, risk to future children and prenatal diagnosis. Where molecular diagnosis was available, a DNA sample from the affected child was analysed if the underlying mutations were not already known. In most cases, mutation testing was available in a laboratory within the UK, but occasionally samples had to be sent abroad for analysis. Carrier testing was offered to members of the extended family if this was available for the specific condition in the family. Diagrams were used to explain the pattern of inheritance and all individuals/couples were offered a letter summarizing the information discussed, written in the language of their choice. None of the families declined these letters. One family requested a letter in Gujarati. All remaining families requested letters in English and indicated that either at least one family member spoke and read English or that it would be easier for them to use a letter written in English. The information was tailored to the specific needs of the family and care was taken to avoid using technical or medical terminology.

The genetic health visitor was aware that not all family members were literate and in each case the letter was followed up with a telephone call to go over the content and answer any questions. With their verbal consent, a copy of all correspondence was sent to the individual's general practitioner.

The service was evaluated using a questionnaire designed to collect both quantitative and qualitative data about the service. Responses were analysed using the SPSS (Statistical Package for Social Sciences) and thematic analysis.

Results

Uptake of genetic services

In 40 of the 42 index cases (95%), the parents of the affected child/children took up the genetic service offered. One couple declined as they felt they already understood their genetic risks and the timing was not appropriate for the other couple whose third affected child was in the terminal stages of their illness at that time.

Index couples

All the families seen by the service were of Muslim religion. The ethnic background of 33 of the index families was Pakistani and seven were Indian. Thirty eight out of the 40 index parents seen (95%) were married consanguineously. In only two cases were both partners born and brought up in the UK. There were 13 couples where both partners were born and brought up in the Indian subcontinent. Fifteen counselling sessions were conducted entirely in an Asian language (Urdu or Punjabi), three entirely in English and 22 using a mixture of Asian and English languages.

Of the 40 index parents seen, 29 had one affected child, six had more than one child affected by the same disorder and five had children affected by two different autosomal recessive disorders. Only 19 out of these 40 couples had previously been referred to the genetic service. Genetic testing was available for the condition in 29 families, but only 15 had previously had mutation analysis performed.

The underlying mutations in the remaining 14 families were identified as part of the service development by testing the child and confirming carrier status in the parents.

Carrier testing

The index parents had 334 siblings. One hundred and four lived within the Blackburn and Darwen PCT catchment area and could be included in the service development. Most of the remaining relatives lived in the Indian subcontinent. Forty six siblings were not seen mainly because they had completed their families or were not at increased risk as they had married outside the family. It was considered inappropriate to contact relatives in two families because of recent bereavements and three index couples did not allow contact with any of their relatives (two for personal reasons and one because they did not accept scientific explanations). Only six siblings who were offered the service declined. The affected children had 89 unaffected siblings. Most of these were under 16 years of age and were not included in the service development, but will need to be offered genetic services in the future.

A total of 71 relatives were seen and counselled. This included 52 siblings of index parents, eight siblings of index cases and five of their spouses as well as three sets of grandparents. Of these 71 relatives, 53 were married consanguineously and 18 were single. In 12 cases, no carrier test was available. Where carrier testing was available and appropriate, only three relatives declined this. Altogether, 50 carrier tests were performed and 25 carriers of the familial mutation were identified. Six of the carriers were single and planned to have their future partners tested if they married within the family. Eight couples were removed from risk because the other partner was not a carrier. Four carriers did not have their partners tested (two lived abroad). Two couples without affected children were identified as carrier couples.

Requests for prenatal diagnosis

During the 2-year period of the service development, a prenatal test (first trimester chorionic villous sampling) was requested by eight couples, including one of the carrier couples who had been identified by the service before they had an affected child. Four prenatal tests were for congenital adrenal hyperplasia to determine the need for continued pre- and postnatal treatment. Terminations were not requested for the two affected foetuses identified. Two prenatal tests were requested for spinal muscular atrophy (SMA) type I, a condition that results in early childhood death. Both pregnancies were found to be affected and in each case the parents requested termination of the pregnancy. Two prenatal tests were requested for life-limiting metabolic conditions and both were found to be unaffected. No prenatal tests were requested for the pregnancies at risk of cystinosis, but neonatal testing was organised since early detection of the condition in babies known to be at risk enables early and hence, more effective treatment. One couple asked about the possibility of pre-implantation genetic diagnosis (PGD).

Evaluation of service intervention

Service evaluation was based on 46 completed questionnaires out of 72 distributed (response rate, 64%). The questionnaire contained five questions requiring tick box yes/no or multiple choice answers and four questions requiring a rating score answer. Two free text comment boxes were also included to allow respondents to explain how the information they had been given had helped and to give their general comments on the service and how it could be improved. The questionnaire was sent out by post. Follow-up phone calls were made to couples who were known not to be fluent in English, by an Asian-speaking member of the service development steering group who was not directly involved in service delivery. She went through the questionnaire using Asian languages as necessary and recorded the responses.

Both quantitative and qualitative data were obtained and analysed. The service was reported to have been useful by 97% of respondents who particularly valued being given information about the condition, having an explanation of the risks to future children and an explanation of genetic implications for members of the extended family. Eighty four per cent felt they understood more about the condition as a result of the consultation and 71% felt that genetic information would be helpful in making marriage and reproductive decisions. Overall, 66% said they were happy to have been contacted proactively about the service and 75% said they were happy to have received the service. Nine per cent felt they should not have been approached and 7% were not happy to have received the service. Only 30% of respondents found it easy to discuss the hereditary nature of the condition with their relatives and 15% stated that they found this very difficult due to the sensitive nature of the information and potential stigmatization and blame.

Most respondents wrote additional comments about their experience of the service. Thematic analysis identified four main themes (Table 2), namely: lack of knowledge, language barriers, cultural barriers and utility of genetic information.

Many respondents commented that prior to being offered the service, they had been in a position of *not knowing*, through lack of understanding about the genetic basis and inheritance of the condition. They indicated that they did, subsequently, understand and accept the explanations given to them by the counsellor. One couple, who had only

Table 2 Themes identified from the feedback from index parents and relatives seen as part of the service development

Themes
Lack of knowledge
• Many respondents reported that they had little or no knowledge about genetic issues before being seen.
• Not all couples with affected children realised they could have healthy children.
• Genetic explanations were generally accepted once understood.
Language barriers
• Language was identified as a major barrier to accessing services.
• Individuals who did not speak fluent English found it easier to understand and discuss information directly with the counsellor in their own language.
• Many couples used both English and Asian languages during consultations, changing from one to the other depending on the topic being discussed.
Cultural barriers
• Many felt that their culture was not generally understood or accepted
• Several respondents specifically reported that they felt they could be more open because the counsellor came from the same cultural and religious background.
• Some couples reported that they had previously only listened *out of politeness* to information given by non-Asians
Utility of genetic information
• Most respondents commented that they would wish to utilise genetic information when deciding future marriages in order to minimise the risk to offspring.
• Some felt that the easy step would be to marry outside the family and others stated they would consider arranging marriages to more distant relatives.
• Carrier testing prior to marriage was an option considered when planning for the future.
• Carrier testing, after marriage, for their future spouse was considered appropriate by individuals who knew they were carriers.
• Some couples would consider prenatal testing or pre-implantation genetic diagnosis for high-risk pregnancies

affected children, had not realised there was a possibility of having healthy children and this new information altered their future reproductive plans. Understanding why there were risks to extended family members encouraged many index couples to give information to their relatives once they appreciated how this might benefit them even though this was a difficult thing to do. Very few extended family members reported having had any prior understanding of their increased risk, but most decided to have carrier tests when these were offered.

Language was identified as a major barrier to accessing services and understanding information. Less than half the families seen spoke fluent English and even those that did often reverted back to their own language when discussing sensitive or complex issues during the session with the counsellor. Removing language barriers was essential in ensuring that complex genetic information could be effectively explained. Relying on interpreters, especially when these are family members, is not always satisfactory.

Several respondents specifically reported that they found discussion easier and more open because the counsellor had the same cultural and religious background as themselves. Comments made by others also indicated that the absence of language and cultural barriers was key to the successful uptake of the service. Many families felt that non-Asian people did not understand or respect their beliefs and customs.

The professional view that accurate information is a pre-requisite for making informed decisions was confirmed by the families who expressed their intentions to utilise this information when deciding future marriages, in order to minimise risk to offspring. Some felt that the easy step would be to marry outside the family. Those still wishing to arrange marriages within the family stated that they would consider the possibility of carrier testing potential suitors or arranging marriages to more distant relatives. As indicated by the requests made for prenatal testing, this is also an acceptable procedure for some couples.

Since the evaluation questionnaires were completed anonymously, responses from families with conditions for which genetic testing was not available could not be separately identified. Altogether, eight families fell into this category. Parents of all the index cases took up the offer of genetic counselling for themselves. The service was offered through them to their relatives, although the genetic counsellor did not proactively follow this up. In only one family did a relative subsequently request an appointment and receive genetic counselling. This limited response reflects experience from the service offered in the genetic clinics prior to this service development, suggesting that both the lack of proactive approach and lack of genetic testing contribute to low uptake of the services

Discussion

This service development was successful in providing genetic information and testing to a sub-set of Asian families in Blackburn who had children affected by autosomal recessive disorders and enabled us to identify lessons learned and make recommendations for service provision. Focusing on families that already have an affected child and where definitive carrier testing can be offered is likely to provide the most effective intervention.

Language and cultural barriers have previously been identified as factors affecting access to medical services for ethnic minority populations. These issues can be addressed

by providing culturally appropriate services (Yoong et al. 2005). Receiving information and explanations through interpreters is not always effective (Browner et al. 2003) and the families offered our service appreciated having this provided by an Urdu-speaking health professional. The concept of genetics was new to many families and difficult to explain as there are no words in Urdu vocabulary for terms such as "genes" and "chromosomes". Even couples who spoke fluent English reverted back to their native language at times during the consultations, particularly when talking about sensitive or emotional issues, which would have been difficult with a non-Asian counsellor.

Beliefs on inheritance and kinship in some cultures may differ from the accepted scientific viewpoint (Barlow-Stewart et al. 2006) and the need for multicultural genetic counselling to acknowledge and incorporate familial beliefs and customs is well recognised (Wang 2001). Cultural differences were considered to be a barrier to receiving information by many of the people seen during this service development. They had not previously understood the one-in-four-recurrence risk when they had been given this information without further explanation, and they felt that non-Asian professionals disapproved of consanguineous marriages, especially if they told the couple that this was the cause of their child's disorder. This emphasises the importance of explaining that autosomal recessive conditions are due to a child inheriting two copies of an altered gene (one from each parent) and that this is more likely in, but not exclusive to, consanguineous marriages. When inheritance was explained by the genetic health visitor with the use of simple diagrams, this information was understood and generally accepted. As has been described elsewhere (Shaw and Hurst 2008), there were some families who did not accept scientific explanations and believed that their child's problems were either the will of God or due to external events during the pregnancy. However, lack of knowledge and misconceptions about genetic disease are also common in the general population and are frequently difficult to overcome. Having an Asian-speaking health visitor trained in genetics, from the same ethnic background as the families but living outside the immediate community, was a key factor in providing the service and the families viewed this as being a culturally appropriate service, which maintained their privacy.

Sharing of information between family members was another key element in delivering the service. Most parents of the affected children did share genetic information with family members as they realised it was important to do so, although they did not always find this an easy task because of the sensitivity of the information and its consequences. It is therefore important that they are supported in this process by a health professional. Some couples wished to keep the information private and felt that they carried some degree of blame for their child's condition. Others felt some degree of stigmatization and hence, were reluctant to pass this on to relatives.

During the project it was apparent that the availability of the service became known within the local ethnic community and several independent approaches were made to the genetic health visitor from other families. Participation of the health visitor in health-related programmes broadcast by a local Asian radio station also helped to disseminate information about the service.

The majority of individuals/couples seen, stated that genetic information would be useful when planning marriage and pregnancies. Those planning to marry within the family said that they would want their future partner to have a carrier test performed. Some felt they would be more likely to marry outside the family, although it remains to be seen whether there will be an actual change in marriage practices within these families. Experience from the service development also indicates that some couples will consider prenatal diagnosis, highlighting the importance of providing appropriate information in advance of pregnancy for couples at high-genetic risk.

Lessons learned

- Language and cultural barriers to genetic counselling are reduced by having appropriately trained genetic counsellors from the same cultural background as the family.
- Sharing information with other family members is difficult for many parents who have children affected by an inherited disorder and they may require support to achieve this.
- Information is appreciated and does empower individuals/couples to make informed choices about marriage and reproduction.
- Marrying outside the family or to more distant relatives may become an increasingly acceptable means of avoiding genetic disorders in high-risk situations for some families.
- Carrier testing is acceptable and often provides reassurance to couples at potential risk.
- Prenatal and pre-implantation diagnoses are acceptable methods of preventing recurrence for some families.
- Asian family and community networks can play an important role in increasing community awareness of genetic risks.

Conclusion and recommendations

Experience gained during this service initiative has led us to make the following recommendations for developing genetic

services for communities that practice consanguineous marriages.

- All consanguineous couples with a child affected by an autosomal recessive disorder should be referred to their local/regional genetic service.
- The underlying gene mutations should be identified where this is possible.
- A proactive approach to offering genetic service is needed for families at risk of specific autosomal recessive disorders.
- Carrier testing should be offered to relatives as this is very important in making appropriately informed marriage and reproductive choices.
- Trained genetic counsellors from specific ethnic groups are required.
- Simple explanations of complex concepts are needed and using diagrams is often very helpful.
- Providing written information is important as this aids recall and can be shown to other health care providers or to relatives.
- Genetic services for ethnic minority populations can be community based, but must link into the Regional Genetic Services.
- A joint primary/secondary/tertiary care approach is a successful model for providing access to services for ethnic minority groups.

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