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Tragedy of the children born with genetic defects because their parents are cousins:

By SUE REID

A young mother opens her kitchen fridge, taking out a mango yoghurt for her 11-year-old son. She calls him to the table three times. When the boy fails to appear, she runs up the narrow stairs of their terrace house in a former Yorkshire mill town to get him.

Minutes later, the boy finally enters the living room. Imran is a handsome lad and seems perfectly normal. He has just spent the day at his school in Bradford, where he is often top of the class.

Look a little closer, though, and you can see hearing aids tucked behind each of his ears. Imran is profoundly deaf because a vital nerve which carries sounds to his brain has failed to develop.

Medically, there is nothing that can be done to cure his disability. It is the same affliction that has struck his teenage cousin, a girl called Myra. Two of the children's uncles also suffer severe deafness. Is this a tragic coincidence and are the family just unlucky?

According to Imran's mother, the answer is an emphatic "No".



Union: A Muslim couple marry in traditional dress

"I married my first cousin, which is why Imran is deaf," she says. "Myra's parents are also first cousins, which is why she is also deaf."

"When I started my family I was just a young girl. I had no idea that marrying a close relative would be medically dangerous for any children I had. My parents did not know either. Now our son is paying the price for our ignorance."

The mother (whom we will call Zuhra) agreed to talk to the Mail only on condition of anonymity.

She is terrified of being identified and condemned by her extended family of 100 members, spread across Northern England, for speaking out about one of the most controversial - and taboo - subjects in multi-cultural Britain: inter-marriage between cousins which has left hundreds of children damaged or dead.

"My parents would think I had betrayed them," she says. "They were born in Pakistan and are stuck in the past. They are good people, but they can't accept that my son's deafness has been caused by my husband and myself being so closely related."

"My father would like my oldest daughter, who is 18 and at college, to marry her cousin. He already has a male relative in mind. But I will do everything to avoid it happening."

This week, Government Minister Phil Woolas provoked a furore by warning of the health risks of cousin marriages among British Pakistanis. He claimed the practice was sending the number of birth defects among children in these communities soaring.

The MP for Oldham - where one in seven are of Pakistani or Bangladeshi heritage - described the issue as the "elephant in the room": a contentious matter that was never talked about.

His words were echoed by Ann Cryer, the Labour MP for Keighley in Yorkshire, who says cousin marriages are medieval and designed to keep wealth within families.

"The problems provoked are not fair to the children or to the NHS. If you go into a paediatric ward in Bradford or Keighley, you will find more than half of the kids are from the Asian community," continued Mrs Cryer.

"Since Asians form only 20 to 30 per cent of the population, you can see that they are over-represented."

"There was one poor girl who had to have an oxygen tank on her back and breathe from a hole in the front of her neck."



Furore: Government Minister Phil Woolas warned of the health risks of cousin marriages

"Her parents were warned they should not have any more children. But when the husband returned again from Pakistan, within months they had another child with exactly the same condition."

It is not the first time that Mrs Cryer has raised the dangers of cousin marriages. She caused uproar by commenting: "It is heartbreaking when grandparents are so keen cousins should marry that the family health problems continue throughout generations.

"A doctor told me that one Pakistani family believed it was the will of Allah, because doctors were doing the wrong thing or the mother was a bad woman . . . this is not acceptable."

So what is the reality? British Pakistanis, half of whom marry a first cousin, are 13 times more likely to produce children with genetic disorders than the general population, according to Government-sponsored research.

One in ten children of cousin marriages either dies in infancy or develops a serious life-threatening disability.

Although British Pakistanis account for three per cent of the births in this country, they are responsible for 33 per cent of the 15 to 20,000 children born each year with genetic defects.

The vast majority of the problems are caused by recessive gene disorders, according to London's Genetic Interest Group which advises families affected.

Everyone carries some abnormal recessive genes, but most people don't have a defect because the normal gene overrules the abnormal one.

But if a husband and wife *both* have an abnormal recessive gene, the couple have a one-in-four chance of producing a child with defects - including blindness, deafness, heart or kidney failure, lung or liver problems, and myriad of neurological ailments.

Even their healthy children have a one-in-four chance of being a carrier of the defect with drastic implications for the next generation.

The result is that children of firstcousin couples, whatever their ethnic background, have the same six per cent chance of having a baby with defects as a woman of 41 conceiving a child. This is twice the national average. And few realise that the problem includes other ethnic communities from southern Asia, the Middle East and Africa. Yet it is only part of the picture.

A community nurse and genetics counsellor in Yorkshire told me this week that the 'trouble really starts' when a first cousin marries a first cousin and the couple's own grandparents are cousins, too.

"I have heard of first-cousin marriages going back generation after generation in some families. The chances of disability among children then increase enormously."

Of course, unrelated couples can also have babies that are born damaged, maybe as a result of the mother binge-drinking or taking drugs during pregnancy.

The incidence of mothers choosing to have children late in life is also having an impact on birth defects.

But Dr Peter Corry, a consultant paediatrician at St Luke's Hospital, Bradford - where nearly one in five of the population is of Pakistani heritage - has revealed that 140 genetic disorders have been diagnosed in the city during the past few years.

Some are very rare and, until recently, unknown in Britain. In a typical health authority area, the number of such disorders would normally be between 25 and 30 a year.

Medical research has shown that many of these genetic disorders include neuro-degenerative conditions, where the proper functioning of the brain and spinal cord gradually decline after a child is born.

According to Bradford's District Infant Mortality Commission (which was set up to examine the problem), at least five more children a year die in the city than in areas with a similar economic profile but where there are no first-cousin marriages.

This week, I spoke about the medical consequences with paediatric nurses, community health workers and midwives in the North, Birmingham (where genetic disorders among the Pakistani community are twice as high as among the general population) and London.

One staff sister who has worked in a Midlands children's ward for 13 years said: 'It is terrible to watch. Very few people in the NHS are prepared to talk about this openly. Every day, we see the sad results of blood relatives marrying.

"The other day, a very young mother came in to give birth to her third child. Her eldest boy has already died of a neurological degenerative condition while her daughter, who suffers the same brain disorder, is getting more disabled every day.

"When the baby girl arrived, she had problems breathing. She was not reacting like a normal newborn. The mother, who is married to her first cousin, was crying because she suspected what the future holds.

"The eldest son's head started to be unsteady after his first birthday. By the age of two, doctors confirmed he was mentally retarded. He became paralysed at three and just faded away."

While many doctors and nurses refuse to comment publicly, the debate over cousin marriages is being discussed freely on websites.

An Asian health worker recently posted this sad message: "I went to two special schools on Monday. One for children with physical disabilities; one with kids who had learning difficulties.

"The children at the second school were aged 13 to 19. None of them was capable of functioning beyond the behaviour expected of an infant. They all wore nappies. They didn't speak, a few grunts aside. All needed inordinate amounts of special care, from doctors, speech therapists, nurses, tutors and so on. The parents are drained, both financially and emotionally.

"There were six 16-year-olds at the second school, five Pakistani and a Tamil. All had consanguineous [blood-related] ancestry. I can rest my case: cousin marriages should not be allowed."

A 42-year-old physiotherapist, working regularly in three of London's most famous teaching hospitals, says that even the most dedicated health workers are growing disheartened by the burden of looking after so many damaged babies from cousin marriages.

She said: "The paediatric intensive care beds are being blocked by these tragic children. They have medical problems that will last a lifetime. Most can never be cured by drugs, by an operation or therapy.

"In one NHS hospital that I visited this week, children in half the 20 beds of the high-dependency unit were from blood-relative unions. One was a British-born Iraqi boy of 16 - his parents are cousins, his grandparents on both sides are cousins. No doubt his ancestors are cousins, too.

"He is mentally incapable. He lies in huge nappies. He cannot speak, he is fed by a tube. He should not have been on the ward, but it was deemed the best place because he had the mind and bodily functions of a baby."

She added: "In another hospital, in East London, four out of five of the £1,850-a-week paediatric intensive care beds are taken up by children with genetic disorders from inter-family marriages.

"The only young patient who could really be made well again had been admitted for more conventional treatment - he was knocked down by a lorry."

So how has this medical tragedy been allowed to happen?

Marriages between cousins are popular in many ethnic communities because they are thought to create stable relationships. Money and property is also kept in the family. According to society elders, it is better to pick a nephew or niece whose character you know as a spouse for your child rather than a stranger.

Such marriages are traditional in many countries. Throughout South Asia cousin unions comprise 23 per cent of all marriages - in Iraq it is 50 per cent and in parts of Saudi Arabia it is nearly 60 per cent.

These figures are believed to be reflected among the same ethnic groups in Britain.

The Human Genetics Commission in London says that counselling - and screening - should be offered to all bloodrelative couples, preferably before they conceive, in order to establish the risk of a genetic abnormality in their future children.

It would then be up to the couple to decide whether to have a family, or seek help through medical technology to have healthy offspring.

But there are some - even at the heart of the Asian community in Bradford - who believe that cousin marriages are outdated and have no place in modern society, especially if a child faces death or a chronic illness .

One of those is Zuhra, the mother of deaf Imran. She said: "When I married, I had no idea there was a problem about my husband being my cousin. It never crossed my mind that I would have a poorly baby.

"My parents were culturally backwards. They came from a rural village and moved here so my father could work in a wool mill and send money back home. They are not cousins themselves - because they had no cousins who were suitable - but they believed in cousin marriages.

"I only realised there was something wrong with my son at two when he didn't start talking. My husband's brother - who is also my cousin - has a girl, Myra, with a hearing problem. The penny dropped that it might be something within the family."

Genetic tests eventually conducted on her and Imran confirmed her suspicions.

She continued: "My sister is married to another of my husband's brothers and we were talking about it. I said we must not allow our children to marry each other.

"I explained my children and her children have the same sets of grandparents. They are genetically almost as close as brothers and sisters, not cousins. She agreed."

Zuhra's own wedding, which took place 20 years ago in Yorkshire, was organised by her father-in-law. Three of her six siblings are also in a cousin marriage.

"It was cultural thing, not religious. There is no insistence on these kind of unions in our holy book, the Koran, which actually warns against blood relatives marrying if there are weaknesses in the family.

"I am not angry with my parents, or even my father-in-law. They knew no better. To get support, I joined a small group of other Asian women with disabled children. Nearly half were born of cousin marriages."

She adds: "There is a British Pakistani family nearby who have intermarried and intermarried. Two sons died, another is hearingimpaired, a third has a brain problem. Their mothers say it is just bad luck."

Zuhra does not agree. She tidies up the tea table and lets Imran go back upstairs, before whispering to me: "If I had had an inkling that a marriage to my cousin would make my youngest son deaf, I would have made sure I never conceived him."

What a heartbreaking admission for any mother to have to make.