Why set up a community genetics service? : Hear from the local commissioners

Recessive disorders in consanguineous families is an important local health issue. In 2005, former Consultant Paediatrician Dr John Benson stated in a letter to the BMJ:

“the simple message for the communities that favour consanguineous marriage is that if a recessive disorder is found in the family, then genetic advice should be sought before marrying and having children…..For family groups where there is no recessive disorder, cousin marriage remains a viable option” (BMJ, 2005;331;1475).

The child death over view panel (CDOP) is a function of the Local Safeguarding Children’s Board (LSCB), its remit is to review child deaths and look for common themes to help inform local safeguarding and public health services. In Oldham and East Lancashire, since the themes from CDOP started to emerge, it has been noted that the children from black and minority ethnic communities are over represented in the child mortality figures and after the neonatal period, the largest cause of death is in children suffering from congenital abnormalities and genetic disorders.

National data and research suggest that there is likely to be increased risk of consanguinity-related disorders for children born to parents who are in a consanguineous union. Oldham and East Lancashire have a significant proportion of people from populations in which cousin marriage is common.

In research undertaken in 2010, within England, Oldham was identified as having the 8th highest proportion of parents believed to be related. This is comparable to East Lancashire where 75% of Pakistani’s in Blackburn are married to a relative (Khan et al., 2010). A broad estimate would suggest around 20 births annually in Oldham with consanguinity related disorder, of whom around eleven each year would live with a chronic disability and the other children may not live beyond the first year of life.

This evidence shows the need to support informed marriage and reproductive choices within these families by promoting genetic literacy and enhancing access to genetic services. Based on this there is an exemplar family centred genetic service at the Royal Blackburn hospital for families living in Blackburn with Darwen and East Lancashire and one in Oldham Royal hospital for families in Oldham.

To enhance access to genetic services and support families with genetic conditions has led to the funding of a community genetics team. The role of the team is to increase awareness amongst professionals and the local population in relation to the effects that consanguinity could have on a child’s health, with a specific emphasis on developing and maintaining support for families affected by genetic conditions. Over time, it is hoped that this will have an impact on child mortality figures and certainly improve access to genetic advice and support for the population of Blackburn with Darwen, East Lancashire and Oldham.

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