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Re: Recessive Genetic Conditions – the experiences of parents and professionals

I was very pleased that Healthwatch chose to focus on this as a priority, and an example of how health inequalities experienced in the early years can have a profound impact on the life course for both children and parents. This is an issue that crops up consistently at the Sheffield Child Death Overview Panel.

It is clear from the report, and we know from other intelligence, that not enough people are receiving access to the information at an appropriate point to make informed decisions and this unmet need is concentrated among individuals and communities who consistently experience discrimination within services and wider society.

The report highlights that more and a wider group of professionals need to take ownership of the current situation in Sheffield and recognise their responsibility to meet the needs of communities that are particularly affected by recessive genetic conditions. There is a range of support available to equip staff with the skills and competencies to do this, including the Sheffield Genetic Literacy project which Public Health fund. There is scope for more joint action to identify affected families and enable them to benefit from improved access to genetic counselling and specialist services.

We will be seeking to work with GPs in particular to be proactively identifying and referring more people for enhanced genetic support. Their role and influence over individual behaviour is crucial. The report showed that having that extra information and culturally appropriate emotional support for families was an important and re-occurring theme.

We have had and should continue to play a pivotal role in bringing together professionals from key settings (including maternity, health visiting, primary care and the genetics service), and in helping to develop the national evidence base to demonstrate what measures are most effective in improving genetic awareness and increasing access to culturally appropriate support.

Of course, we need to apply the learning about inequalities which the COVID pandemic has highlighted particularly in BAME communities to improve the information and advice which families receive about these conditions and their access to clinical genetic services.

Notwithstanding the pandemic (which has significantly altered my day to day priorities) I remain committed to supporting this area of work.