Aesha's* story

Aesha has been accessing support through Women Zone as part of the Genetics in Communities project. This is her story.

Aesha came over to Bradford when she was aged 16, speaking no English. She was married and at 18 had her first child who was diagnosed with a rare genetic condition.

"The doctors told me they were concerned because my daughter wasn't lifting her head properly. It took a long time to get a diagnosis but eventually they told us our genes matched and it was bad luck because we weren't cousins. They said that my daughter was blind and would never have sight.

"I was scared, about lots of things. I remember the room was spinning. I didn't know where I was. I didn't know what to say to anyone. I was devastated and had no support. We are not cousins, so how did it happen to us? Nobody explained it to us at that time.

"I heard my mother-in-law talking, saying her son's life was destroyed. We were all blaming each other. They were in pain; I was in pain. None of us knew what was happening and we had no support. I was struggling listening to all the talking; it was stressful and there were arguments. I couldn't take it."

Just getting by

"From that time for five years we just coped with it. We didn't know what we were doing but we just tried. It's still emotional for me because if we had support from WomenZone at that time we'd have had the reassurance that there is help out there.

"After my second child was born with the same recessive condition my husband and I separated because we were at breaking point. We needed support as a family. We felt like our life had stopped. It was the best thing for me to do to get out but I was worried if I would be good enough for my children."

Genetics in communities project

"What WomenZone and the Genetics in Communities project is doing is amazing. It makes me happy to know that there is more awareness and other parents and families will get support. It would help calm your nerves to know you are not alone and there is lots of help available.

"I came to all of the groups and classes and it was really nice to see other parents and learn about genetics. I found out what genetics actually was, it was explained exactly how it happens and why. It's not just about cousin marriage. I remember all the support workers, all the teachers. I always say they are part of our family. I remember every single person's name. My daughter is a strong individual because of them.

"Now we know the questions to ask in future and the confidence to ask for support if it is missing. For me I didn't know support was out there, so I didn't ask. There are more opportunities now. I don't have to worry about it anymore."

Life-saving support

"For me, community centres like WomenZone are life-saving. I had no family in this country when my husband and I separated, and I struggled. But these community centres - Karmand Centre,

SureStart, WomenZone – these are the few places where I feel at home. I can come and ask for help if I need it.

“During COVID-19 when I heard these centres might be closing down I was having a nightmare. I was thinking, people like me, what are they going to do? Who are they going to turn to? Because there are lots of people out there who don’t have any support and these are centres help them. Not many people can speak English and it’s a very big support.

“I’ve always been a talkative person, I just needed to be heard and for someone to sit and listen. The most painful part is when you’re alone and no one can understand how you’re feeling. Nobody gets you.”

A brighter future

“It’s a good future for other parents and other families. The Genetics project can save people from breaking point. My daughters don’t understand why their dad is not there and it hurts.

“My daughters will feel stronger when it comes to marriage for them because they will have lots of support. I am happy for them that their future is stronger that what mine was. I feel happy for all children and families out there in the same situation because I know there is the support for them.”

Supporting families

Mazish works at WomenZone and has supported Aesha through the Genetics in Communities project, she said: “This is a traumatic story and we have referred Aesha into other services at WomenZone as well as the Genetics project, linking her in with Talking Therapies, which helps people talk through trauma.

“Aesha is a very strong and inspirational lady. This project has helped her get clarity around genetics and to know that in future she can help others by sign posting them to the service - we’ve seen a lot of advocacy coming through Aesha, which is really important. It’s helped her because she now feels like she’s empowering other people which was the focus of the Genetics project. We want to empower people who then go on to empower others.

“We ran a number of workshops, starting with how the body works, how a genetic condition could affect a person, then we moved on to what genes were and where they were found. We covered recessive conditions, how they are passed on and how this works in a family dynamic with the same recessive condition.

“Aesha is a lot more accepting of what has happened, she knows it’s not her fault, it wasn’t her husband’s fault and that is the biggest change. When we first started, she wasn’t in that space.

“We could see exactly what the people attending the sessions wanted and we adapted the service to give them what they needed. We built up a relationship with Aesha which took time, it didn’t happen overnight. Personally I connected with her, we had a shared connection and I want the best for Aesha and her family.”

Thank you, Aesha, for sharing your story. You can learn more about the Reducing Inequalities in Communities (RIC) programme here.

**Please note that this name has been changed to protect anonymity.*