

Co-producing a new care pathway for Down's Syndrome

One of the most rewarding pieces of work during 2017-18 was the development and launch of the new care pathway and clinical guidelines for Down's Syndrome by families, carers, the CCG, the Downright Special Network, local health professionals and people with Down's Syndrome.

Initial discussions with parents and carers had identified gaps in their awareness of services which had resulted in children missing out on vital support. They highlighted the difference in quality of care they had received, and their wish to have a consistent approach to referrals and support while maintaining personalisation.

The CCG responded in bringing together a Downs Syndrome specialist nurse and local support groups to work with the families, carers and health and care professionals using an 'experienced based' co-design approach. A series of in-depth focus groups for parents and carers and for professionals explored key issues and barriers in accessing health services towards developing a new pathway.

It was clear during the process that many parents had not had the chance to voice their experiences of health care at the point of diagnosis and their day-to-day interactions with



health professionals. As a result more sessions took place to ensure that the pathway reflected these unique perspectives.

This piece of CCG-led engagement involved 36 health and social care professionals, 21 parents and carers, and 6 people living with Down's Syndrome. When parents were asked how they would like to launch the

pathway, the overwhelming response was for a celebration both of, and for, their children to coincide with World Down's Syndrome Awareness Day 2018.

At, what proved to be a very emotional event, parents spoke of their pride and gratitude to be able to develop the pathway.

Find out more about the Down's Syndrome pathway for Hull at www.hullccg.nhs.uk/downssyndromehull/