

## Hannah's Story

## **Dental Services in Bolton**

Shared in November 2022

Hannah is 13 years old and has a rare genetic condition called Cornelia de Lange Syndrome (CdLS). It affects around 1 in 30,000 people. It causes a broad range of symptoms, ranging from mild to severe, and can affect a person's growth, skeletal system and internal organs and can cause learning disabilities.

Hannah was referred to Bridgewater's Dental Service by her NHS dentist. The Dental Service have seen Hannah from a young age and she has regular check-ups with them.

Hannah's mum says:

"Given Hannah has profound disabilities, any medical procedure can be extremely



distressing for her and diagnosis of an illness can be hard to ascertain. She can't explain how she's feeling, she often can't indicate where pain is either. And so to achieve the best possible health outcomes for Hannah, good medical care requires creativity, flexibility, knowledge, skill, and excellent critical thinking – often thinking outside the box... or even casting that box aside. It also requires partnership working...with parents and sometimes other colleagues too."

"From the friendly and welcoming reception staff through to the dental team, Hannah is seen as an individual in her own right. The dental team seem to have enough time to work with Hannah at a level and pace suited to her. If Hannah doesn't feel comfortable sitting in the dental chair, the dentist will try to examine her whilst she is sat in her buggy. There has also been a time when Hannah was examined on a mat on the floor... and Hannah seemed much more comfortable there."

"There are many strengths of the team, from good communication – Hannah, despite being non-speaking, is always communicated with – to their flexibility in how they examine Hannah. Also that Hannah usually has the opportunity to see the same dentist on each visit...one who is more aware of her strengths and needs. My child, like many others, requires sameness and routine."

The Dental Service asked Hannah's mum how they could make the service better for her family and other patients. Hannah's mum recommended booking patients in for their next appointment whilst they are in the clinic to ensure the appointment time is suitable and to prevent delays, promoting the service to the wider SEND community including parents and carers, and employing additional experienced dentists to serve the growing numbers of people requiring the service. The dental service are currently looking at how they can implement these recommendations.

Thank you to Hannah and her mum for sharing their story and for giving us feedback on how we can improve our care even more.