

## **Patient / Service User Stories**

**B – 3<sup>rd</sup> November 2015**

If you access more than one service they do not work together.

Access to information is not there – providers don't share the overall picture with each other or with service users/carers.

B has 2 children aged 5 and 6 years with a genetic muscle condition. In the 5 year old the physical aspects of condition began to affect mental development.

The son was diagnosed late because very little known of his condition. It was hard to get a diagnosis even though the mother saw all the issues. Clinicians only dealt with their part of the problem and specific symptoms could not see the whole in the way mother did.

Medical professionals not always aware because condition is rare. Diagnosis of sons ASD opened door and led to eventual diagnosis of complete problem. One doctor was able to diagnose both the physical manifestation and the effect on the brain which appeared as ASD.

Daughter same but then not ASD, in reality she may have been better off being misdiagnosed with ASD because of the doors to treatment that offers.

Clinicians need to see the whole picture not just their specialism and all appointments should be in one location to avoid distress for the children and to make logistics easier.

Children have had access to a 20 minute appointment in school setting. This is much better because it is less disruptive, take 20 minutes out of lessons for the child rather than half a day.

Son had feeding problems as a baby caused by condition and began to lose weight – it took 7 months before anyone would listen to the mother concerning her fears – son referred to speech therapy but had to wait another 4 months to access the service.

Speech therapy one of the most important services accessed but also one of the most inconsistent. 9 out of 10 therapists were locums which meant restarting each time with the background story.

Portage really helpful.

Homestart was really good supporting parents as well as children – but lost funding.

When children were younger there were all sorts of appointments for all sorts of checks – had to fight just to get both children seen together at one appointment.

It was left to the parent to try to coordinate appointments and ensure clinicians had full notes of whole issue. No one suggested care plan until Homestart were in picture, from then all involved in care planning.

Providers were constantly saying they had no money or resources.

Occupational Therapy waiting list was 10 months. Both sensory and physical Occupational Therapy needed but 5 month wait to transfer from one to the other.

It does seem that he/she who shouts loudest gets the service.

Information really hard to get – the local offer page on council website tells you what the council offer but no detail and very hard to navigate through.

Services ok but you always hit that wall – no money – no joined up working.

Someone visits you for an appointment with child but only have notes for their service not all the child's issues. Need some way that all notes are shared.

Need consistency with who sees the child so that relationships can be built with child.

Therapists were removed due to restructure but never replaced - daughter left without therapist.

Parent has had to act as coordinator of services to help get transition of care in place.

Some form of self referral to services would be really good.

CAHMS = helpline – extend this to other services.

Parents could benefit from one or two hours a week offering support where parents can meet and share stories, experience and support – even if virtual drop in.