National Assembly for Wales Children, Young People and Education Committee CAM 31

Inquiry into Child and Adolescent Mental Health Services (CAMHS)

Evidence from : Conwy BIG Community Voice

Response from a group of parents working with Conwy BIG Community Voice (Emma Roberts, Project Officer for Conwy BIG Community Voice, NWAAA - emma.roberts@nwaaa.co.uk)

The group was started to allow adults respite care for their children and allow them time to relax and chat to other parents going through similar things. All children who attend the activity have different disabilities, mental health issues and different needs and require different levels of support; this is given by the organiser and a group of volunteers, the parents are also always present but discussing issues in a separate room. The group meet every week including in school holidays. Conwy BIG Community Voice joined the group formally to enable the parents to get their voices heard about services which affect themselves and their children and to speak to services both local and national about issues they have experienced and how they feel services should change.

4 parents out of a group of 6 responded to the consultation and look forward to hearing the results. These were 2 parents acting alone and 1 couple.

While consulting with the parents, they each had a piece of paper with set questions on to reflect the section what the Welsh Assembly was interested in hearing about.

Do you think there are enough early intervention services?

*There appear to be no access to early intervention unless you meet certain criteria. As a lay person you have no idea what to ask for during or after the diagnosis pathway.

- *Progress for autism diagnosis seems slower in Wales to England. I'm not concerned this is a bad thing as autism can be easy to misdiagnose.
- *No. Without the school nurse giving advice and guidance and referring my son I would not have known and become aware of the procedures thus making us feel alone and isolated.
 - Access to community specialists is...

- *Difficult.
- *Very hard to access.
- *Through referral we didn't have to wait too long and the specialists were extremely helpful and understanding.
 - Are CAMHS involved enough with other services?
- *I actually don't know. They appear to inform other services when decisions are made.
- *Yes I think so.
- *No. They provide you with an information pack in order to pursue organisation and services yourself.
 - Do CAMHS have enough resources to help?
- *No.
- *When you eventually get an appointment.
- *No. They are extremely understaffed causing long waiting lists and lack of communication.
 - What is access to CAMHS like?
- *Very slow, referral to first visit is too slow for families who need help. Once you have a diagnosis they then discharge you, can be slow to get back in for review.
- *Torturous.
- *Very length and time consuming which causes further anxiety and stress.
 - Does CAMHS promote the best for children? Why?
- *Not really, I felt my son was not involved in the diagnosis process. I felt they needed to see them more to make a correct diagnosis.
- *Understaffed and rushed.
- *Not sure as still in the process of recently being diagnosed.
 - Any other comments about CAMHS?
- *CAMHS need to be clearer about their role as a diagnosis service.
- *Local CAMHS need to have up to date details of all groups in the locality who work with children with mental health issues.
- *We were lucky to see the same person throughout the process, but others had several different professionals.
- *CAMHS need to inform parents of all assessments that are being done, and not allow parents to find out via their children.

- *Seems extremely unfunded and discharge policy is not beneficial to the children or families.
- *Once seen by them process is then actually quite simple.
- *I had to wait months to even receive the reports from CAMHS regarding my son.
- *I was constantly pursuing CAMHS to obtain further communication in regards to actions, delegated staff, reports etc.