

North Somerset Parent Participation Forum

Our Voice Counts

Open Meeting 20th April

Notes Made at the Health Workshop

Issue 1. Families need more information and support following diagnosis

The group talked about their experiences of getting a diagnosis. It seems to be that if a family and their child have a prompt/early diagnosis support is put into place in a straightforward way. However, many people's experience is of having to spend time (sometimes many, many years) chasing a diagnosis so that they can get some help and support. Some members of the group said that 'undiagnosis' is the hardest thing! The descriptions used were of empty/lonely years.

It was generally felt that people should be able to get help and support when they are experiencing difficulties/differences with their child whether there is a formal diagnosis or not. One person described this as 'we need a service that says to people who are struggling 'you do need that help' – whether there is criteria match to service provision or not!

The group discussed the experience and voice of parents as being the most useful guide – being unlistened to becomes frustrating and adds to the stress people have (especially when they are confused and anxious because they know there something that needs to be attended to.

A discussion regarding the potential for keyworker system to address many of these issues took place (see Issue 5 for notes)

Issue 2. Despite fantastic planning and liaison with consultants and senior therapists prior to hospital visits, experiences during appointments can be devastating for children and their parents when these plans are ignored. How can this be avoided in the future?

This common experience seemed to regularly involve just one person not believing/thinking that they had to follow the given requirements (the carefully arranged plan) to help the child through the health experience. Often the health care team around the child would have worked really hard to get supports set up to meet the specific needs of the child. Having thought everything was arranged people spoke of feeling hugely disappointed and frustrated when a key person at the health care setting in question had elected to not follow the process. Some major effects and worrying outcomes

have been experienced because of this. The group talked about the need for work to be done with consultants/doctors. North Somerset is apparently going to do some work with the Doctors at the BRI – the groups asked who would be doing this and what would be the content of that work?

The group also asked about the possibility of being involved in the training that medical students receive.

The 'All About Me' booklet could be extended out to use with other services – this might offer some better understanding in the medical arena? The group would also like this to be looked at.

Issue 3. How can we achieve easier/ongoing access to CAMHS (Child & Adolescent Mental Health Service) for children with complex additional needs? This was a recommendation arising out of regional consultation but families are finding in practice that they are forced to return to their GP for re-referral following discharge. How can parents contribute to planning and development of this service?

The group included a representative from the CAMHS service (Mary Fenner). Questions regarding the possibility of being more flexible about referral and re-referral for children with additional/complex needs took place. Mary explained how recent changes meant that Elaine Boulton and Sarah Robinson are now part of the CAMHS team and take a specific focus on our children. Mary explained that caseloads are kept open as long as it is seen that their involvement is necessary. The group explained that whilst they understood the process, the fluctuations over long periods of time meant that often our children get their files closed and then, at some point further down the line, can urgently need help and support again. They reported lots of problems associated with getting a further referral made and spoke of waiting long periods of time before getting much needed help. Mary said that she would go back to the team to discuss the issue. Paula also said that she would look for the reports that were produced as part of a regional piece of research/action learning (led by David Goodban of what is now the South West Development Centre) – which included responses from parents/families in N. Somerset about the CAMHS service. She would then let Mary have the information for them to use in their thinking and planning. Mary explained that the service was eager to find ways to include and involve families in a structured and useful way.

Issue 4. Children with autism but without a diagnosis of learning disability, who present challenging behaviour at home, are currently unable to access the MAST (specialist behaviour support) service. These children's difficulties do not fit comfortably within the CAMHS remit either as they do not arise out of a mental health issue. How can their needs be met?

This issue remains outstanding for exploration, discussion and potential problem solving.

Issue 5. Lead professional/keyworker: When children have complex needs and a range of services are involved, how can parents remain well-informed about their children's condition, care and treatment? What are parents' rights to be copied into reports concerning their child's health care? What are the arrangements for the appointment of Lead Professionals or key workers, to ensure holistic planning and joined up services for our children?

This discussion arose out of the groups exploration of Issue 1. Marry Fenner informed the group that North Somerset already have a ?consultation document circulating relating to the adoption of a Lead Professional system. This would, it seems, involve a paid worker being allocated this role (as a part of their existing role) where a child/family have anything more than one agency involved in their care, treatment and support of the child (across the range of children's services). The group said that often the Health Visitor in the early years seemed to do this kind of job – and that this had worked well for them. But this then gets lost as time moves on. The group also wanted to know what N Somerset's proposals involved, in much more detail, so that they could weigh up whether they were being offered a keyworker system (where they could act as keyworker for their child if they chose) or whether it just about professionals taking on the role.

The group also discussed whether this process would offer improvements in the experience for children as they move into adulthood (and adult services). Would better co-ordination across services include health transition and safe/seamless health support at this crucial time?

Outcomes for the working group:

The group thought that the combined issues 1 and 5 should be the focus for the working group for the next six months before the next Open Meeting: Diagnosis/information/ health care support and co-ordination and the Lead Professional Role.

A number of parents signed up for the Working Group. However, neither of the two professionals that joined the workshop were indicated as key people for this role and so we need to seek some representation from appropriate services/personnel.

- Maxine Grantham - parent
- Cathy Fuller – parent
- Helen Ash – parent
- Debbie Bench – Family Support Disabled Children's Team
- Vanessa Phelps –
- Paula Edmondson – parent (steering group member)