Notes from meeting with NEL Parent Participation Forum held 13 June 2016

The meeting was attended by seven representatives of NELPPF, a HWNEL volunteer and myself. We focussed on the positive question: what makes a great appointment', recognising that we were talking about both GP appointments and those with secondary care/specialist doctors.

We looked at some of the positives in the local situation:

- It was relatively easy to find information on GPs and GP Practices.
- Parents can guide to assist practitioners

However, there were also negatives:

- Perceived negativity of (some) practitioners (towards special needs)
- Frequent use of locums or staff on short-term contracts frustrates continuity

A number of issues were feeding into the need to constructively navigate the system for appointments. The Child Development Centre was currently discharging children with special needs aged 15 back to their GP and/or CAMHS unless they had special needs. There were concerns about how much help a GP could reasonably offer and how many. For example, would they refer to the Autism tool-kit recently drawn up by NHS England? Reference was being made to referral to the adults learning disability team but it was not clear how this fitted with a smooth transition to adult services when the child was still only 15. There was felt to be a greater need for more transparency

The context of financial constraints on health and social carer was recognised but that this had to be balanced by a recognition of patient/user rights. Those rights will include what is stated in the NHS Constitution e.g. on waiting times and what it is on the Local Offer. A comparison with best practice elsewhere also informs local arrangements.

Exercise

We drew up top tips for securing a good appointment and a lot of suggestions were made:

- Prepare: write down or be clear what you need to ask the doctor. Having a request in writing is sometimes helpful. Plan in advance for more complex situations.
- Make sure you see the doctor you want – even if that means waiting longer.
- Recognise that you do not always need to see a GP and that there are increasingly other health partners available e.g. pharmacists. Know who you want to get help from.
• Ask for a telephone consultation (triage) if that will suffice.
• Consider the whole dynamic: actual appointment, waiting times, environment, support during appointment.
• Transparency, honesty and understanding (no blagging).
• Show commitment: if you say you are going to act on something, do it within reasonable timescales to enable family support e.g. letters.
• Book a double appointment if you need extra time.
• Remain calm, pleasant and confident (but take tissues if you know it’s going to be hard)
• Use visuals.
• Let the young person have their say (if accompanying them).
• Take all records (especially when you are seeing someone new).
• Ask for outcomes to be put in writing.
• Be understanding but assertive. Do not accept a `no’ if you disagree – go away, consider your rights and return - negotiate.
• Ask/chase – don’t wait to be offered.
• Know your rights (if in doubt, find out).
• Know what you will accept (your fall-back position).
• Know what positive alternatives you have if you feel you are getting nowhere.
• Know how to complain if you feel the service/professional has failed you.
• Know what support is available to help you complain.
• Know who can help you if you are stuck.
• Make sure what works is shared with others.

Paul Glazebrook

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