Grassroots Event Feedback form

Borough: Kingston
Organisation: Kingston Carers
Key contact: Kate Dudley, 020 3031 2751, ceo@kingstoncarers.org.uk

Type of meeting, audience and how many attended:
- Music and dance evening
- 1:1/group talks
- Carers
- 20 + people

Date of meeting/ conversation:
- Friday 22nd April 2016, 6.30pm – 9pm

What are your experiences of local health services?
What works well? What could be improved?

Primary Care

Access
- Getting a GP appointment is difficult – you cannot get the same day appointments unless you ring at 8am and then you can’t get through. This is why people go to A&E.
- Not heard of 111
- There is an issue with consistency around GPs – you may not always get your GP as they have long waiting lists.
- Patient Choice – “I don’t feel like I have a choice of who I see – if I’m fussy I won’t get an appointment”
- Receptionists can act like gatekeepers and ask untactful questions to parents of children with learning disabilities. One parent was asked why they were calling on behalf of their child when she was over the age of 18. The parent had to explain that the child had severe learning disabilities and was non-verbal. Of note – specific feedback received about the attitude of a receptionist at the orchard practice.

Length of appointment
- Need to have longer with the GP when discussing complex cases – including mental health concerns. Carers may have their own mental health issues that should be picked up during the appointment.

Care navigation
- Very difficult as a carer to navigate through the care system. GPs aren’t great at giving out advice
- Carers have had to do their own research to find the right care for their family member. “We’ve had to find everything out ourselves”.
- Information leaflets should be present in GP surgeries.
- It would be helpful to have a mental health nurse at the surgery to help navigate to the appropriate service

Reception staff
• Receptionists at GP surgeries need training. “I booked an appointment for my daughter who has LD – was asked if my daughter should be booking this appointment as she is 38. If the receptionist looked at her notes, she would have seen my daughter is non-verbal”

Caring for the carer
• “My GP never asks me how I’m feeling – how I the carer feels”
• Need to look after the mental health needs of the carer

Urgent & Emergency Care/Hospital Care

Urgent care
• “I have a new Urgent Care Centre down the road from my house – I don’t know what it’s there for? I can’t use it unless I book a GP appointment beforehand. “

Navigating the system
• Navigating the A&E system as a carer is very difficult.
• “Taking your disabled child to A&E is very difficult, no one explains what’s going on to you”

Workforce
• All Hospitals should have a learning disability nurse.
• “Nurses are excellent at Kingston Hospital, do such a great job”

Complaint system
• Person raised a complaint against Kingston Hospital and but nothing has ever been done.

Cancelled appointments
• “My appointment was cancelled – I was never told why?”

Mental Health Crisis
• Some carers have turned to A&E in desperation for support. However, the mental health needs of their ‘cared for’ are not well addressed in emergency departments.

Support for people with learning disabilities
• An experience was sited of a parent taking their screaming, non-verbal child to A&E and having to wait 7 hours before they were seen. No LD specialist on site to support.
• There needs to be a clearer protocol for what to expect at A&E when treating someone with a learning disability. Both carer and patient did not know what to expect.

Mental health

Continued support
• There should be long term support provided for people once they’ve been discharged from care (whether this is as an inpatient or community patient). Often people will snowball into a crisis again as no further support is given to help them maintain their health and wellbeing.
• When services say that a patient is being ‘discharged back to the GP’ essentially they mean that they are being discharged back to the carer. And the carer does not always know what support to give them in order to keep them mentally and physically well.

Parity of esteem
The mental and physical needs of people need to be addressed in tandem. Cases noted when carers have called out Drs to assess their frail relative and they have only dealt with the physical needs and not their mental health.
**Voluntary Sector**

**Value of support in the community**
- Kingston Carers have saved my life and my sanity.
- I am a different person because of Kingston Carers.

**End of life**
- Princess Alice Hospice is run by the voluntary sector, how does it care for patients at the end of their lives so well?

**Out of Hospital**

**Learning disabilities**
- There are not many services that are suitable for people with profound learning disabilities.

**Prevention**
- There should be more support for people to live healthy lifestyles. There is over a 3 month wait to see a dietician at the orchard practice.

**Any further suggestions about what could be done to improve services?**
- A helpline for carers – carers don’t know where to go for help
- A rapid response team for people with a MH crisis.

**Positive feedback about services**

**Kingston hospital eye unit**
- The eye unit at Kingston hospital was praised on a number of occasions not only for the effective treatment that they provided but also because they have very dementia friendly staff – that treated the patient with dignity and respect.
- Patient noted the success of their cataract operation – and that they do not need glasses for the first time in their life.

**Tolworth hospital - memory clinic**
- Nurses were particularly responsive to the needs of the patient and of the carer – subtly checking information with the carer without undermining the patient.

**End of life care**
- Wife died at home and spent the last two weeks in their family home. The care she received was excellent and the family appreciated her being with them at the end.