



DRAFT HEALTH MEETING MINUTES 18/06/19

Lucy Fullard (LF) welcomed everyone to the meeting. Parent Carers introduced themselves and gave a brief description of their experiences of using Health Services.

Bren McInerney (BM) Care Quality Commission Community Volunteer

Hannah Williams (HW) introduced herself as the senior nurse lead for community quality. Hannah has the lead for quality across a number of areas including Carers.

Jennie Shine (JS) introduced herself as the Senior Commissioning Manager for Children's services in Gloucestershire working closely with Social care and Education. Her portfolio covers the hospital trust and community services but not mental health services. She has a background in nursing and wants to ensure that she commissions services that meet the needs of children and young people and their families.

Debbie Clark (DC) introduced herself as Lead Commissioner who works across Health and Social Care and recently recommissioned the two new Carers contracts. Engagement took place with over 400 people to help inform the procurement. Her current responsibilities include the Proud to Care Programme, promoting more employment in care roles, particularly that of personal assistants. She has a background working in the voluntary sector including the RNID (Royal National Institute for Deaf People) and the BLF (British Lung Foundation) before joining the NHS.

Dr Imelda Bennett (IB) introduced herself as a having been a Consultant Paediatrician who worked with many children with complex needs, and who now has roles in the Clinical Commissioning Group as Designated Doctor for Safeguarding Children, and for Children in Care and Adopted.

DC explained that they all came to the meeting to listen to Parent Carers views and experiences, they hoped to have an interactive conversation, to establish how well communication is working, to share the process of mapping health provision to families whilst ensuring that they also work with the Parent Carer Forum.

Engagement with Carers

A new Partnership Board for Carers has been established, similar to the Boards for Learning Disabilities, Physical Disabilities and Autism. The Board has a varied membership and agree key priorities for the Carers work programme for the year ahead. The first meeting is taking place on 26th June.

People Plus is also setting up a Carers Reference Group which will bring together many organisations involved in supporting carers.

INTEGRATED CARE SYSTEM

Nick Relph is the Interim Chair of the Integrated Care System (ICS) which will apply across Gloucestershire and will focus on the individual rather than on service boundaries and restrictions.

BM has met 1:1 with Nick and believes Nick is committed to meeting Carers and getting their opinions and experiences. BM could facilitate setting up a meeting between Nick and the Parent and Carer Alliance in due course as and if appropriate.

BM feels that it is a disgrace that cyp had not been included originally in the integrated care system review and is pleased that Chris Spencer, Director of Children's Services is now involved. DC suggested that she and BM talk after the meeting as BM says an Action Plan needs to be communicated.

BM also said that Mary Hutton, ICS Lead and Accountable Officer for the CCG has committed to meeting with the Alliance

LF thanked BM for his support for Parent Carers and for enabling these meetings and explained how he has been awarded an Empire medal.

Communication

There was a discussion about the need for better communication between services, as well as the frustration of being assigned a service which carries out a single assessment, provides e.g. equipment, then discharges the cyp and can't be contacted about how effective the provision is over time, or how it no longer meets a need due to e.g. the cyp growing. There are also issues with communication between and within services due to IT systems not joining up

The cc list used by hospitals when issuing letters are not being updated. As a result some organisations no longer involved with a cyp are receiving sensitive information whilst those that are involved are not getting any information. IB recommended taking in a letter to the clinic which states who should be copied in.

Families described receiving letters, nursing notes and EHCP forms which were either not those of their cyp, or partly had another cyp information in them. HW asked to be emailed the details of these as she has an Information Governance role

Updates on medication for a cyp be made over the phone in conversation with a Paediatrician, but schools will only allow medication to be given at the dose on a pharmacy label. IB advised that a change of medication form should be completed by the Paediatrician and sent to the GP. It can be copied to the carer. It may also be possible to get a copy of the changed dose from the Pharmacy.

A parent experienced poor care in an out of area hospital as, due to her cyp being non-verbal, there was insufficient 1:1 care provided to support nutrition, hydration and intimate care needs and prevent the cyp being harmed

JS explained that the Well Child nurse role is about supporting cyp who have care from different hospitals and where the cyp care is at risk of failing due to issues with communication between the hospitals. The need for the well child nurse to support a particular cyp will be identified by their Paediatrician. Staff injury had delayed this role.

Families going through the process of a personal budget from continuing health care funding have been told that there is a cap on the hourly rate available. JS explained that there is an indicative budget calculation and that if this is not sufficient then there is a need to negotiate the case with Commissioners. HW can provide guidance on CHC personal budgets and can be contacted directly for advice

Therapies

There is also an issue when cyp are no longer assigned a therapist but have surgery and a service which is not familiar with the cyp meant that equipment provided was unsuitable and there was no post-surgery follow up. On a show of hands 29% of those attending had been provided with inappropriate equipment, costing services money and failing to meet the needs of the cyp.

One family explained how they had multiple therapists from Physio and OT for their children as different therapists were assigned to mainstream students than for special school students

JS explained that she is doing a review of therapies and has a list of which will be focused on including Speech and Language, Occupational therapy and Physiotherapy and would like parent carer input

ACTION - HW and JS both said that assessments should be holistic and that they can challenge this with providers if given examples.

Diagnosis

There was a discussion about the difficulties which arise in trying to identify a cyp's additional needs by being given a diagnosis. Some families described a difficulty in GPs being able to progress a referral to see a Paediatrician. When cyp are not given a diagnosis – how this can make it difficult to describe a cyp's needs to other organisations such as schools, and concerns raised that condition statistics will be incorrect if there is a significant number of cyp whose symptoms aren't identified by a diagnosis.

IB explained that diagnostic criteria can limit what diagnosis can be given, and that symptoms that might lead to a diagnosis of e.g. Foetal Alcohol Spectrum Disorder can also occur in children who do not have a history of exposure to alcohol in the womb. While a diagnostic label can give an idea of how a condition will affect a cyp, and could help a child to understand more about the cause for the symptoms that affect them, individuals with the same diagnosis can present very differently. Current medical knowledge is limited, both by testing capability to identify abnormalities, and the understanding of what an abnormality might mean. Genetic testing can identify differences but there is not always the medical knowledge to understand how a particular chromosome might contribute to the symptoms experienced by the cyp.

HW stated that she is happy to work with parents to develop pages on Gcare – a web based platform which is available to GPs and Practice Nurses and which lists medical needs including rare conditions. IB advised that such information should only include what can be delivered in practice, and that this is a good opportunity to co-create. ACTION- parents to contact IB/HW to progress if required.

Support in Schools/EHCP

Discussion about the family's views being discounted in preference to that of schools e.g. Family identify behaviours which may result in a diagnosis of ADHD, but school state 'the cyp is fine when with us'. Several parents stated that their child may mask their symptoms whilst in school, but come home and 'explode' as a result of containing the stress of not having their needs met in school. The parents expressed concern that needs are not being identified either by school or by health professionals due to concern over how to fund support for these needs.

A recent EHCP Tribunal also identified that information on diagnosed health needs had not been transferred into the cyp EHCP meaning that the correct outcomes and provision had not been identified.

Carer Knowledge and Support

Families described how their own knowledge, being 'Experts by Experience' is often not respected and used to ensure future plans will be effective. This is being recognised and included in the training of health professionals, with a 'proud to care' and 'personalisation' focus. Trainee doctors also visit some families to learn from them. Carers could also share their experiences as part of training ACTION

Parent Carers, especially those whose cyp have complex needs, need safeguarding and protecting so they can continue to support their cyp. Having Care Coordinators can help to support families who have to rely on support from many different organisations, which often have different cultures and terminology. This can be especially important in pre and post-surgery planning when care and support needs can significantly increase ACTION

DC advised that GCC is starting to map the training and support available to Carers as there is a good opportunity to develop this. A new engagement officer for Parent Carers, Matthew Smith, is starting week commencing 24 June who will have a role in ensuring better communication with carers

Learning Disability review

Medical training does not cover dyslexia as this is diagnosed by education specialists. However the review into Learning Disabilities can connect dyslexia into the role of a cyp as student, and their educational development as part of ensuring a holistic assessment of the cyp and integrated health care. This review will cover the school age Autism pathway and Neurodisability pathway.

Some of this work has been drafted and JS is due to meet with Education next. Following this the pathways will be reviewed by parents and then added to GCare, an information site which can be accessed by GPs

Mental Health

Several parents described how their cyp have needed to reach crisis point before being able to be referred to CAMHS, that there are long waiting lists and that a lack of understanding of their cyp's needs is wasting time. Others stated that despite their cyp being suicidal and self-harming they are being referred to the charity Teens in Crisis for education rather than to CAMHS for their cyp to have treatment.

HW said that care coordination for cyp is not just one organisation's responsibility and will find out where systems are in moving this forward? ACTION - HW to discuss with the lead Commissioner for children and Lead Commissioner for Mental Health.

Transition

Another continuing area of concern is the Transition from Paediatric to Adult services, especially for cyp with additional needs. LE has seen some improvements especially since she worked on a Transition policy

The Paediatrician's role is to consider the cyp holistically, but there is no equivalent in Adult services, meaning that care is the responsibility of the GP, who may not have experience of complex needs. There is also an issue with over 16 year old cyp being admitted to Adult wards.

The process of Transition – Ready, Steady, Go; is being reviewed with a focus on how well this works for complex cyp

Discussion highlighted that another Transition – that of home to school is also an issue as projects which have been successfully supporting children have to stop as despite no change in circumstances other than age, children are no longer eligible for the support.

A Specialist nurse, Rebecca Duggan, has been appointed to support the Paediatrics to Adults Transition. The aim of this role is to reduce emergency admissions by preventing cyp reaching crisis point. Becky only works with children/young people who have epilepsy.

SOCIAL CARE

There are also issues causing confusion with the Transition within Social care. Within the disabled children's social care service there used to be more experienced social workers who were able to support families whose cyp have complex needs. Not having a key ongoing contact causes concern and can lead to hostility as well as a failure to communicate with other professionals involved with the cyp. The CCG are freeing time to train social workers at the planned new social care academy

Currently if a young person has a complex and life limiting condition that requires palliation they are managed by Dr Emma Husbands, Consultant in Specialist Palliative Care in Gloucestershire.

Fabricated and Induced Illness Procedures

DC read out the joint statement issued in response to the FII report produced by the Parent and Carer Alliance

IB is working with GCC representative Andy Dempsey and LF and DS from PAC. Initial work has shown that the FII flowchart was not embedded in training and some families had their cases escalated inappropriately. A new draft flowchart has been circulated and some responses made by PAC.

New procedures may include an alternative term to FII, the provision of an independent advocate (Barnados), and will take into account the national focus on papers produced by Dany Glaser.

Families expressed concern that FII accusations are made by organisations other than health. DC stated that the training in the new procedures will be multi-agency

Future Meeting

8th October for a 10am start at The Club at Tuffley Park - to follow up on discussions and actions from this meeting

Glossary:

LF: Lucy Fullard; LA: Louise Arnold, LE: Louise Ellis – directors of Parent and Carer Alliance. DS: Duncan Siret Advocate and PAC steering group member

Bren McInerney (BM)(his role description ?)

Hannah Williams (HW) introduced herself as the senior nurse lead for community quality. Hannah has the lead for quality across a number of areas including Carers.

Jennie Shine (JS) introduced herself as the Senior Commissioning Manager for Children's services in Gloucestershire working closely with Social care and Education. Her portfolio covers the hospital trust and community services but not mental health services. She has a background in nursing and wants to ensure that she commissions services that meet the needs of children and young people and their families.

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