

## **Discussion note – Children with Complex Needs NHS Tees**

### **1. What is the definition of 'Children with Complex Needs' that NHS Tees uses to guide its operation?**

NHS Tees does not have an agreed definition. There is no agreed standard definition of complex needs in policy or across professional groups. Though NHS Tees and CCC use recommended guidance and professional tools to determine a child's on-going needs.

### **2. According to that definition, how many children with complex needs does NHS Tees pay for their on-going care? At what cost?**

Calculating exact numbers and associated costs is difficult as there is no agreed definition of complex needs and many children will use multiple services on an on-going basis and at undetermined levels.

To examine numbers further would require setting parameters to which children would be defined as having complex needs which may be useful in some instances such as calculating spend but inflexible or restrictive when determining resource. NHS Tees current contract framework utilises block payments and isn't tariff based further complicating the detangling of usage of multiple services and differing specialist levels. However determining approximate costs would not be impossible but would require further engagement with a range of healthcare professionals from across both acute and community settings and engagement with children, young people and families.

Here are some examples of services and the various ways that complex needs are defined:

#### **2.1 Children's Continuing Care (CCC):**

A continuing care package is required when a child or young person has needs arising from disability, accident or illness that cannot be met by existing universal or specialist services alone.

There is no agreed definition of 'Complex Needs'. As part of the assessment CCC use the nationally recommended Decision Support Tool which contains ten care domains which each have up to five levels of needs. Children who score 3 high's or 1 severe or 1 priority will usually qualify for continuing care however this tool outcome does not inform the decision alone. The outcome of the assessment is taken in to consideration along with professional reports and involvement from those involved with the child, e.g. physiotherapists, specialist Epilepsy Nurses, consultants and evidence from documentation e.g. incident reports etc.

With a continued focus on Personalisation and the announcement that from 2014 all individuals that qualify for CCC will be offered a personal budget it is critical that NHS Tees and going forward the local Clinical Commissioning Groups (CCG's) understand the potential impact. As of December 2012 during 12/13 CCC have supported 24 children at a cost circa £400,000.

## **2.2 Paediatric Therapies:**

South Tees Hospitals Foundation Trust Community Paediatric Therapies Identify 3 groups of children with complex health needs

- A) Children with life limiting or life threatening conditions who may be technology dependant with health funded complex packages of care
- B) Children with multiple and profound impairments, multisensory impairment and severe and complex learning disability
- C) Complex physical health care needs

Within these three categories they currently have the following numbers within caseload A) 10 B) 343 C) 40 this is 30% of the entire caseload. Here is an example of how determining cost would not simply equate to 30% of the total block contract as this particular caseload due to complexity and level of usage may place a greater demand on the service overall.

### **Speech and Language**

Numbers on caseload were there are additional needs related to the 'complexity' of speech, language or communication issue.

- complex physical and learning difficulties requiring communication aids: 17
- complex Autism and learning difficulties requiring specialist SLT input: 160
- complex dysphagia and learning difficulties requiring input from 2 specialist SLTs: 17
- learning difficulties and specific speech language and communication impairment: 42 in mainstream schools and 197 in Special Schools
- complex pre-school special needs pre-diagnosis / assessment / differential diagnosis: 89
- complex Specific Speech, Language and communication need (covering more than one modality e.g. disordered speech AND disordered language) - 58

### **3. How well advanced/resilient is the local market for services aimed at Children with complex needs?**

Evidence tells us in the future there will be more children with complex needs due to increased length of life with increased complexity in conditions which are risks to the current market as demand will be greater. Local services are advanced and deliver evidence based quality practice. Further needs assessment is required to understand resilience in terms of future demand. As personalisation increases consideration will also need to be given to the quality and skills of providers outside of the NHS so as to support families to make safe choices.

### **4. Does, in the view of NHS Tees, the local market in services for children with complex needs, require further stimulation/development?**

As previously highlighted greater numbers will create greater demand alongside increased focus on delivery of the Personalisation agenda it will be essential that families who qualify for and choose to use a personal budget have access to services that meet their needs from

a provider of their choice. NHS Tees and moving forward the CCG's will need to work with individuals and providers to ensure flexible innovative solutions are available. Locally on Teesside we have a dominant Foundation Trust health economy.

**5. Does, in the view of NHS Tees, NHS Tees (and the coming CCGs) have a role to play in stimulating the market?**

NHS Tees and CCG's have a role in stimulating the market and will need to communicate with providers offering active support to recognise the opportunities personalisation provides and redesign services accordingly.

**6. To what extent does NHS Tees commission with a focus on high quality outcomes for Children with Complex Needs?**

NHS Tees commissions services based on high quality outcomes and is particularly guided by national policy related to children with disabilities.

**7. How would NHS Tees describe its working relationship with the local authority, in relation to services for Children with Complex Needs?**

NHS Tees has a positive relationship with Children's services both commissioning and operational functions. An example of this has been the recent joint commissioning of short break provision for children with a disability.

NHS Tees is fully engaged with Middlesbrough Children Trust arrangements.

In relation to CCC NHS Tees currently works in partnership with the Enhanced Needs Panel where cases are more complex and joint commissioning may be considered.

**8. How does NHS Tees work with the families of children with complex needs, to ensure that their feedback shape services and service design?**

NHS Tees encourages patient experience gathering as a key quality requirement for all healthcare contracts. You're Welcome accreditation was offered as a CQUIN, an NHS contractual incentive scheme, in 12/13 and will be again within 13/14 and continues to be embedded within all new service specifications for children's services.

South Tees Hospitals NHS Foundation Trust strategically prioritises the involvement of Children, young people and families. Each individual service will have a process for feedback. They have a youth group that meets monthly and has been involved in a variety of participation activities.

CCC do not gather feedback from families in a formal manner but informally through on going contact and dialogue. This is to be developed further once an effective tool has been developed to use appropriately with both children and families.

**9. Does NHS Tees have a view on what the future demand on such services will look like as demographics change?**

This is difficult to model at this time as current data collection is not aligned to inform future planning though the introduction of the maternity and children's secondary uses data set will inform future planning. We do know that excellent neo natal care and continually improving medical care that allows children with a range of conditions to live longer and in better health will continue to impact on services locally to understand an plan accordingly needs further assessment. Linked to further assessment is the proposal locally to co-ordinate work related to Maternal Health with a particular focus on Low Birth Weight of which a paper was presented to Scrutiny earlier in December.

This will be supported by the changes related to Special Education Needs legislation. Draft legislation requires data-sharing across agencies to support early identification, intervention and integrated assessment 0-5.