



How the views of children, young people, parents and carers influenced plans for services in Devon

February 2018



The views of people in Devon

Over many years we have talked to children, young people, their families, schools and other organisations about the services that are available in Devon. We published the views gathered between 2011 and 2016 in a document and published it on our website in June 2016.



In the winter of 2016/17 we checked some of the themes that arose from these views with parents. We asked for more information about what the experience of those themes felt like.

Healthwatch Devon and Parent Carer Voice forums helped us do this.

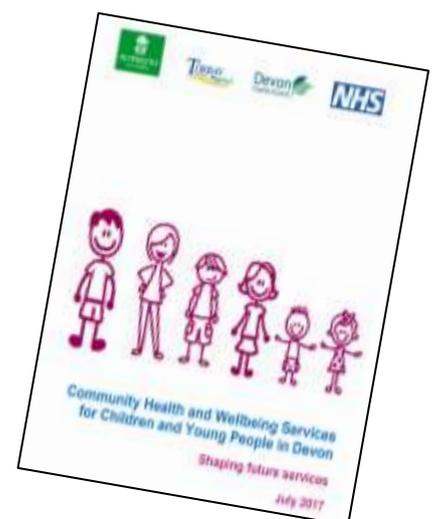
In the Spring of 2017, we took the themes and experiences that people had given us and developed principles for a future service. We also described critical factors that it must have in order to be successful for children, young people, their families and carers.



Then, once again, we worked with the people of Devon to get their views on what we had created from their feedback so far.

Over the summer and autumn of 2017 we asked them to tell us if we were on the right track in how we described how services should be for the next 7-10 years.

The comments we received have been taken into account in all of the documents we have produced for this re-procurement of services. We have also used social media to ask further questions to help us further develop our thinking.





The outcome of the most recent engagement programme is finalised in this document.

Over 900 individuals and organisations were contacted for feedback during the summer engagement period. We spoke to over 200 children, young people, parents/carers, community organisations, clinicians and health and social care professionals using various forms of engagement including social media.

In June, the children's page of the CCG website was the most visited in its history (n=2000).

Why this engagement process was important

The full engagement process gave us valuable insight and information on the wishes of children, young people, families and professionals on their services. We have used the key messages from this insight to frame all of the stages we went through and the documents we produced for this procurement.

It was important that the engagement continued while the specifications for a new service were being drafted, enabling us to test and alter things as we went along. We feel this means the specifications now more accurately reflect people's views.

Without understanding, through engagement, what is important to people who use, work in and refer to the services, the specifications would more likely be a repeat of current contracts and not be able to resolve any problems. We feel we have been able to strive for something different that we hope will resolve the systemic problems we currently experience.

The messages we heard and how people prioritised them are being built into the questions we will ask each of the bidders in the procurement process itself. Parents, children and young people are being directly involved in designing questions and evaluating responses to them, therefore directly influencing who is chosen to be the new provider/s of services in Devon.

What the engagement told us

Having reviewed the feedback, there are some clear areas for improvement that need to be undertaken by the current providers. Rather than wait a year until the new contract, we have already asked them to tell us how they are tackling each of the issues that their service users and other service professionals have raised:

- CAMHS (rapid response, waiting times and transition)
- Autism – reduce waiting times for diagnosis
- Routine collection and action on experience [*of service users* sic]
- Single point of access to increase opportunities for integration
- Better communication between all
- Tackle barriers to accessing services
- Quicker response times by professionals to phone calls

- Review the super-hubs – are they working?
- School records clear when a child is adopted
- No support for 0-13 year olds with mental health issues in East Devon
- Staff morale
- Staff retention
- Response re cognitive behavioural therapy service cessation

Critical Success Factors

Together, we have agreed the following as the critical success factors. These have come directly from what people have told us and will be the signs of success that we will want to see achieved by the organisation that provides the services from 1 April 2019.

- An **integrated, personalised** model of provision that can respond to the holistic needs of a child or young person, their families and carer
- Seamless **pathways of care** and support that transcend policy, organisational and service boundaries
- **Sustainability** of provision by ensuring **best value for money** without reliance on additional investment
- An improved offer of local, **universal** support with timely **access** to **targeted** and **specialist services**
- Improved opportunities for children and young people at **transition** points in their life

Key Principles

The feedback we have received through all our engagement has helped us agree principles that our future service should be built upon:

- **Prevention is a fundamental aspect of provision:** whereby the provider priorities the early identification of each child or young person's needs and risks to health so as to help avoid them becoming ill.
- **Early help should be embedded across the system:** children and young people their families and carers will be offered help and information early in their life and early in the development of specific needs, whether these be health and/or care or educational needs.
- **Innovation and evidence based provision:** we and providers will continuously strive to improve the lives of children and young people through innovation and ensuring the best and most current evidence is used by existing practise and systems. Together we will use technology and different ways of working with children and young people, using methods of communication that will engage them effectively.
- **Sustainability is key:** we and providers will use early help and proactive intervention, will help drive sustainability of the system. However, we will also need to ensure efficiency and effectiveness through the use of technology and good workforce management.

- **Systems should be responsive and accessible:** the system will respond to the changing needs of the population delivering support that is designed with children, young people, their families and carers and that is delivered at the right time and in the right place.
- **Services should be personalised and use a strengths based approach:** this develops choice and control for children, young people, their families and carers using known information to tailor and personalise the response.
- **Systems and services should be integrated:** to ensure that it is united by a common focus on delivering outcomes for children, young people, their families and carers within a co-ordinated seamless experience. There is 'no wrong door' and professionals are able to work across the system to deliver the best possible care. The integrated system uses information and data to develop and deliver effective practise. It is also capable of understanding, managing and accepting risks with children, young people, their families and carers.
- **Build upon the strength and resilience of individuals, families and communities:** recognise that children and young people live in families and communities; value and enable the role these play in developing and sustaining happiness, wellness, health, and safety. Empower children, young people and their families to help themselves, build resilience and safely manage risks.

How did the feedback influence the procurement process?

Throughout this process we worked with an engagement steering group that was chaired by a parent from Devon Parent Carer Voice and involved Torbay Parent Carer Forum and Healthwatches from Plymouth, Devon and Torbay. This group gave essential guidance on how to ask our questions and how to enable as many people as possible to take part. Via commissioners, it referenced back to the SEND Steering Group that had been operating in Plymouth for some time.

Children, young people and parents are now fully involved in the process to select new provider/s of services. Parents are being trained alongside CCG and Local Authority staff to become evaluators of the bids received. Living Options Devon is facilitating groups of children and young people to enable them to design questions that they want asked during the formal selection process.

During the pre-procurement process a common question was how we would be monitoring the new provider. This is a key question that we have been discussing with the steering group and the parents who are involved with the procurement process. Together we are devising a way they can be involved with routine contract monitoring meetings with existing and future providers.

During the pre-procurement phase, one of the most consistent issues raised was how families struggle to get advice or help when they need it, feeling vulnerable when they are hanging on with little information, or need to wait for a new referral back to a service they have previously used.

Commissioners responded to this by putting forward a co-ordinator role. In their minds, this role would support parents to navigate the system, keep them informed of next steps and put them in touch with other organisations and support groups where needed. During the engagement process, we tested this concept; would the role be well received? What best could this person do to support families? We received mixed reviews with some people stating that they would be an

extremely helpful addition to the services. Others felt that it would add complexity to their lives. Whilst reference to this type of role remains in the procurement documentation, we continue to work with stakeholders to define the precise nature of it and check whether it is still needed.

As well as direct feedback we received on proposals, discussions with parents and the siblings of children with a range of conditions and/or disabilities were invaluable. These discussions are currently influencing commissioner thinking with regard to both the selection process of the new provider/s and the design of the system going forwards.

Some examples of the direct impact of the feedback on how the specifications and requirements for the future service were drafted are as follows:

For **Neuro-disability**, the commissioner – Jo - heard that parents were not so focussed on waiting times but how they were supported between referral and appointment. There should not be delays waiting for diagnoses before being able to receive any help, but the service should be needs-led. Reviewing the feedback has reminded her reminds her that she had put the right thing in her specification and has included what families told us they wanted.

The overarching service specification has been amended to ensure that provider/s provide relevant information and support whilst children, young people and families are waiting for an appointment.

For **Child and Adolescent Mental Health Services (CAMHS)**, the engagement confirmed that what the commissioner – Louise - had been hearing previously was still the same. It confirmed the approach she was taking; moving away from diagnosis-led to needs-led, was right. In order to ensure the move from diagnosis to needs-led, we will work with providers during the mobilisation phase of the procurement process.

It was important to Louise that she heard from people who haven't used CAMHS and those who tried to access the service but didn't meet criteria before. She also wanted to talk to people who had been through the system.

Through engagement Louise heard a sense of realism. She felt people don't necessarily expect an immediate service but want to know what the expectation is and what they can do in the meantime.

Louise recognises that she needs to keep listening to young people and their families to design a transition system that works for them.

In **Plymouth** changes have already been made to stop bureaucratic referrals between services and improve communication to keep people informed as to what is happening. They had heard a clear message that people don't want separate services. To reinforce this, they took the word 'referral' out of the procurement documentation.

For **Community nursing and learning disability nursing**, the commissioner – Siobhan – heard that availability of service need not necessarily be 24/7. Families said that they would feel comfortable as long as there is a plan and they can access services regularly. Weekends and evenings would be helpful. Hearing that message shifted Siobhan's thinking.

The feedback has helped Siobhan realise there is a gap in service provision for some people at end of their life and for very complex care, so she is looking at how to address this now.

The **Integrated therapies** commissioner – Kate – felt that the understanding of peoples' experience was an essential part of the jigsaw to help us answer the question 'what does good look like?' The other jigsaw parts were data, quality, feedback from providers and other organisations interacting with the services, as well as our own experience as commissioners.

The engagement reports enabled us to ask questions of current and potential providers in a different way, challenging them with what people were saying if it didn't match what the providers were telling us.

The feedback directly influenced the language and phrases that Kate used in her specification. When finalising it, she used the engagement report and specific feedback to check whether she and others thought that the negative issues that parents raised would disappear, over time, with this new service.

Overall, the head of this project – Sharon – noticed that what we heard through engagement defined the Critical Success Factors, which are the golden thread running through the whole process, as well as the principles and the outcomes framework.

The outcomes framework has become a good starting point for the Devon, Torbay and Plymouth-wide Sustainability and Transformation Partnership workstream that focusses on children, young people and families.

Sharon heard a lot about how families struggle to cope when there are additional needs. She will address early support for parents through her work on maternity and perinatal services.

What will happen next?

Parents, children and young people are involved in the procurement process and will have an opportunity to discuss the future service with the organisations hoping to provide it.

We will co-design with parents, carers, children and young people a quality monitoring process for the new service. This will focus on how people experience the service and how the provider organisations listen to feedback and develop their services accordingly.

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