The re-commissioning of children’s community health services in Bristol: The engagement phase

How we involved the public and what they told us

Annabel Wilson
## Contents

Executive Summary ................................................................................................... 3

1. Introduction........................................................................................................ 12
   1.1 The engagement phase .................................................................................. 12
   1.2 Duty to involve ............................................................................................ 12

2. Methodology: ‘How we engaged’ ....................................................................... 12
   2.1 Who we spoke to ......................................................................................... 12
   2.2 How could people get involved? .................................................................. 13
   2.3 Face-to-face engagement: What did we ask? ............................................. 13
   2.5 How did we make sense of what people told us and write up our findings? ... 14
      2.5.1 Data .......................................................................................................... 14
      2.5.2 Analysis .................................................................................................... 14
      2.5.3 Feedback to participants, colleagues and partners ................................... 14

3. What did we find out? ........................................................................................ 14
   3.1 Overarching Themes ................................................................................... 14
   3.2 School Nursing ............................................................................................ 15
      3.2.1 Key Messages .......................................................................................... 15
      3.2.2 School Nurses need to understand ........................................................ 16
      3.2.3 What could be improved ......................................................................... 16
      3.2.4 What the school nursing service could look like ..................................... 16
      3.2.5 What school nurses need to understand about young carers ............... 17
      3.2.6 School nursing for LGBT young people ............................................... 17
      3.2.7 School nursing in special schools ............................................................ 17
      3.2.8 Parents ..................................................................................................... 18
      3.3.9 School nurses should be ...................................................................... 18
   3.3 Health Visiting Service .................................................................................... 18
      3.3.1 Key Messages .......................................................................................... 18
      3.3.2 Health visiting for young parents ............................................................ 19
      3.3.3 Parents Vision for the health visiting Service ......................................... 20
   3.4 Community Paediatrics and Therapies ........................................................... 20
      3.4.1 Key Messages .......................................................................................... 20
      3.4.2 Community Paediatrics (Community Paed) ........................................... 21
      3.4.3 Speech and Language Therapy (SALT) ............................................... 21
Executive Summary

How we’re engaging with the public in Bristol

What we’re doing....
- holding focus groups around the city
- going where young people, parents and carers are
- working with our current provider to speak to people using children’s community health services
- we have a survey for parents and young people on our website

Who we spoke to....
- Over 140 young people
- Over 100 parents

The people we spoke to were.....
- current users of the service
- people who used to use the services
- potential future users
- people who had an interest in community health services

Equalities
- We have spoken to people with different protective characteristic
- 16% of people were BME

The places we’ve been so far are....
Public and patient Vision for children community health services: Overarching themes

- Be able to access a service when you need it and not just when things get worse
  - Consistent practice
    - Good internal communication
  - Proactively communicate with families
    - Professionals who are passionate
      - Easy access to information
        - Integrated services
      - Smooth transition between services
  - More appropriate ways to feedback on services for young people
    - Flexible
What people have told us so far……

**School Health Nursing**

**Key Messages**
1. Most young people who attended a mainstream school do not know if they have a school nurse
2. Most young people don’t know what a school nurse does
3. All young people think that school nursing is an important service
4. Young people want to be able to access more health services in school

**School Nurses need to understand that….**
- Our physical and emotional health are linked
- Not all young people pretend to be ill
- It is important to know how to work with young people so you are approachable
- That different young people have different needs – we want you to understand our cultural or religious backgrounds
- You should be based in a confidential location

**School Nurses should be….**
- Friendly
- Knowledgeable
- Honest
- Sympathetic and not accusing
- Easy to contact
- Understanding
- Have time for us
- Not judgemental
- Helpful

**What could improve….**
- Be more visible
- Tell us more about what school nurses do
- Have more time to be in school and build relationships

**School nursing for young carers….**
- It is important that school nurses understand the challenges young carers face
- It is important that young carers get support inside school
- We need someone we can go to when things aren’t going well that we can trust and who will listen

**School Nursing in special schools….**
- Communication with parents is very important
- Assigning children a named nurse works well
- More approachable than doctors
- Some parents feel they should have more specialist knowledge
- Need better links with the continence service

**LGBT young people….**
- Give information about blockers and hormones
- Deliver more inclusive PCHE
- Raise awareness of LGBT in schools (posters)

**Poster made by young carers**
Health Visiting

Key Messages
1. There should be more health visitors
2. Health visitors can be perceived as judgemental especially for young parents
3. Flexibility of baby clinics works well
4. The service works really well when health visitors have good links with other agency such as the hospital or GPs
5. Should have more specialist knowledge of children with complex needs
6. Health visitors should make an effort to contact families

Parents vision for the health visiting service.....
• a place to go for advice and guidance
• a service that signposts to other services such as support groups, educational opportunities, childcare etc.
• seeing the same health visitor over the years
• having the option of seeing a health visitor at home or at a baby clinic
• a service that proactively communicates with families

Young parents want....
• to feel like we are not being judged! This will help us talk about issues we are having and not feel scared
• someone to be your friend not looking down on you and always thinking they know best
• to build relationships
• health visitors to focus on helping us better ourselves by open door to opportunities instead of trying to teach us how to parent
• the service to involve young people in recruitment and training
• to access health services in school
• health visitors to help us access groups so we don’t feel so isolated
• to be seen the same as adults

Parents of children with complex needs want....
• to see a health visitor more often
• health visitors to have more specialist knowledge to identify disabilities and offer support
• health visitors to be approachable professional
• health visitors to know what is going on with their child’s health and proactively offer support during difficult times
• help with specialist referrals
• have a good knowledge of available services and support
• communicate with other health services my child uses

What could be improved....
• if you move area it can take a long time to get a new health visitor
• more proactive communication
• bring back the 18 month check
• helping mums get out of the house
Vision for Community Health Services

- Proactive professionals who keep parents informed
- Professionals read patients notes before seeing them
- Professionals respect parents and value their expertise
- Easy access to information about their own or their child's condition
- Parents/ carers and professionals working together
- Available in schools
- Access to services throughout a child's schooling
- Professionals act as advocates for their patients

Key Messages

1. These services need to increase their capacity
2. There needs to be consistent practice across the city
3. We need clarity around where to go if we are not getting the help we need
4. There needs to be clearer pathways for accessing services
5. Services need to work better together
6. Professionals should be open, honest and realistic
7. Parents who shout the loudest get the most help

Community Paediatrics

This works well and we should have more....
- clinics in schools
- specialist nurses support
- referrals to other services
- support for parents after diagnosis
- more teams like the autistic outreach team

What could be improved...
- professionals punctuality and reliability
- absence and maternity cover
- more communication with family

Physiotherapy

This works well and we should have more....
- Available in schools
- Being encouraging
- Share information with home
- Accessing equipment

What could be improved...
- saying the same things to young people as said to their family
- giving information proactively instead of asking for questions

Occupational Therapy

What's missing....
- a key worker that co-ordinates all community services for families
- a helpline - “We don’t always need to be enter into a process we need someone we can talk to about a specific thing at a specific time” (quick access to information and guidance)

What’s missing....
- difficult to access
- increased capacity
- equipment decisions based more on need than how much things cost
- more contact with young people in secondary school

Lots of positive feedback!!!!!
# Speech and Language Therapy (SALT)

## Key Messages
1. Young people said this service is really helpful!
2. It is good that this service is available in children centres and schools.
3. SALT plays an essential role in the assessment process.
4. Needs better communication with parents/carer.
5. There is less support for young people at secondary school.

## Young people like that....
- they get help to speak clearly
- they are encouraged
- are given good exercises
- they are guided to do it themselves gradually
- they are taught different ways to communicate
- they get help in school

## Parents aspirations for SALT are....
- it pushes against the assumption our children can't communicate
- therapists having regular contact with our child
- parents have the opportunity to attend a SALT sessions with their child
- more group therapy for young people
- parents have a way of asking therapists questions

## Communication with home could look like....
- communicate outside of the annual review
- knowing more about the tools and techniques therapists use would help parents do the same
- important to have consistency between school and home so our children have a voice
- sharing the small things our children do with parents would make a big difference
- Using video links to show progress would be good!

## What could improve....
- waiting times
- SALT for those with English as an additional language
- keyworker to co-ordinate all CCH service

## How SALT links with other CCH services....
- there are inconsistent referral routes across CCH
- needs better links with CAMHS and other CCH services
- good relationship with children centres
# Continence service

## Key Messages
1. Better relationships must be built between professionals and parents/carers
2. The assessment process needs to be simplified
3. The service needs to become more flexible
4. The service needs to become children focused

## The health service need to understand....
- Our children need continence pads, the doctors have agreed this we are not making it up
- Parents are not trying to abuse the system, it is the system that doesn’t work
- As parents accessing the continence service is stressful, if when we speak to you on the phone and we are irritated please don’t hang up or threaten us try and understand our frustrations

## What’s missing....
- Access to clinical waste collection
- There is a lack of changing facilities in the community
- Information about alternative services/products

## Reflection on the process....
- This service could save money if it picked up wrongly delivered unused products
- The weight of a used pad should not determine the size of a pad it should be understood that as children/young people get older they grow
- There should be flexibility about the amount of products delivered at any time
- If you run out of products you cannot get more
- Often if you are changing your product there is periods when you are left without

## Reflections on the products....
- Products should be high quality
- You should be able to mix products so you can have day and night time pads
- Pull-up should be available to help encourage continence
- Washable products should be an option

## Parents vision for the continence service.....
- Ran like a service for children not adults
- A responsive service that reacts quickly to changes in circumstances
- A service that encourages continence and works closely with physio’s
- A more informal service that works with parents and understands them
- A simple pathway without lots of complicated assessments
- A flexible service that allows you to mix products
# Child and Adolescence Mental Health Services (CAMHS)

## Key Messages
1. Hit rock bottom before you can get help service
2. Difficult to access
3. Lack of signposting to alternatives
4. Transition between children’s and adult’s mental health services is difficult
5. More support for young people with autism and ADHD

## The health service need to understand....
- There is a lot of stigma around mental health that stops people accessing help
- The health service should help to raise awareness around mental health
- Self-harm is a common for young people
- Tumblr and other social networking sights promote depression and self-harm
- We see the GP as the first point of call but they don’t seem to know enough about mental health and services

## What else could improve....
- Flexibility
- Multi-disciplinary working
- Knowledge around YP with disabilities
- Diversity in workforce
- Other professionals knowledge of mental health and services available
- Easy ways of feeding back on service received

## Lower level support could look like....
- Project work with youth clubs
- Music or art therapy
- Access to sports facilities
- Referrals to Princes Trust and other work programmes
- Off The Record – but not if it’s always full
- Working with VCS
- On –line support
- Helpline
- Emotional support available in schools

## What CAMHS is missing....
- Early intervention approach
- Crisis team or out of hours support service
- A process for transition that works
- Support and information for parents and carers looking after young people with mental health

## Mental health services for BME community....
- Easier to relate to professionals who understand our cultural and/ or religion
- As boys we would prefer an online completely anonymous service

## Reflection on CAMHS process....
- First appointment takes too long and you are likely to be turned away.
- You are expected to answer lots of questions and tell life story in first session – this is too much!!
- Should get a call a week after referral.
- Should be email contact whilst waiting for first appointment

## CAMHS should feel....
- Colourful
- Welcoming
- Positive – change the name

## CAMHS services for Parents....
- I have to hassle the service for help
- Needs to take a whole family approach
- Help during diagnosis as well as afterwards

## Professions should....
- Be interested
- Passionate about young people
- Not judge you
- Use language young people understand
- Offer practice support
- Have empathy
- Listen
- Build relationships overtime
- Be honest – not walk on eggshells - be straight!
The next steps....

We use what you have told us to design a service model.

We consult you on the service model and you tell us what you think.

We use your responses to improve our original service model.
The re-commissioning of children’s community health services in Bristol: The engagement phase

How we involved the public and what they told us

1. Introduction
In Bristol the Clinical Commissioning Group (CCG) and its partners are re-commissioning children’s community health services. This report will outline how members of the Clinical Commissioning Group (CCG), Local Authority and NHS England (NHSE) have engaged with the public so far, what we have heard and what our next steps will be.

1.1 The engagement phase
At present the re-commissioning of children’s community health services project is in the pre-procurement phase. This phase exists to give us (the commissioners) the opportunity to better understand the current service and to make sure the services we commission in the future meet the needs of those using them.

1.2 Duty to involve
We know that listening to public helps us to design better services. This is recognised on a number of levels and is written in law. The CCG has a statutory duty to involve patients, carers and the public (including children and young people) in the development of commissioning plans to change and develop local health services.

2. Methodology: ‘How we engaged’
This report will now discuss how we worked with children, young people, parents and carers to gain a better understanding of their experiences of and aspirations for community health services in the future.

2.1 Who we spoke to
We aimed to speak to a mixture of people across the city. These included people who used current community health services, people who used to use the services, future users and those who had an interest in children’s community health services. Here is a list of the groups we targeted:

- Parents and carers of children with complex needs
- Parents and carers of children with learning difficulties
- Parents and carers of children who use mental health services
- Parents of children who use universal services (school nurses and health visitors)
- Young people with complex needs
• Young people with learning difficulties
• Young people who use mental health services
• Young people who use universal service (school nursing)
• Parents, carers and young people who may use community health services in the future

2.2 How could people get involved?
There were different ways that these people could engage with us:

• We designed an online and paper survey for young people and another for parents and carers. These were advertised in schools, children centres, libraries, and doctor’s surgery’s and on the CCG and councils website. We hired an external consultant who we tasked with gaining the views of minority communities in Bristol.
• We went out to different youth and parent groups across the city and held focus groups or one-to-one discussions with those we met. We did this because we understood that in order to get people involved we had to be flexible and go to where they were.
• We worked with local special schools and attended youth councils and parent/carer evenings and events.
• We worked with the existing provider to reach current service users.
• We held an event in partnership with the Bristol Race and Equality Health Partnership (BREHP) to target people from BME communities

2.3 How did we access these groups?
To reach our target groups we had to work in partnership and build relationships with a range of different organisations, in both the public, voluntary and community sector. We worked with people who work directly with young people, parents and carers such as schools, Banardo’s, Bristol Parent Carers, Wecil, Basement studios, Mentality and many others. We had to be flexible in our approach in order to gain the views of young people. Many groups we attended were in the evenings or on weekends and were in a variety of locations. We are very grateful to all those who helped us gain access to these groups.

2.4 Face-to-face engagement: What did we ask?
Sessions were designed to capture what children, young people and parents and carers said in their own words. We did not want to prescribe or restrict what people told us so we asked open ended questions. During the focus groups, we began with a brainstorming exercise to ensure people knew what community health services were. From this exercise the facilitator could work out which services the young people, parents/carers had experience of or were interested in which shaped the focus of the session. After this activity the group were asked 3 questions:
• What works well?
• What could be improved?
• What would you like the service to be like in the future?

What they said was recorded on post-it notes and stuck on to a simple matrix which was used to stimulate group discussion. During One to one discussions, the same three questions were asked, but there was no brainstorming activity.

2.5 How did we make sense of what people told us and write up our findings?

2.5.1 Data
The information we collected was a mix of:
• Written notes
• Post-it note activity notes
• Researchers reflections

2.5.2 Analysis
Findings were analysed and themes were identified and written up in this report. We have presented overarching themes as well as findings by service. Important consideration was paid to those with protected characteristics during the analysis. The settings in which people accessed health services were also taken into account.

To make this report more accessible and easier to read; one page summary sheets have been produced for each service (please see Executive Summary). These summary sheets were also taken to some of the recent focus groups to check that they reflected the experiences of others.

2.5.3 Feedback to participants, colleagues and partners
We understand the importance of keeping people we have spoken to informed. This report and the summary version will be shared with all the group leaders and staff we have worked with to access young people, parents and carers. Whilst engaging with people they were also informed of where they can find this report and when it would be published. Moreover, we will re-contact those we spoke to during the engagement phase of this project and give them the opportunity to comment on the proposed service model in the consultation phase.

3. What did we find out?
This part of the report outlines what people told us about community health services.

3.1 Overarching Themes
These themes came up during discussions that weren’t specifically related to services. This is what people told us they want from all children’s community health services regardless of their speciality:

• Be able to access a service when you need it, not just when things get worse
• **Consistent practice** – people want to be able to access the same quality of service regardless of where they live in the city.

• **Good internal communication** – people need professionals from different services to communicate with each other, they need to know what each professional is doing and how they fit into the bigger picture of a child’s care.

• **Proactively communicate with families** – young people, parents or carers do not want to chase the people they are working with. They don’t want to leave messages and not get a response. They want professionals to proactively engage with them when it is necessary and are responsive when required.

• **Professionals who are passionate** – no one wants to work with a person who does not want to be there. Young people, parents and carers want to work with people who like what they do and are passionate about doing a good job.

• **Easy access to information** – People need to know what is out there! What help is available? Where that help is? How to contact help? This is something parents, young people, carers and professionals need. An advanced information hub that helps people access the information they need when they need it.

• **Integrated services** – people don’t want to know about background information they don’t need to know they are using different community health services they just want community health services to feel like one joined up entity

• **Smooth transition between services** – people need to know what happens after children’s services. They need to be supported through this transition and they need professionals to be realistic about expectations and help all involved to adjust to this.

• **More appropriate ways to feedback on services** – people want to be able to comment on the service they have received in an easy and confidential way and they want their feedback to shape services continuously.

• **Flexible** – parents and young people felt the children’s community health services need to be flexible and able to provide an individualised service and not take a one-size-fits-all approach.

### 3.2 School Nursing

#### 3.2.1 Key Messages

• **Most young people who attended a mainstream school did not know if they have a school nurse** – when asked about school nursing the response from most young people was “I don’t know if we have one”. Parent’s responses were similar.

• **Most young people don’t know what a school nurse does** - for those who knew they had a school nurse they were unclear about who they were, what they did and how to contact them.
• All young people think that school nursing is an important service – no young person thought that school nurses were not important but they suggested that they were not there enough. If they were there more, they thought the service would have a bigger impact.

• Young people want to be able to access more health services in school – across all focus groups a strong theme was that being able to access health services on school grounds was important to young people. They felt that school nurses could act as a bridge between school and health care.

3.2.2 School Nurses need to understand....
Young people who attended mainstream schools often had a more negative experience of the school nurse service than their counterparts attending special schools. They knew less about them and in their experience the school nurse was not always as helpful as they thought he/she could have been - they were more likely to be met with accusations than support. They thought it would be helpful if school nurses understood that they could have emotional worries that can sometimes affect their physical health. In their view, the school nurse’s role was to help with medical problems or emergencies and they felt that the school nurse should have a role in supporting their emotional wellbeing. Young people also felt it was important for school nurses to have a good understanding of different cultures and religions.

3.2.3 What could be improved....
• Visibility - young people said the school nurse should have a more visible presence in the school. Some young people mentioned that school nurses introduce themselves in an assembly at the start of the school year. They said this was not enough. They would like to see posters around the school advertising the school nursing service.

• Clarity – as well as making a school nurse more visible in schools they need to make their role more clear and let young people know what they do and how they can be contacted.

• More – school nurses do not spend that much time in school; this makes it hard for young people to build a relationship with their school nurse.

3.2.4 What the school nursing service could look like....
• An approachable service – young people often discussed the professionals need to be friendly, understanding, non-judgemental and have time for them. They found these people approachable. This should be a part of the school nurse role.

• Confidential – this is very important to young people. In order to engage with a service they need to know how confidential the service is and this should be made as clear as possible. The more they are assured a service is confidential the more likely they will be to use it.

• School nurses were described as part of the school body; they felt like they worked for the teachers rather than for young people. They felt the school
nurse should be independent as this would create more trust and better relationships.

- As mentioned above the young people felt that the school nurse should be able to support them with their emotional wellbeing as well as their physical health. This was a very strong theme. It is important young people have someone who will listen to them when they are worried or have problems. They saw the school nurse as having a role in this in the future.
- **Signposting to other services** – young people understand that the school nurse will not be able to help them with everything. However they think a key part of their role should be signposting them to other services. This means they need to be knowledgeable and know what services are available for young people and how they can access them. Young people said that a school nurse could be the first point of call through which they could access other health services.

### 3.2.5 What school nurses need to understand about young carers....

For young carers it is important for them to access support in school because at home they have caring responsibilities for someone else. This means that when they are at school they can be tired or distracted and therefore, it is important that they have a place in school where they can go for support. Young carers don’t want to be treated differently from other young people but they do need supportive adults in school who understand the challenges they face, who listen to them and are willing to be there for them. They felt that this could be the school nurse. It is important that people in schools know what young carers are and where they can get support because often young carers don’t tell anyone. Many of the young carers we spoke with said they know other people who are carers but these people keep it a secret. Confidentiality is once again very important for this group of young people.

### 3.2.6 School nursing for LGBT young people

Young people who are Lesbian, Gay, Bisexual or Transgender would like the school nursing services to have an understanding of what this is like for young people. They would like the school nursing service to help raise awareness in school through contributions to the PCHE lessons. Young people said that seeing posters LGBT posters in school makes them feel like it is okay to talk. Having one of these posters in school nursing office would make them more approachable. One young person mentioned that it would be beneficial if school nurse could offer for advice young people on hormones and blockers if they are trans-gender. Like other young people this group felt school nursing had a key role in signposting young people to other services.

### 3.2.7 School nursing in special schools....

- In general the young people we spoke to about school nurses were happy with the service they received. They described school nurses as helpful and nice. The main issue they had was being left in the nurse room for too long for example they would say they’ll be a few minutes but take longer.
3.2.8 Parents
- Think having school nurses on site was a good thing
- Parents who had good communication with their school nurse value the service more. They found school nurses more approachable than other professionals. They appreciated going to the school nurse for a second opinion if they had any worries or concerns. They felt the school nurses were supportive and helped them to have confidence in their own decisions.
- In some schools young people are assigned a nurse. They felt that this worked well as the nurse was able to build a stronger relationship with the young person and was able to better understand their health needs.
- Some parents felt that nurses didn’t know enough about their children’s health needs and felt that they should have more specialist knowledge.
- Parents also liked that the nurse could use Lifetime paper work which meant they didn’t have to spend time telling another professional their story.

3.3.9 School nurses should be....
- friendly
- knowledgeable
- honest
- sympathetic and not accusing
- easy to contact
- understanding
- have time for us
- non-judgemental
- helpful

3.3 Health Visiting Service

3.3.1 Key Messages
- **There should be more health visitors** – people who use this service are aware of the lack of health visitors in the city. They notice the effects this has on the service. Mostly people felt Health Visitors do their best and provide a good service but if they had more time it would be much improved.
- **Health visitors can be perceived as judgemental (especially for young parents)** – this was the most common criticism of the service. Parents do not want to feel like a Health Visitor is criticising them; they want to feel supported.
- **Baby clinics work well** – to gather parent’s views we visited a few baby clinics across the city. Most of the people we spoke to had positive experiences of this service. The clinics that were held in children’s centres or in a separate space of a GP surgery received better feedback than those sessions where parents had to wait in the main GP waiting area. This was mainly because the waiting times felt shorter and there was a space for children to play. Occasionally the health visiting session coincided with ‘Stay
and Play’ sessions within children centres which parents thought worked really well. Parents like that they could visit different clinics across the city but felt that this should be publicised more. They also liked that they could “just turn up” without an appointment.

- **The service works well when Health Visitors have good links with other services** – parents often discussed examples where their Health Visitor, GP or other health professionals worked together to help their family. In these cases they felt they received a really good service. They felt that this communication was important as for many parents the Health Visitor was considered more approachable than other professionals. When there was a lack of communication between professionals the service experience was less positive. Parents told stories of getting mixed advice from different professionals and being passed between professionals who were unsure of each other’s responsibilities.

- **Health Visitors should have more specialist knowledge of children with complex needs** – these parents often described feeling let down by their Health Visitor. They would like to know how their role fits within the bigger picture of their child’s care. They felt that if Health Visitors had more specialist knowledge; they could offer better support. They suggested that identifying disabilities should be a bigger part of their role. One parent said “I don’t see my health visitor often but whenever my daughter has been in hospital she calls to check everything is ok”. Parents expressed that they would like their Health Visitor to know what “was going on”. They would like them to have good links with the other professionals they work with and help them with specialist referrals when necessary.

- **Health visitors should make an effort to contact families** – This was a very strong theme. People felt their Health Visitor should contact them at least every 6 months. They understood that health visitors were busy and felt that a phone call would be a good way to communicate. First time mums and parents with children over 2 raised this issue most often. Other people felt that the 18 month check should be reintroduced.

**3.3.2 Health visiting for young parents....**

Young mothers were critical of the service. They often felt that they were judged and patronised by professionals because they didn’t make an effort to understand their style of parenting. Instead they believed Health Visitors focused on making them do things their way which made it hard for them to open up to professionals. Building relationships was very important; they want to access a service where they are not scared to ask for help when something goes wrong. To build trusting relationships, they felt it was important to see the same Health Visitor and that this person should understand young people and feel passionate about working with them.

Young mums also discussed access to Health Visitors. At times they found this difficult. They said that although their Health Visitor is supposed to be their first point
of call; receptionists often stand in the way. They felt receptionists wanted to know why they were calling. For young people confidentiality is very important and many people did not feel comfortable explaining themselves.

Young mums felt that the support they needed from Health Visitors was different from ‘older’ parents. They want help to access information about different life opportunities as well as get advice about debt, housing, managing money alongside information about childcare. They also discussed the fact that being a young mum can be isolating. They like meeting other parents but prefer going to groups designed for other young mums as they feel more comfortable.

Some of the young people we spoke to had been involved in the recruitment of the Family Partnership Nurses. They really appreciated this opportunity and genuinely believed they had helped recruit people who would be good at their job. They felt there should be more opportunities like this for young parents and felt that they could also play a role in training staff.

3.3.3 Parents Vision for the health visiting Service…

- **A place to go for advice and guidance** – parents want to feel supported and reassured by health visitors who have good knowledge and expertise.
- **A service that signposts to other services** – this service should help parents access other services and support systems when they need them.
- **Seeing the same health visitor over the years** – the service should be as consistent as possible so that parents and Health Visitors can build strong relationships.
- **Having the option of seeing a health visitor at home or at a baby clinic** – this should be a service with options where you can see a health visitor in the community but if you really need to you should be able to see someone at home.
- **Proactive communication with families** - Health visitors should check in with families to make sure everything is okay.

3.4 Community Paediatrics and Therapies

3.4.1 Key Messages

- **These services need to increase their capacity** – most of the young people we spoke to felt they saw their health professionals enough. However, parents/carers felt their children would benefit from more input from health services.
- **There needs to be consistent practice across the city** – the people we spoke to liked that health services were available in their local area but felt it was important that services operated similarly across the city.
- **We need clarity around where to go if we are not getting the help we need** – people were often unsure about who to talk to when they felt they
needed more or different support. This was especially confusing when young people accessed their health services within a school.

- **There needs to be clearer pathways for accessing services** – people felt that accessing services was difficult; this was especially the case when they didn’t have a formal diagnosis. Referrals from paediatricians sometimes took a long time and there was often a breakdown in communication during this wait which caused parents/carers to feel unsure that progress was being made.

- **Services need to work better together** - health professionals who work in different areas need to be aware of what each other are doing and work together so that the services children receive are joined up.

- **Professionals should be open, honest and realistic** – parents and carers want professionals to explain clearly what a service can offer. Being unclear can mean that parents/carers don’t know what to expect and leads to them forming negative perceptions of services.

- **Parents who shout the loudest get the most help** – accessing community health services is often a battle. Many parents felt that they have had to fight for the support they received and all are aware that those who do not fight are likely to be worse off.

### 3.4.2 Community Paediatrics (Community Paeds)

This service was seen as essential as it helped families access other services they need. Parents and carers felt that there needs to be good communication between them and the community paed. It was evident that those who had experienced good communication felt they had received a better service. Better communication was linked to those who saw their community paediatrician in schools. These parents seemed more satisfied with the service. The main difference appeared to be that they had better access to them; they were able to contact them if they had a question and received a response quickly. For these parents/carers they felt that seeing their community paed once a year was enough. However, parents who were unable to access their community paed often felt they lacked clarity around their role and often felt let down by a lack of follow up after appointments. Moreover, these parents were more likely to have experienced professionals being late or cancelling appointments.

Parents and carers felt that they were able to build better relationships with specialist nurses because they listened to them and spoke to them using language they understood, skills they believed some community paeds lacked. They would like community paediatricians to recognise and respect their expertise as parents/carers.

### 3.4.3 Speech and Language Therapy (SALT)

This service received really positive feedback from young people. They completely understood how this service had helped them and felt it had made a real difference
to their lives. Of those we spoke to they felt that they saw therapists for the right amount of time and they liked that they were able to see them in school. They found professionals very encouraging and they liked the methods they used to help them improve their language and communication skills.

The parents and carers we spoke to in children’s centre settings felt that the support they received from the speech and language therapist was invaluable. They found that they supported them through the diagnosis process and that they helped them to co-ordinate their child’s care.

Parents spoke about how important it was to access speech and language input in early years but also felt that it needs to be available throughout a child’s life if necessary. There seems to be a lack of support within secondary schools. Parents/carers understood that teachers within these settings adopted this role but they felt that they lacked the expertise to do this affectively. Moreover they felt that it was difficult for teachers to do this when they were in a busy classroom full of children with additional needs. They felt that this was a service area that would really benefit from more investment.

A lack of communication between SALT and home was a very strong theme. Parents often don’t know what a speech and language therapist does and they felt they only get an update within the annual review. Parents who did have a relationship with their child’s therapist felt more positively about the service. Parents/carers really want to be kept informed and would like to know more about techniques they could use at home. One parent said that “I need to know what the speech and language therapist does otherwise when my daughter gets home it is like her voice has been taken away”. Parents/carers suggested therapists could communicate through video, phone or could write a note in their child’s school planner.

3.4.4 Occupational Therapy
The work that occupational therapists do was highly valued by parents and young people. Parents/carers particularly appreciated the work they do around sensory issues and would like to access more of this type of support. The main criticisms of this service were that it is hard to access; often taking a long time, that there should be more support available to children in secondary school and that occupational therapist (OT) decisions are often based on financial factors rather than need. Due to this it is hard for families to get the right equipment for their child.

3.4.5 Physiotherapy
Unlike the comments made about OTs, people felt that physiotherapists (PT) were really helpful in accessing equipment and often felt that they did the job of the OTs. Both young people and parents felt that the PT service was really helpful. The main issues were that there should be more support available, stronger links with the continence service and that therapists could communicate better with families. One
young person also felt it would helpful if PTs gave information more proactively as she found it hard to ask questions when put on the spot.

3.4.6 What's missing….
- Parents and carers strongly articulated the need for a **keyworker** who could co-ordinate their child’s care. This role was seen as really important in ensuring professionals communicated with each other and with a family effectively. Community health services can often feel very disjointed and it is felt that a keyworker could greatly improve a family’s service experience.
- Parents and carers also felt that a **helpline** would be useful. Often parents have a question that needs a quick response. They don’t need to see someone or be referred or entered into a larger process. They just need to speak to someone with expertise that can advise them there and then. At present when parents/ carers try to contact a professional it can take days or weeks to get a response.

3.4.7 Vision for Community Health Services
- **Proactive professionals who follow up and keep parents informed**
- **Professionals read patients notes before seeing them** – young people, parents and carers do not like when they go to an appointment and the professional they are seeing appears unprepared. In order to deliver personalised services professionals have to be aware of their patients.
- **Professionals respect parents and value their expertise** – parents want to work in partnership with professionals and want their input to be valued and taken into account when planning their child’s care.
- **Easy access to information about their child's condition** – parents want to feel supported by this service. They need access to information about their child’s conditions and about different services available to them.
- **Parents/ carers and professionals working together** - Parents/carers want to access a service that works with them to become the best parent/carers they can be so they can give their children the best chance in life.
- **Services available in schools** – it is easier to access services when they are in school. It means that a child’s school attendance is not affected and that health and education can work closer together.
- **Access to services throughout a child's schooling** – children and young people should have access to the same quality of support from early years and throughout secondary school.
- **Professionals act as advocates for their patients** – parents want to work with professionals to access the support, they don’t want to have to fight them for help.
3.5 Continence service

3.5.1 Key Messages

• **Better relationships must be built between professionals and parents/carers** – although parents have a good relationship with the school nurses (who carry out continence assessments) many described their relationship with the wider continence service employees in a negative way. This mainly came from what they perceive to be a lack of understanding, empathy and respect.

• **The assessment process needs to be simplified** - parents describe the pathway as complicated and at times unnecessary. Many parents highlighted “the battle of changing nappy size” which they feel should be made simpler. Also, the needs assessment that determines the amount of pads you are allocated is ineffective. Currently this process involves monitoring their child’s fluid intake and weighing the nappies, which is time consuming and unpleasant.

• **The service needs to be more flexible** – parents and carers feel that the current service is not individualised and instead takes a one size fits all approach.

• **The service needs to become more child focused** - parents and carers feel that the current service was designed with adults in mind and as a result the products available and the attitudes of the professionals is not young people friendly.

3.5.2 What the continence service needs to understand....

Parents and carers want professionals to understand that the continence service experience is very stressful. They don’t feel that professionals believe they need continence pads and as a result everything is a battle. They feel that professionals think they are trying to abuse the system (which is not the case) and in turn they are not helpful. They believe this relationship could be better if there was mutual respect between professionals and parent/carers.

Parents and carers understand that the pads are designed to be absorbent but it is difficult to leave their child in a pad when they have soiled them. Although the pads are designed in a particular way they still often leak. Many parents and carers expressed that if their child is unwell they understand it is their responsibility to buy more pads. They don’t want pads in excess; they just want what they need without having to fight for it.

3.5.3 What the continence service could look like.....

• There should be a continence service that is designed for children. This means it encourages continence; works closely with PTs and provides appropriate products such as pull ups or pads that are not “adult shape”.

• The service should be responsive when things change for example if you need a new size because your child has grown or a child needs more pads.
When there is a change the service should be able to manage this well, ensuring that a child is never left without a product.

- The service should feel more informal. At the moment when things change a complicated process begins in which you have to prove you are not lying. It would be good if the service felt more informal and more trusting.
- It would be good if there was more flexibility around products. At the moment you can only get one type of pad. This means you can’t have more absorbent pads for the night time. Parents and carers spoke about having to use two pads at night and then being left with one for the day.
- If the wrong products are delivered to a household there is no way of returning them. The new service should allow for this to save money.

### 3.5.4 Reflection on products.....
- Parents would like to have access to high quality products. “Fixes” were often discussed and seen as poor quality.
- It would be good if we had the option to use washable products.

### 3.5.5 What’s missing....
- There is no access to clinical waste collection which means that soiled pads have to stay in the domestic bins for up to two weeks.
- There is a lack of changing facilities in the community – when you have a child that has very complex needs leaving the house is hard. It is made even more so if you cannot change your child in public places.
- There is not much signposting to other sources of information about continence products and advice.

### 3.5.6 Other comments
- Parents discussed the differences between the continence service in South Gloucestershire and Bristol. This can be confusing as children from both areas often attend the same school. It would be good if the same service was available in both areas.

### 3.6 The Lifetime service
Parents reported extremely positive experiences of this service. They felt that Lifetime nurses were always there for and that they played a crucial role in coordinating their child’s care. Their advice to commissioners was not to change this service.

### 3.7 Children and Adolescence Mental Health Services (CAMHS)

#### 3.7.1 Key Messages
- ‘Hit rock bottom before you can get help’ service – many of the young people (or their parents) tell stories of having to hurt themselves and/or be admitted to hospital before they get help. Many of these young people were
turned away from CAMHS after their assessment appointment as they did not meet the threshold.

- **Difficult to access** – it is hard to be referred into CAMHS by a professional. Once you have been referred there can be long waiting times—and even when you access the service; help is not guaranteed.

- **Lack of signposting to alternative services** – professionals across the board (GPs, CAMHS employees, youth workers, social workers, school nurses, teachers) seem to lack knowledge of what mental health support exists and how young people can access help.

- **Transition between children’s and adult mental health services is difficult** – this is difficult for young people in many ways. CAMHS support ends on a young person’s 18th birthday. Young people felt they were unable to access support for a significant length of time. Not reaching the threshold for adult mental health services was also discussed. They also found adult services difficult as they were expected to be more independent and make decisions—they said this was not the case in CAMHS as their families were more involved.

- **More support for young people with autism and ADHD** – Parents spoke of their children being turned away from this service or professionals feeling that they could do little to support their children. Parents felt that if they had more expertise of their conditions they could help them with their mental health. They would like more support with anger management and developing self-regulation.

### 3.7.2 The health service needs to understand....

There is a lot of stigma around mental health for young people. This can stop some young people asking for help. At the same time for some young people there is something “cool” or accepting about being depressed and self-harming. For example young people discussed national self-harming day on Facebook where young people upload pictures of their self-harm “trophies” or scars and share them online. There are online communities where people who feel isolated or sad can meet and find a sense of belonging. The amount of young people with mental health problems are increasing. Young people felt that the health service should make mental health more of a priority and help to raise awareness and promote ways to maintain good mental health.

In terms of accessing services for many young people GPs are the first point of call for any problems. They feel it is important that GPs are kept up to date about mental health services that are available. They often discussed GPs and spoke about their lack of knowledge or confidence to discuss mental health with them as young people. Young people have said that GPs will often recommend medication over a service that could help.
3.7.3 How CAMHS could improve....

- **Be more flexible** – CAMHS are flexible in some ways. For example they can come to your house and see you. Young people have said they really appreciate this and think it should be expanded. They also felt it would be helpful if the service was available in the evening and on the weekend. They said when you have a mental health conditions school is hard enough; it becomes more difficult when you have to miss school for appointments. Moreover they suggested there should be a better system in place for handling missed appointments. Sometimes they can’t make an appointment and as result they have to wait a long time before they see anyone. Also, if they don’t contact the service, they will not contact you so the whole service can stop at a time when you need it most. They think the service’s professionals need to be more pro-active.

- **Multi-disciplinary working** – CAMHS seems to stand alone; they felt it struggles to communicate with other professionals they may work with. The service would be better if it was more integrated with other services.

- **Knowledge of young disabled people** – parents with children with complex needs feel that their young person’s disability was not always understood by CAMHS professionals. Young people discuss the importance of CAMHS being accessible. For example, they said professionals should know sign language.

- **Diversity in the workforce** - young people from BME backgrounds often spoke about the importance of having people they can identify with within the mental health service. They said they find it easier to be open and honest with people who can understand their culture and/ or religion. They said that people who are from a minority group understand what that feels like and the impact that it can have on your life.

- **Professional’s knowledge of mental health** - people who work with young people need to know about mental health services and understand the basics of mental health. Young people often feel like they are not advised or directed to places where they can get help.

- **Transition** - to improve this, young people felt it should be better planned. There should be an official handover involving the young person, their current CAMHS professional and their new adult professional. They said this was supposed to happen but because people were busy it often doesn’t.

3.7.4 What CAMHS is missing....

- **Lower level support** – young people and parents both felt it was important that this service became an early intervention service as opposed to a service that reacts to crisis.

- **There isn’t an “intensive team” equivalent in CAMHS (out of hours support).** Young people spoke about A & E being their only option which they did not feel was appropriate or helpful.
• Being able to meet people who have used CAMHS and have got better when you first start your treatment would help young people to see that you can get better. This would also be positive for those who have had help.
• A positive name for the service – they said CAMHS has negative connotations and makes them think of mental hospitals – they think the name should not include the words mental health.
• Young people mentioned that often their parents find it hard to know what to do when they are unwell. They feel it would help them if their parents were given more information about their conditions and taught strategies that could help them.

3.7.5 What lower level CAMHS could look like….
• Project work with youth clubs – short course, once a week for 6 weeks, combining expression with a project.
• Music and art therapy
• Access to sports facilities
• Off the record – Counselling service: this would only be effective if it had the capacity to help young people.
• Referring to other voluntary and community services – mentoring schemes etc.
• Referring young people to Prince’s Trust and other agencies that can help provide opportunities for young people.
• Online help and support – this was a strong theme in the BME community especially for males. They think there should be a service you can access online that is completely anonymous but where you can talk to someone about your problems.
• Helpline – a number young people could ring to talk about their problems or find out about services in their area.
• Website – interactive website that uses videos to raise awareness and share positive experiences.

3.7.6 Young people’s reflections on the CAMHS process….
• First appointment takes too long and you could be turned away – feel like they have given up on you.
• Waiting for 8-12 weeks and then finding out that you are not eligible for a service is not good. Why can you not find out if you are eligible before you wait that long.
• You are expected to answer lots of questions and tell your life story in the first session – this is too much! You do not know the person and you have to tell them everything and if you can’t, they say you don’t need help.
• The person who has referred you should be able to talk through the exact process of what will happen next.
• Young people should get a call a week after referral with an update on what will happen next and to let people know that they haven’t been forgotten.
• There should be a person you can contact by email whilst waiting for your first appointment

3.7.7 Professions should….
• Be interested
• Passionate about young people
• Not judge you
• Use language young people understand
• Offer practical support
• Have empathy
• Listen
• Build relationships overtime
• Be honest – not walk on eggshells - be straight!
• Not break promises

4. Next steps

4.1 How will we use the information we have gathered so far?
The information we have gathered so far will be used to develop a new service model for children’s community health services. This means it will outline how these services may look in the future. The model itself will be co-created with young people, parents/ carers and professionals.

4.2 What is the next phase of the re-commissioning process?
Once this has been designed we will enter the next phase of the re-commissioning process which is called the consultation. The aim of this phase is to find out what people think of the model(s). This is very important because it is a chance for us to check that we have listened correctly and incorporated this into our plans.

4.3 Who will we engage with during the consultation?
During this phase we will engage with young people, parents, carers and professionals. We will share our plans with patients, members of the public and professionals we have already spoken to as well as others who have an interest in or experience of children’s community health services.

4.4 How will we engage?
The difference between the engagement phase and the consultation phase is that we are moving towards more structured discussions and consulting on a plan that we have designed having heard people’s views. During this phase we will engage via a number of different channels such as face –to –face engagement and online/ paper surveys.
Appendix

Appendix A: Children's Community Health Services Patient and Public Involvement Events

<table>
<thead>
<tr>
<th>Date</th>
<th>Event</th>
<th>Numbers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>August</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2nd</td>
<td>LGBT Group</td>
<td>3 Young people</td>
</tr>
<tr>
<td><strong>July</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1st</td>
<td>Briarwood school youth council</td>
<td>7 Young people</td>
</tr>
<tr>
<td>3rd</td>
<td>Knowle Clinic Health Visiting</td>
<td>8 Parents/ Carers</td>
</tr>
<tr>
<td>9th</td>
<td>New Fossway Youth Council</td>
<td>9 Young people</td>
</tr>
<tr>
<td>14th</td>
<td>Charlotte Keal Health Centre (Health Visiting)</td>
<td>6 Parents/ Carers</td>
</tr>
<tr>
<td>16th</td>
<td>Hartcliffe Children's Centre health visiting</td>
<td>6 Parents/ Carers</td>
</tr>
<tr>
<td>19th</td>
<td>Briarwood school Parents/ Carers</td>
<td>6 Parents/ Carers</td>
</tr>
<tr>
<td>21st</td>
<td>New Fossway Youth Council</td>
<td>8 Young people</td>
</tr>
<tr>
<td>25th</td>
<td>Henbury Court Children Centre</td>
<td>?</td>
</tr>
<tr>
<td><strong>June</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2nd</td>
<td>BME forum</td>
<td>3 Young people</td>
</tr>
<tr>
<td>2nd</td>
<td>NEET young people</td>
<td>11 Young people</td>
</tr>
<tr>
<td>9th</td>
<td>Vinney Green</td>
<td>est. 12 Young people</td>
</tr>
<tr>
<td>9th</td>
<td>Out and about (Hartcliffe)</td>
<td>10 Young people</td>
</tr>
<tr>
<td>16th</td>
<td>Listening partnership</td>
<td>6 Young people</td>
</tr>
<tr>
<td>16th</td>
<td>ADHD parent support group</td>
<td>4 Parents/ Carers</td>
</tr>
<tr>
<td>19th</td>
<td>Meriton School</td>
<td>6 Young people</td>
</tr>
<tr>
<td>20th</td>
<td>Long Cross early birds</td>
<td>4 Parents/ Carers</td>
</tr>
<tr>
<td><strong>May</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5th</td>
<td>Mentality</td>
<td>3 Young People</td>
</tr>
<tr>
<td>5th</td>
<td>Sensory support youth group</td>
<td>9 Young people</td>
</tr>
<tr>
<td>12th</td>
<td>Young women’s and girls group</td>
<td>6 Parent/ Carers</td>
</tr>
<tr>
<td>12th</td>
<td>Boys club Docklands</td>
<td>7 Young People</td>
</tr>
<tr>
<td>19th</td>
<td>Children’s hospital youth Forum</td>
<td>6 Young People</td>
</tr>
<tr>
<td>19th</td>
<td>Women’s group - Full Circle</td>
<td>6 Parents/ Carers</td>
</tr>
<tr>
<td>19th</td>
<td>Young carers</td>
<td>16 Young People</td>
</tr>
<tr>
<td>26th</td>
<td>Forward Youth Group</td>
<td>6 Young People</td>
</tr>
<tr>
<td>26th</td>
<td>Barnardos Group</td>
<td>5 Young People</td>
</tr>
<tr>
<td>26th</td>
<td>Out and about (Hillfields)</td>
<td>2 Young People</td>
</tr>
<tr>
<td>26th</td>
<td>ADHD parent support group</td>
<td>4 Parents/ Carers</td>
</tr>
<tr>
<td>April</td>
<td>Basement studios</td>
<td>11 Young People</td>
</tr>
<tr>
<td>------------------</td>
<td>------------------</td>
<td>-----------------</td>
</tr>
<tr>
<td>7th</td>
<td>Basement studios</td>
<td>11 Young People</td>
</tr>
<tr>
<td>14.4.14</td>
<td>Ilminster children centre</td>
<td>9 Parents/ Carers</td>
</tr>
<tr>
<td>28.4.14</td>
<td>Hillfields youth centre</td>
<td>10 Young People</td>
</tr>
<tr>
<td>28.4.14</td>
<td>Claremont school</td>
<td>3 Parents/ Carers</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>March</th>
<th>Bristol Parent Carers Annual Conference</th>
<th>40 Parents/ Carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>3rd</td>
<td>Bristol Parent Carers Annual Conference</td>
<td>40 Parents/ Carers</td>
</tr>
</tbody>
</table>