

**Torbay Parent Participation Forum
ICS reprocurement event
21 November 2016**

Torbay Parent Participation Forum organised an engagement event to enable South Devon and Torbay Clinical Commissioning Group to ask parents about their experiences with children's health services.

The questions asked were based on the questions being asked across Devon in order to influence the drafting of the next specification for integrated children's services. These questions were devised from the themes that had arisen through many different kinds of engagement over the last few years.

The new children's contract, which will be in operation from April 2018, may include CAMHS, learning disability services and the child development centre in Torbay.

The questions are also available online via <http://healthwatchdevon.co.uk/re-procuring-childrens-services/>

The CCG is very grateful to Torbay parent Participation Forum for organising this event and enabling feedback from parents to influence the drafting of the specification.

How could transfer between services become easier and more effective?

Child Journey

Waiting times

- Great Ormond Street model – 2 days and everything looked at.

Information/access

Information about service on diagnosis .

Local offer doesn't have good quality info on it.

Sleep service should be offered more widely.

Online offers exist.

Services should help and guide you.

Useful info when parent suspects Aspergers (now Autism under DS?V)

Tony Atwood: Professional Angle.

- Been there, done that (most recent)
- The Complete Guide to Aspergers (a 'bib;le')

Patricia Romanowski Baste: (Parent angle)

- Aspergers Syndrome: the Oasis Guide.

Location of Services

Everything all in one physical place – 1 team.

Services on the periphery eg audiology

- Torbay and RD&E looking at different things/

Pathways

Poor patient journey.

Parents need to be able to navigate pathways.

Local offer should be advertised to parents who haven't been in recent contact.

Referral onwards eg dietician is hit and miss for CAMHS

(Alternative pathways?)

Use of meditation instead of sleep service.

The look and feel of health services matters.

- Patient knows best
- GP Practices TV's promote, add the online wait time to A&E
- Same place, particularly for a routine.
- Transition – 16 to 25yrs – intro to service & environment
- Chill out area – TV's in waiting room
- Like Torbay out patients
- Access to out of hours not A&E
- Autism & LD friendly environment

Transition from children's to adult services should be easier.

Transition: no one on table had experience of transition but would like:

- a good social worker
- EHCPs would make it easier
- Seamless transition
- Children in system should carry on till 25
- Children with neurological conditions are socially/emotionally behind their peers
- Other transfers happen & 18. If you stay until 25 this would give

Concerns

- Do not know enough about it at this stage
- Quite hard to get a social worker in adults
- Information being passed over. Proforma which parents can choose
- What are adults services
- Don't fall out over system
- How will my child be supported if they don't consent for parents to be involved
- Transition is catastrophic – no adults service

Coordination of care and services is important.

Education:

- social skills groups needed – education, social and communication needs – SALT
- Schools need more knowledge to support CYP, sometimes schools can be a barrier.
- (Ellacombe school) 'understanding your child's MH' (camhs)

Not working together

- Schools don't talk to health
- Services need to speak to each other
- DHRT blocked from in school observation

Understanding the system

- Parents don't understand eligibility criteria – how does this link with ASD
- Use of private psychologist is quicker

Silo treatment

- Only diagnosis for 1 condition. E.g. Once ASD diagnosed reluctant to look at others
- ASD is related to many others condition/ why CAMHS won't support.

- CAMHS turn away ASD diagnosed
- No offer for ASD
- No experience to support

Works well

- Coping cats programme – does work
- One service for children – child centered view TAC
- CAMHS service is good

Parental Journey

- Parent joining not smaller silos
- Focus on a limit of appointments 6-8 weeks
- All experience quite recent
- CAMHS who do they help, ASD CYP quick relaxation techniques – no good

Parental involvement

- CYP assessment is based on what paediatrician feels
- Parent not listened to – you don't get straight on assessment
- Paeds don't like you to have a opinion parents not listened to.
- Parental blame

Support for carers is important including peer support

Peer support:

- Not enough peer support. More like APS.
- SAN for parents who have been through LD nursing team
- Access parent support – Parent run peer support
- Small groups. Keep info confidential so members feel able to diagnosis issues.
- Don't rose tint things, be honest – self-esteem is low enough as it is.,
- Fear of the stigma attached to social worker
- Siblings get forgotten
- Young carers provide support for siblings
- Not everyone knows about young carer's service.

Rights

- Rights in education
- Legal rights
- Afraid to say anything to a professional that might be judge
- Parent who haven't got the ability to research/challenge

Respite

- No respite – it's difficult to get. Situation has to reach a tipping point.
- Respite to be more
- Eligibility for respite – threshold is too high
- Preference for physical disability for respite

Effect on family

- You're in a situation you can't have
- Inputs on whole family
- Emotionally exhausted and hard for single parents
- Sometimes parents don't have enough resilience left!
- Parents carers need to hear reality all the time

If I need a health service, I want some choice about where I go and who I see

- If different provider and move, people shouldn't go back into a new waiting list.
- Provider deliver locally, South Devon & Torbay
- Transition between geographies between providers
- Don't want to 'rock the boat', could I ask to see someone else – fresh pair of eyes.
- Don't get on with Practitioner, able to choose different
- See the same therapist

<ul style="list-style-type: none"> - What is good about local services - People don't know about choice - Most appropriate person - Choice of GP - know the history - Weekend and evening and early morning clinic - Good and bad experience of social workers.
<p>Treatment should reflect the individual's needs</p>
<p>Communication</p> <ul style="list-style-type: none"> - Text reminders are good - If professional changes appointments they should use your preferred communication methods. <p>Location</p> <ul style="list-style-type: none"> - JPU would be ideal - Newton A is a little far - Somewhere familiar <p>Patient Notes</p> <ul style="list-style-type: none"> - ASD should be a flag on the front page of the patient notes so you don't have to explain again – where to start - Then the HC professional would know how to behave <p>Referrals</p> <ul style="list-style-type: none"> - You shouldn't see someone and be able to explain the issues there and then - Services to match individual issues - As a parent you don't know what to ask for because you don't know what exists - Services/departments are disjointed. Professionals don't know what exists - GP should know who to refer onto - Publicise who can make referrals; so parents know who to make an appointment with
<p>Easy access to information and advice about health services – online, phone, leaflets, face to face</p>
<p>Practical help</p> <ul style="list-style-type: none"> - Cerebra – Lending library - Advice for parents e.g. reading and strategies for when a diagnosis has to be made <p>School</p> <ul style="list-style-type: none"> - Parents should be listened to – don't just hear the voice of the school - School info needs to not present a barrier - If there's a problem at school the issues get noticed & addressed - High functioning ASD are not always picked up appropriately at school. <p>Mainstream</p> <ul style="list-style-type: none"> - Teaching all children in schools e.g. how different CYP behave - Offering all children info not just these with diagnosis <p>Local offer</p> <ul style="list-style-type: none"> - If its phone, leaflets etc. you still need to know where to go in the first place - Local offer has been frustrating - Parents get lots of info by word of mouth - See local offer info. On previous question <p>Services</p> <ul style="list-style-type: none"> - Long waits for ASD assessment - Not many services provided by NHS. Most charity or private
<p>What information do you want about what services you're entitled to and know the system works?</p>
<p>Access</p> <ul style="list-style-type: none"> - Single point of contact to get info and support - Views on local offer – not correct, difficult to access

- Communication - how long wait – process who you will see – what is process
- Signposting
- List of recommended counsellors where CAMHS don't help

Early support

- Early bird
- Pre diagnosis – someone to speak to who have gone through it
- Peer to Peer support

Communication

- Improved contact during waiting period – feel abandoned
- Service continuity from 1st contact – streamline
- Support and contact can be email or face to face just get back
- Don't brush us off – if doors close someone to talk to and offer signpost

Problem

- Health need to input to school/SENCOs
- Tell us when they get it wrong (apologies)
- CAMHS do not deal with autism – where does?
- Referral criteria barrier – ADHD- LD & CAMHS

System

- Self referral for CAMHS
- Talking therapist for child & family – Autism
- More ED psych involvement
- More support post diagnosis
- Flow through to adult services

Support from generalists

- Carers support workers in practice
- GP's don't want to help – contact school
- School nurses what do they do?

Adhoc

- Knowledge helps empower
- Educate children young- use of health and keep themselves healthy
- Treat/support the family NOT ie. child – CAMHS parents - DAS

