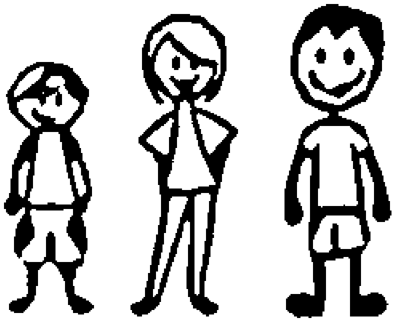
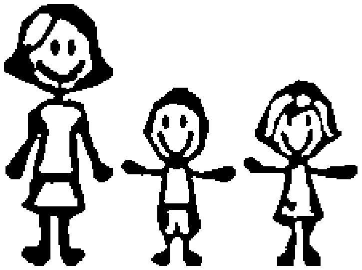


**Community Health and Wellbeing Services
for Children and Young People in Devon**

Shaping future services

DRAFT Engagement Feedback Report

October 2017



Foreword

Marc Carter, Trustee, Devon Parent Carers' Voice

The contracts to provide services for children and young people in Devon are due to be renewed from 1 April 2019. This provides an opportunity over the coming months to review and improve the system of care and support available to children and young people across Devon.

To support this process, over the last few months, local health and social care professionals, clinicians, partner organisations and patient representatives have been developing ideas to form proposals for how future services for children and young people might look.

As a representative of Devon Parent Carers Voice I was pleased to be asked to form and chair a steering group to look at how young people, parents, and carers are involved in this process to 're-procure' health services for children and young people across Devon. The re-procurement is an opportunity to ensure the services delivered are the best they can be.

We have been meeting regularly as a group of parents, Healthwatch and other voluntary sector representatives, NHS staff and local authority officers since May this year.

We have had an important role as 'critical friends' to this process, pushing to secure the very best service for our children and young people. We have also collated what children, young people, parents, and carers have said about their services over the last few years. All this has helped the commissioners understand where things are working well, and where they could be better. This process has directly influenced the drafting of specifications for the new services.

We have worked hard over the summer to gather as many views and different perspectives as possible on the proposals for future services for children and young people. I am pleased to present the fruits of our labour in this draft Engagement Feedback Report and I hope you enjoy reading it. Further information about this process is also on the website:

https://www.newdevonccg.nhs.uk/your-ccg/children-and-young-people-100144

I would like to thank everyone who has taken the time to give their views over the summer, whether that has been via our survey or face to face at an event. Your views will make a difference for our children and young people.

Marc Carter
Trustee, Devon Parent Carers' Voice

About Marc
Marc lives in Torrington with his wife Mandy and their three children (one's an adult) with additional needs. He is a full-time carer. Marc has done a range of voluntary work for a number of years. He is always keen and never afraid to challenge health services, or local and central government, especially when it comes to

matters that affect children's services.

Contents

Are you a parent of a child in contact with services for children and young people? Contact your local support group…

To get involved with Devon Parent Carer Voice, come along to one of our events, read about us online, or contact us at **www.devonparentcarersvoice.org** You can also follow us on Facebook. If you're in Torbay you can contact **www.torbayppf.org.uk**, or in Plymouth **www.plymouthpcv.co.uk**.

1. Introduction

We want all children and young people in Devon to have the best start in life, growing up in loving and supportive families, and being happy, healthy and safe.

The contracts to provide services for children and young people in Devon are due to be renewed from 1 April 2019. This provides an opportunity over the coming months to review and improve the system of care and support available to children and young people across Devon.

Local children and young people, their parents and carers, health and social care professionals, clinicians, partner organisations such as schools and children and young people's representatives helped to develop ideas to form some proposals for how services might look in the future.

It is critical that we get this right, so before making any decisions in relation to the re-procurement, we decided to test our proposals during July, August and September 2017 to see what local people think about services for children and young people now and what they think about our proposals for future services. This document brings together the feedback that has been collected.

2. What services are we talking about?

Services that all children come into contact with at some point and services for children and young people with additional or special needs (up to the age of 25). These are listed below:

Best Start in Life and Promoting Strengths in Families

0-19 year olds public health nursing services (health visiting and school nursing)

Special Educational Needs (SEND) and Children with Additional Needs and Long Term Conditions

- **Nursing and Community Support to include:**
  Complex care | palliative care | community children's nursing children in care nursing service | specialist school nursing learning disability | child development centres and specialist children's assessment centres

- **Integrated Therapies to include:**
  Speech and language therapy | occupational therapy | physiotherapy | reablement officer for visually impaired children (ROVIC) | portage (special needs pre-school education service)

Emotional Health and Wellbeing

Community child and adolescent mental health services (CAMHS) | CAMHS assertive outreach CAMHS crisis response | safeguarding | Autistic Spectrum Condition (ASC)

Journey After Child Abuse Trauma (JACAT)

3. Our proposals

Many different things sit under the umbrella of services for children and young people. These are provided by a range of organisations.

Our proposals below respond to feedback we have heard and we want to design services so that in future they can work much better together as one system.

Good communication with every child, young person and their family so that they always understand their current position on their care plan and know what future steps are ahead and when.

Listen to views from children and young people using services and their families. Their views are considered and used to help improve services.

Services that work on the basis that no referral is inappropriate, providing **one local point of contact** that is available in person and online, identifying needs, signposting to advice or referring into services where appropriate.

The development of a **truly integrated workforce** that, whilst led by specialists, creatively blurs the boundaries between professions to develop a skilled and knowledgeable workforce that shares tasks.

A **rapid triage process** for referrals by a co-ordinator that is backed up by professional expertise offering rapid response where appropriate.

An appropriately resourced **out-of-hours/ emergency and crisis response** that is tailored to meet a range of needs.

Every child or young person will have **a lead professional to act as co-ordinator** who will liaise with the multi-disciplinary team that is delivering their care. The co-ordinator will work with the child or young person and family to develop a personal care plan to achieve specific desired outcomes.

Services which **work in a flexible way**. Services will be supported by additional online information and advice that is designed to be child and young person friendly and is available to everyone for advice and further help if appropriate. This will provide better access to some forms of help outside of normal working hours.

A **fully integrated service response** accessible to and co-ordinated by, the lead professional.

Paperless and mobile working wherever safe and appropriate

4. How we encouraged people to have their say

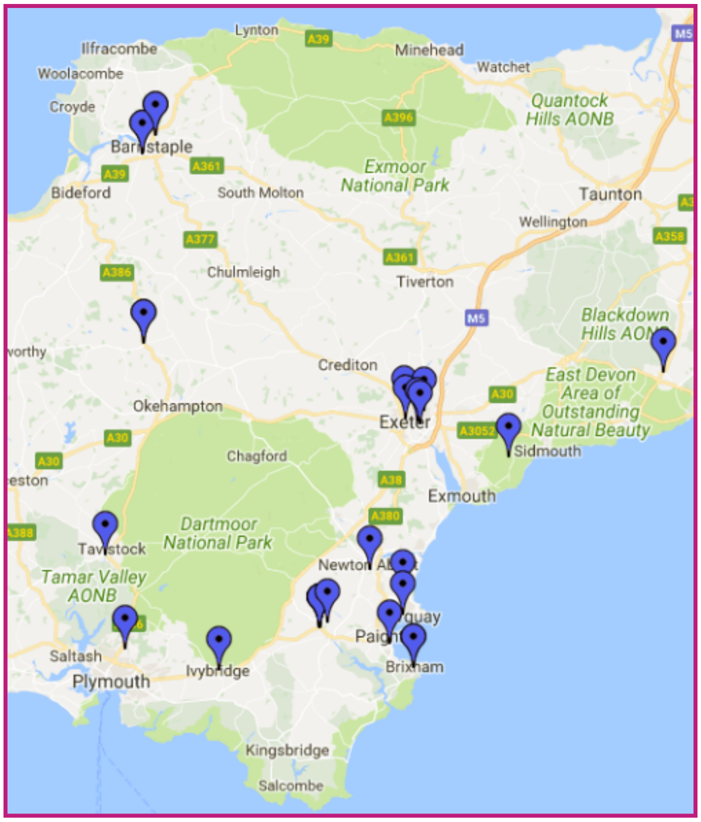
Survey

Between 13th July and 15th September, we sought views on our proposals about future services for children and young people via a survey which was accompanied by our Engagement Document. These were available online, in paper and as *easy read* versions. The survey also included a Freepost address for return of responses via the post.

Face to face

We contacted approximately 900 individuals and organisations across North, East and West Devon, South Devon, Plymouth and Torbay. These included schools, medical centres, youth groups, consultants, the youth parliament and clinics. We contacted groups such as the scouts, brownies and cadet services. We also attended several public events which included Okehampton Fair, Dartmouth Regatta and St Thomas Festival.

The map opposite shows places we visited to speak to people.



We spoke to over 200 children, young people, parents/carers, voluntary workers, clinicians and health/social care professionals about our proposals. We sought consent to attend various groups, events and clinics related to children and young people and accepted invitations to visit the following places to have face to face discussions.

- The Project
- Space
- North Devon Show
- Okehampton Show
- Holsworthy Show
- Dartmouth Regatta
- St Thomas Festival
- Youth Enquiry Service, Exeter
- Paediatric Consultants
- Oasis Children's Group
- Tavistock Specials Training Sessions
- Children Families Partnership
- Ivybridge School Activity Day
- Early Help Forum
- Virgin Care Limited clinics
- Vranch clinics
- Breaking the Barrier – cycling
- Breaking the Barrier – surfing
- Youth Parliament
- 100 Club
- Chestnuts
- North Devon Forum (Autism parent group)
- Devon Ability Counts League Football
- Torquay Fair

Feedback collected during face to face conversations can be found in section 8 of this report.

Telephone and email

A dedicated telephone number and email address were included on all promotional materials and on our website to encourage people to tell us their views or ask questions.

Activity workshops with children and young people

Over the summer, we collaborated with a number of organisations that specialise in working with children and young people to help us gather views. In total, we engaged with approximately 100 children and young people in this way and feedback is summarised in section 9 of this report.

Promotion

We widely promoted this engagement opportunity across North, East and West Devon, South Devon, Plymouth and Torbay, targeting places where it would reach children and young people, parents and carers, health and social care professionals, clinicians and people with an interest in services for children and young people. We sent posters and fliers to many different organisations and centres across Devon.

We would like to say a special ***thank you*** to all organisations that helped us to promote this engagement. In particular the Devon, Torbay and Plymouth Healthwatch organisations helped us to spread the word by distributing materials on our behalf and promoting the engagement on their websites.

In addition, 647 local organisations involved with children and young people have been contacted via email. The email contained details of the procurement procedure and our need for feedback.

All information about this project can be found on our website, where we will continue to post updates:

https://www.newdevonccg.nhs.uk/your-ccg/children-and-young-people-100144

5. Key themes

800 children/young people, parents/carers and health/social care professionals participated in the engagement activity described within this report

Split by engagement activity, approximately:

465 people completed our survey

150 people spoke to us face to face

100 people participated in workshops and activity days

Split by respondent type, approximately:

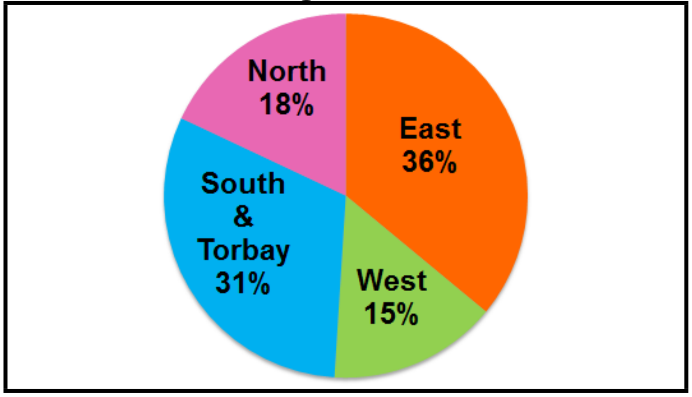
150 participants were children/young people

400 participants were parents/carers

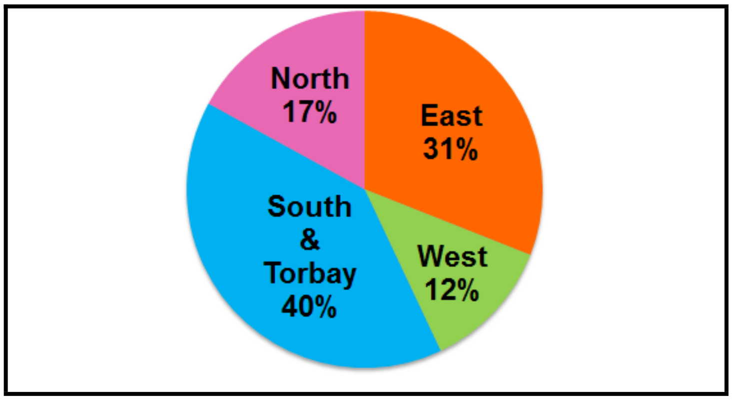
150 participants were health/social care professionals (including workers in local services for children and young people or related services (e.g. education and social work), representatives of organisations/groups with an interest in children's services, GPs/other clinicians and referrers and hospital doctors

Which area of Devon do people live or work in?

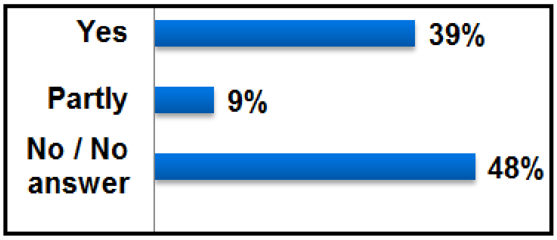
Children/young people and parents/carers live in the following areas



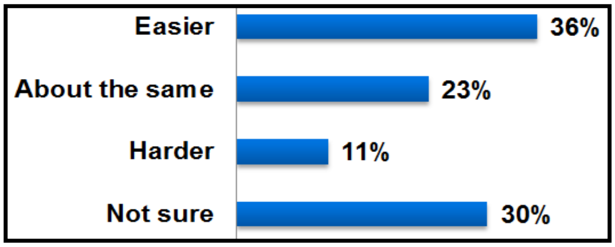
Professionals work in the following areas



How many people that completed our survey had read our proposals?

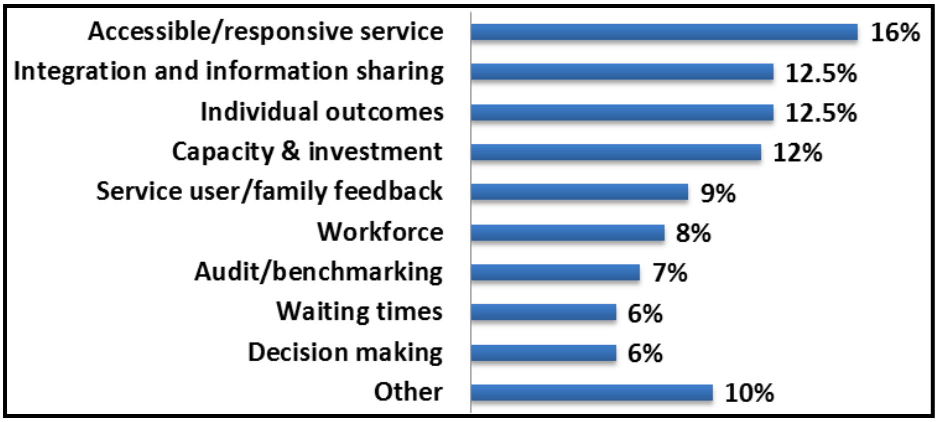


Will proposals make it easier or harder to receive the right support/ treatment?

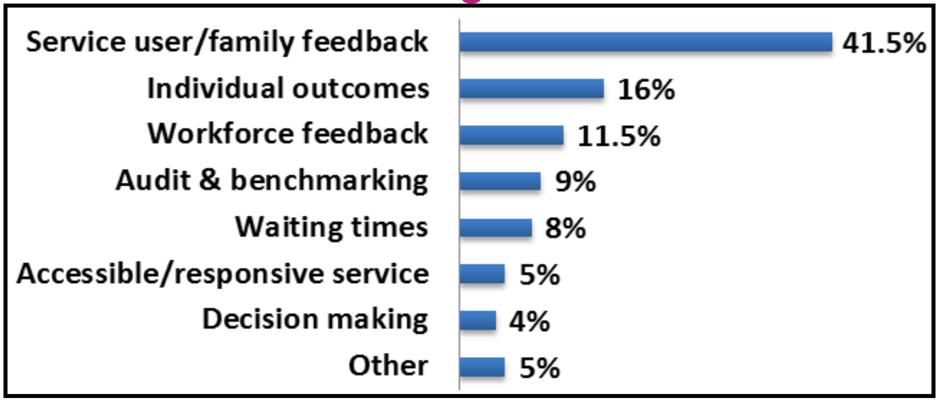


based on 48% of people that had read or partly *read the proposals*

Ideas for assessing suitability of potential service providers



How can we measure ‘good’ when we monitor services?



Top 5 priorities for making the future service model a success

1 **Feeling well informed about waits and treatment**

Having information about how long the child/young person will need to wait for the service and what they can expect from the service when you get it.

2 **One health professional as family liaison person**

One person who the child/young person/family can contact to talk about their care and what they need

3 **Help and advice in one place**

One website, email and phone number where families can get information about help and support, and services they might need

4 **Services are joined up and a separate referral is not needed if you also have a long term condition**

If the child/young person has a long term condition, they don’t need to wait for another referral to get help again

5 **Knowing how to help yourself and what to do if things change**

While a child/young person is waiting for a service, having information about how they can manage, including what to do if their situation changes

Key themes that respondents raised in their comments

Throughout the survey that we ran over the summer, we invited people to give feedback in their own words. Below are the top 8 things that people raised. These themes are set out in greater detail in sections 6, 8 and 9 of this report.

1 **Being patient centred and focusing on individual outcomes**	**This was the most popular issue that people fed back. It relates to the desire to for services that are flexible enough to fit in with the individual service user and their family to some extent, rather than expecting them to fit in with the service. The importance of understanding outcomes and being able to benchmark using outcome measures informed by patient and family experience was also emphasised.**
2 **Feeling informed and supported because services are accessible and responsive**	**Services should be able to offer a flexible service that is set up to respond well. A responsive service would do things such as share service user information so that questions only need to be asked once, offer appointments where services users feel safe and comfortable, offer informal ways of giving quick advice when needed and ensure the service user and their family have a good understanding of what is happening at all times.**
3 **Service/team integration and information sharing**	**Services and teams should be joined up and truly work together, putting the service user at the centre. It should be possible to securely share service user care records across different services and organisations when appropriate.**
4 **Workforce considerations**	**The workforce should be large enough, be well trained, have job satisfaction and should be encouraged to embrace modern ways of working.**
5 **Service user and family feedback should be routinely collected**	**Feedback from people in contact with the services is routinely collected and acted upon to inform service improvements.**

and acted upon	
6 Waiting times	Waiting times should be addressed in services where they are lengthy.
7 Supporting the wider family	Wider family members need supporting so that they can in turn support their loved one who is a service user.
8 Decision making	Organisations delivering services should have clear, straightforward decision making practices when making at all levels. Many people specifically mentioned decision making around budgets and clinical assessments.

Comparing key survey themes with service model proposals and service delivery priorities

Key survey themes	Service model proposals & service delivery priorities
1. Being patient centred and focusing on individual outcomes	**Good communication** with every child, young person and their family so that they always understand their current position on their care plan and know what future steps are ahead and when. An appropriately resourced **out-of-hours/ emergency and crisis response** that is tailored to meet a range of needs.
2. Feeling informed and supported because services are accessible and responsive	Services that work on the basis that no referral is inappropriate, providing **one local point of contact** that is available in person and online, identifying needs, signposting to advice or referring into services where appropriate. **Priority 3** **Help and advice in one place**
3. Service/team integration and information sharing	A **rapid triage process** for referrals by a co-ordinator that is backed up by professional expertise offering rapid response where appropriate. **Paperless and mobile working** wherever safe and appropriate.

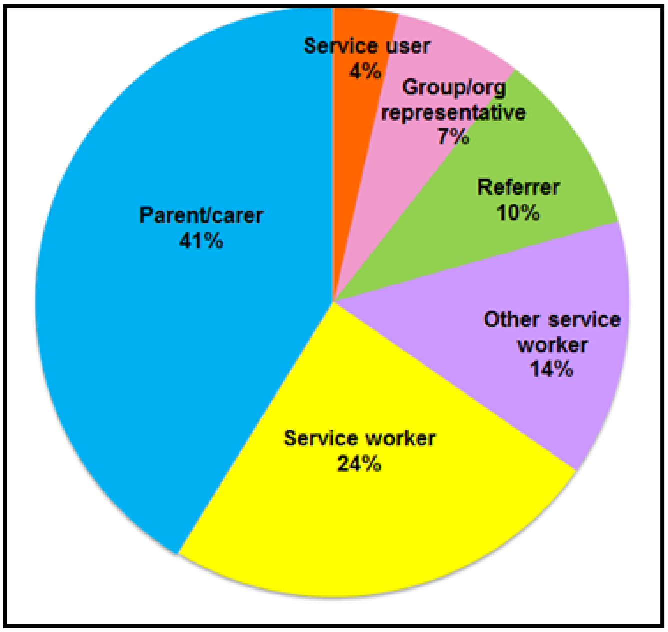
4. Workforce considerations	Every child or young person will have **a lead professional to act as co-ordinator** who will liaise with the multi-disciplinary team that is delivering their care. The co-ordinator will work with the child or young person and family to develop a personal care plan to achieve specific desired outcomes. The development of a **truly integrated workforce** that, whilst led by specialists, creatively blurs the boundaries between professions to develop a skilled and knowledgeable workforce that shares tasks. **Priority 2** **One health professional as family liaison person**
5. Service user and family feedback should be routinely collected and acted upon	**Listen to views from children and young people** using services and their families. Their views are considered and used to help improve services.
6. Waiting times	Services which **work in a flexible way**. Services will be supported by additional online information and advice that is designed to be child and young person friendly and is available to everyone for advice and further help if appropriate. This will provide better access to some forms of help outside of normal working hours. **Priority 1** **Feeling well informed about waits and treatment** **Priority 4** **Services are joined up and a separate referral is not needed if you also have a long term condition**
7. Supporting the wider family	**Priority 5** **Knowing how to help yourself and what to do if things change**
8. Decision making	A **fully integrated service response** accessible to and co-ordinated by, the lead professional.

6. Children and young people's services survey

This section contains results from the above survey which we ran from 13th July until 15th September 2017.

1. Who responded to this survey?

Respondent type



16 Service users (a young person aged 25 or under who has experience of using these services).

189 parents/carers (a parent/carer of someone aged 25 or under who has used these services).

113 service workers (a health, social care or education professional that works in these services).

48 referrers (a professional (for example GP) that makes referrals into children's services).

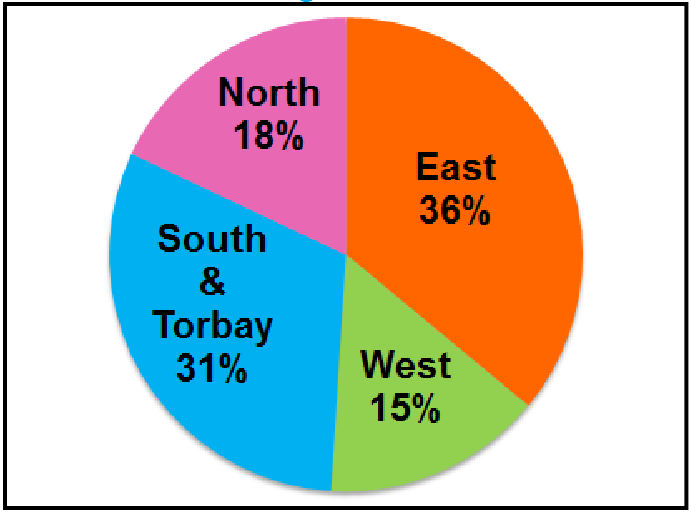
66 workers in related service (other health, social care, education or voluntary sector professional).

33 group or organisation representatives (a representative of an organisation or group with an interest in children's health services provision).

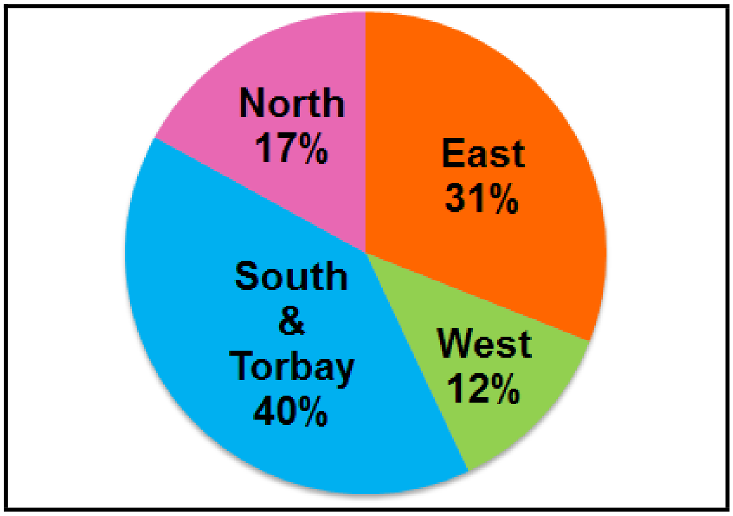
Total number of people – 465

Which area of Devon do people that completed our survey live or work in?

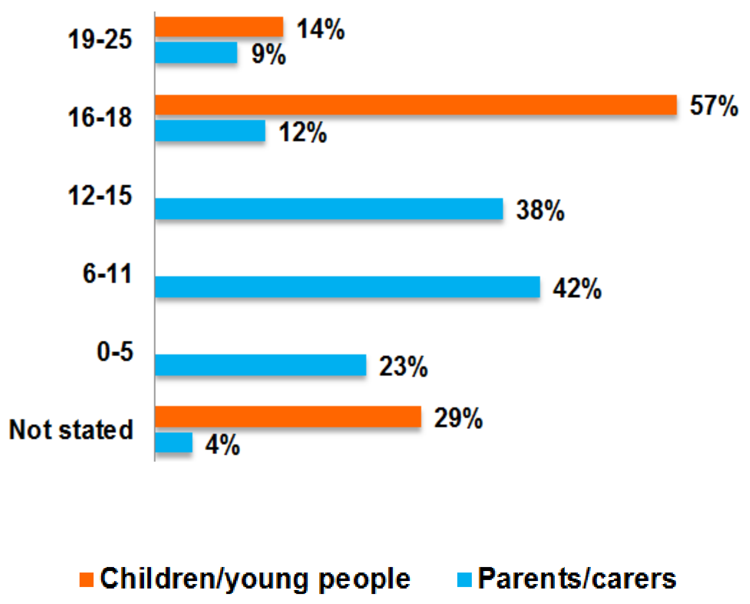
Children/young people and parents/carers live in the following areas



Professionals work in the following areas

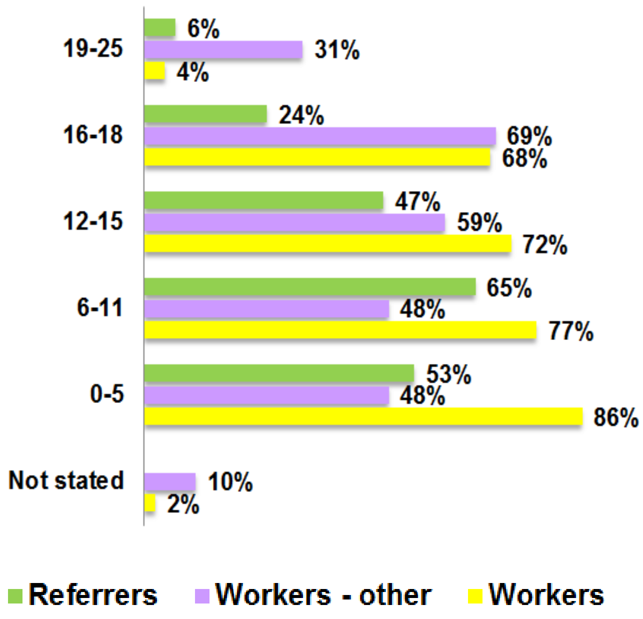


Age of child or young person



7 children/young people, 102 parents/carers responded on their child's age

Age of children & young people professionals work with

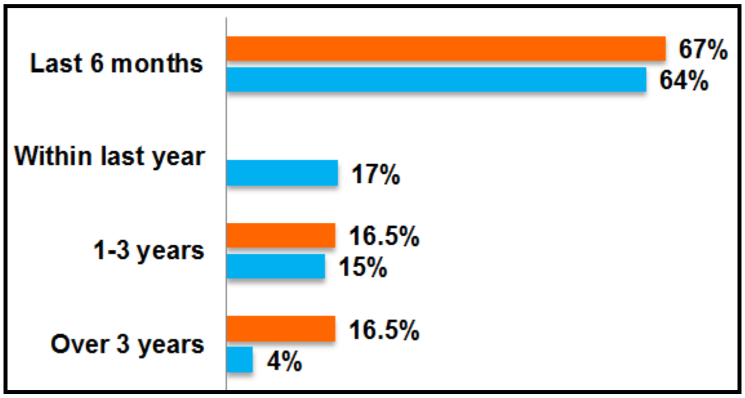


57 workers in children's services, 41 workers in related services, 10 referrers. (See p. 12 for a full description of respondent types.)

Views about current services

2. When did children/young people and parents/carers last have contact with services?

Answered by 6 children/young people and 112 parents/carers



3. Which services have children/young people and parents/carers had contact with in the last 3 years?

CAMHS (Child & Adolescent Mental Health Services).

School Nurse (a nurse that is based in schools).

SEND (help for children with special educational needs and disabilities).

SALT (speech and language therapy).

OT (occupational therapy).

ASD (Autistic Spectrum Disorder assessment).

Health visiting (community nurses for all pre-school age children).

Physiotherapy (therapist for mobility).

Children's Assessment Centres (e.g. John Parkes Unit, Honeylands or Plymouth Child Development Centre).

LD (learning disability services).

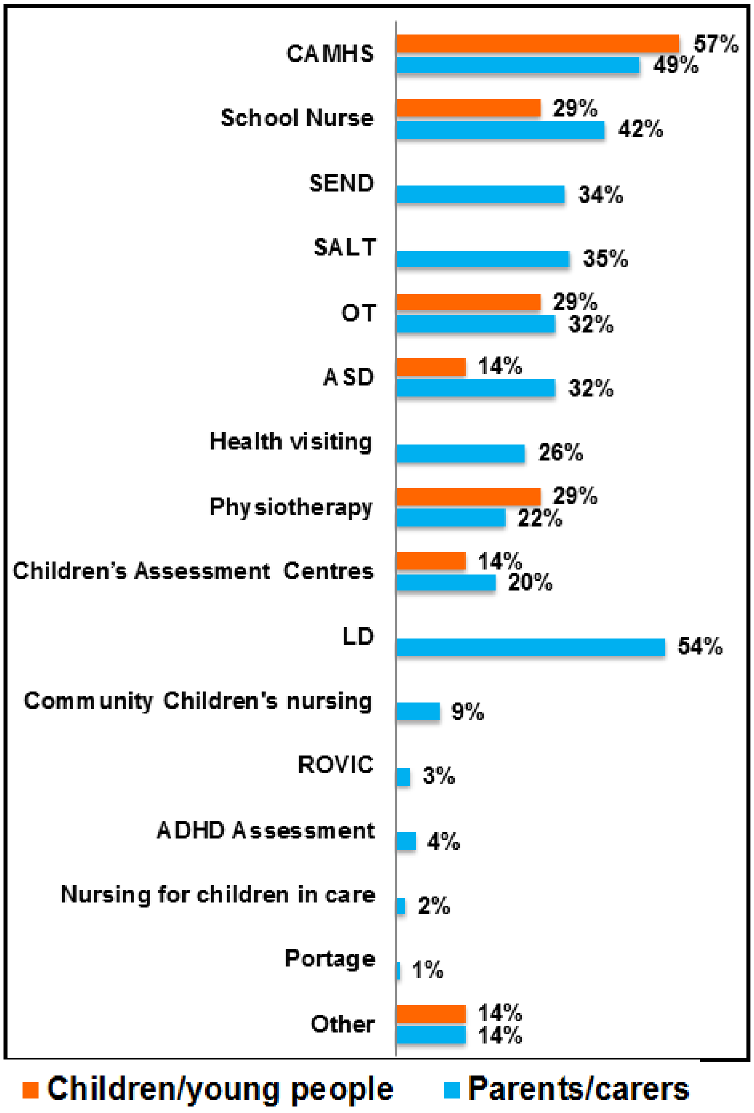
Community Children's Nursing (community nurses for children with special needs).

ROVIC (reablement officer for visually impaired children).

ADHD (Attention Deficit and Hyperactivity Disorder assessment).

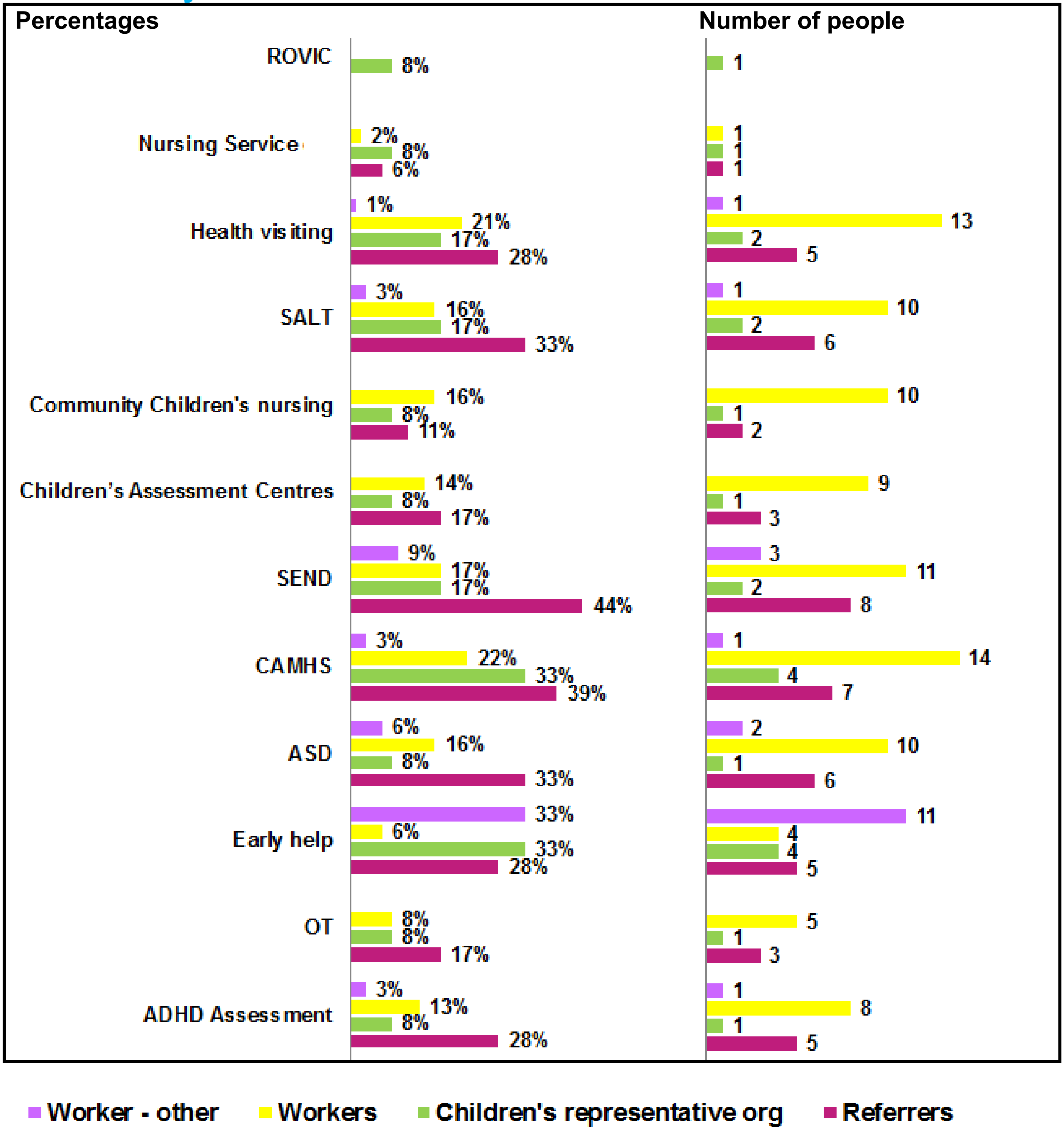
Nursing service for children in care (community nurses for children in care).

Portage (service for pre-school children with special needs to help them to prepare for school attendance).



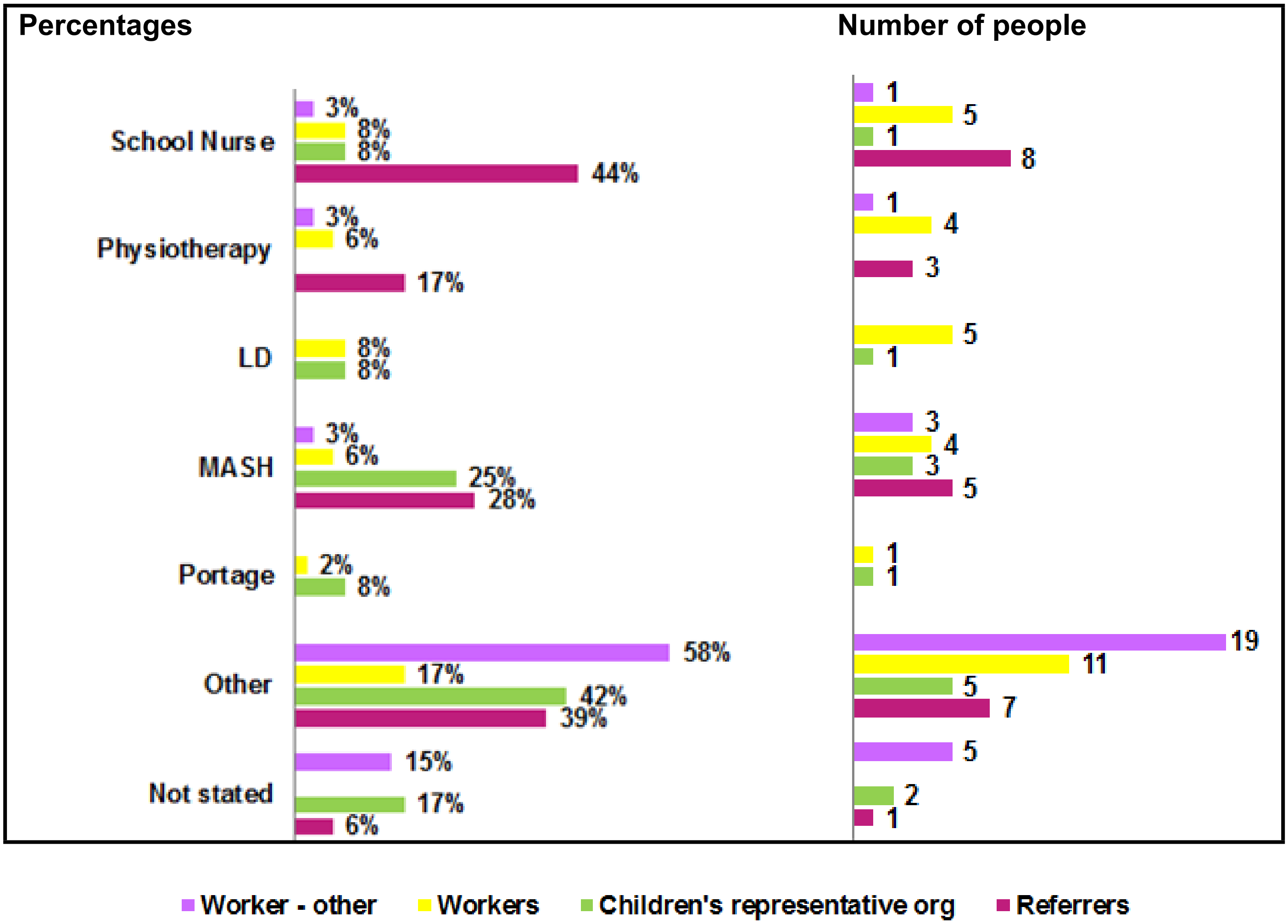
Answered by 8 children/young people and 114 parents/carers.

4. Service areas covered by workers and referrers that completed the survey



Answered by 63 workers in children's services, 47 workers in related services, 18 referrers, and 18 interested representatives of groups/organisations, choosing all services they work with. (See p. 12 for a full description of respondent types.)

4. (Cont'd) Service areas covered by workers and referrers that completed the survey



Answered by 63 workers in children's services, 47 workers in related services, 18 referrers, and 18 interested representatives of groups/organisations, choosing all services they work with. (See p. 12 for a full description of respondent types.)

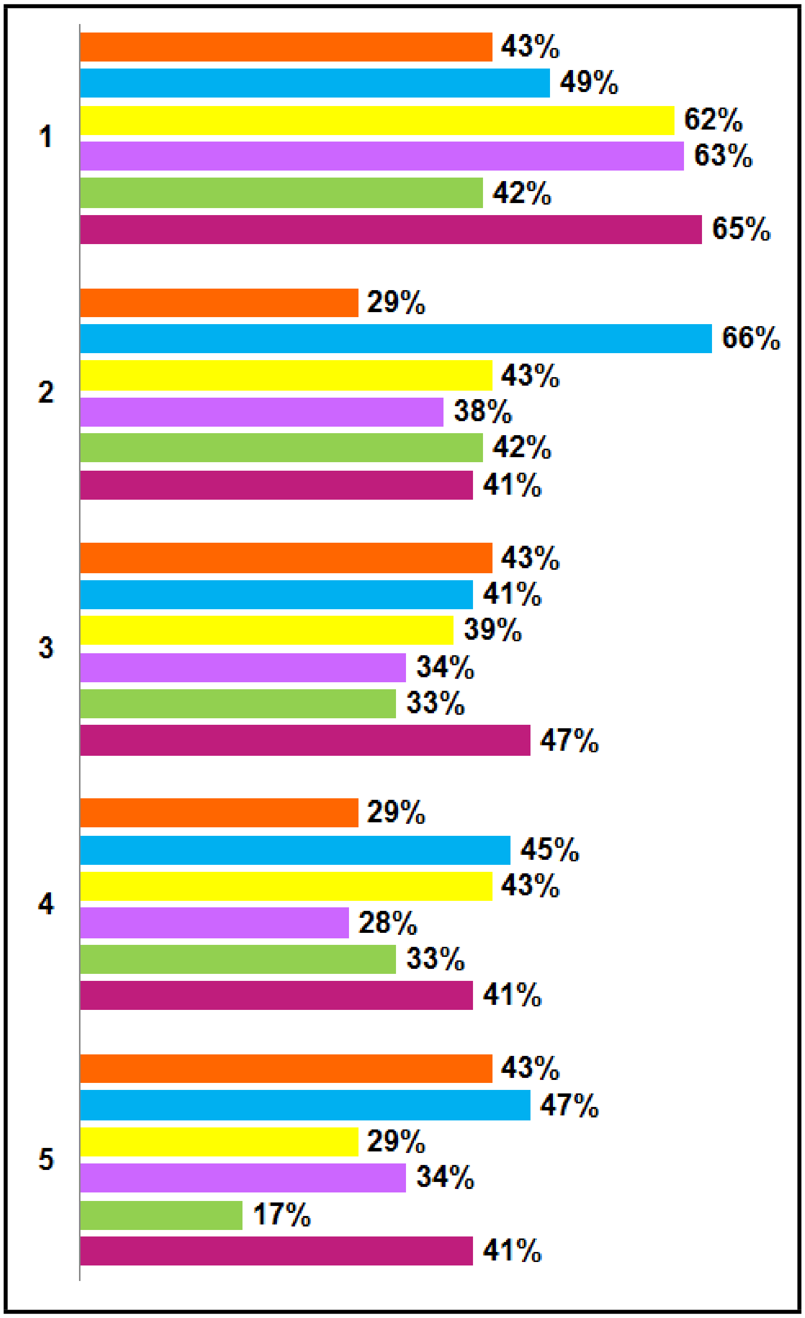
5. How many referrals into services for children and young people are made on average by referrers who completed the survey?

Answered by 18 referrers

Views about the proposed model of care for children and young people's services

6. Prioritising what makes services good

Top five priorities in order of popularity



1 Feeling well informed about waits and treatment: having information about how long the child/young person will need to wait for the service and what they can expect from the service when you get it.

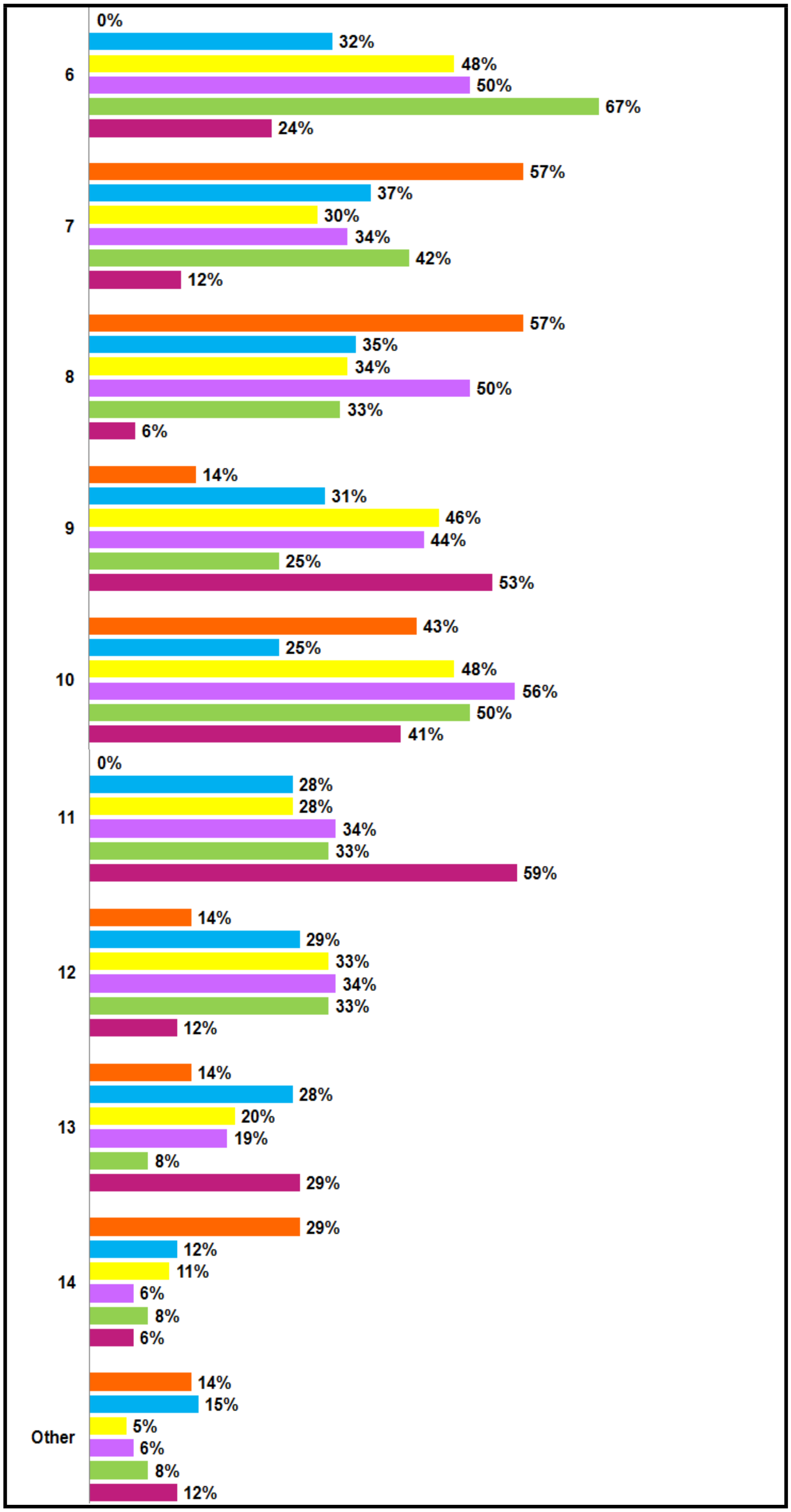
2 One health professional as family liaison person: one person who the child/young person/family can contact to talk about their care and what they need.

3 Help and advice in one place: one website, email and phone number where families can get information about help and support, and services they might need.

4 Services are joined up and a separate referral is not needed if you also have a long term condition: if the child/young person has a long term condition, they don't need to wait for another referral to get help again.

5 Knowing how to help yourself and what to do if things change: while a child/young person is waiting for a service, having information about how they can manage, including what to do if their situation changes.

Other priorities



6. Children/young people are involved in setting goals and decisions about their care
7. Appointments are at flexible times and places to suit family life
8. If children/young people need services, they can get them near where they live
9. Children and young people should be prioritised on risk and need
10. Crisis services are available out of hours
11. Children/young people/families can get quick advice about their situation without needing an appointment
12. Services help children/young people to understand their own health and wellbeing, and be as independent as possible
13. If the child/young person doesn't have the right ‘connection’ with the professional, they can change to another
14. If children/young people need services, they can get them near school

Answered by:
7 children/young people
110 parents/carers
61 workers in children’s services
33 workers in related services
17 referrers
11 interested reps
(See p. 12 for a full description of respondent types.)

7. Comments and suggestions received in relation to priorities

People completing the survey were invited to suggest their own priorities. These are shown below by respondent type. No children/young people or referrers made additional suggestions.

Parents and carers

- As a parent and health care professional I think parents should also be asked to engage with services in a timely fashion if they have requested it and to bring their children to appointments.
- To be able to see a 'named' health visitor rather than someone different each time.
- New mums groups with health visitors to make friends/create support networks.
- Parents wish the professional to understand and know the child's history and do not want to repeat information for no reason.
- Transition to adult mental health needs sorting.
- Specialist staff with experience doing the specialist work they are trained for. Such a shame to see awesome people having to do much lower level work and so getting full up and less able to do what they thought their job was, essentially because of a broken system.
- A set of contact details supplied to all at the start of requiring a service, not having to find out by word of mouth.
- Getting referred in the first place. 11 years of asking GPs & schools to help. Have now given up and am seeking private help on my single parent 12K a year income.
- Information on how to get help when moving to university.
- That there are services available to all children, not services that are only accessible for children with the right diagnosis.
- Before asking what is good, ask the public what isn't working first!
- Train teachers to spot ASD traits quicker.
- Getting support after diagnosis.
- Not using an ‘episodes of care’ model.

Workers in children’s services

- The ranges of problems children have mean that the priorities will differ between conditions. A lot of the roles mentioned are within the remit of their GP.
- I feel all of these are achievable within the present and proposed service design.
- The SPA is an excellent concept but does not deliver on integration currently.

Workers in other services

- Liaise with SENDCO (special educational needs and disabilities support) in school at all times, help without need for diagnosis first is essential to schools!

Children’s group or organisation representative

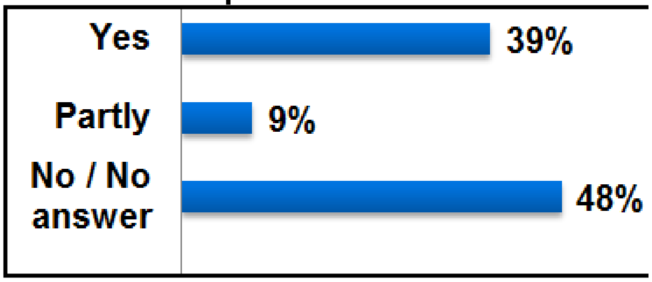
- Just an observation - according to the SEND (special educational needs and disabilities) code of Practice, the one website, email and phone number should be the SEND Local Offer website, email and phone number, spanning education, health and social care.
- Access to residential facilities where need is present.
- Service is 365 days, 52 weeks with cover if required.

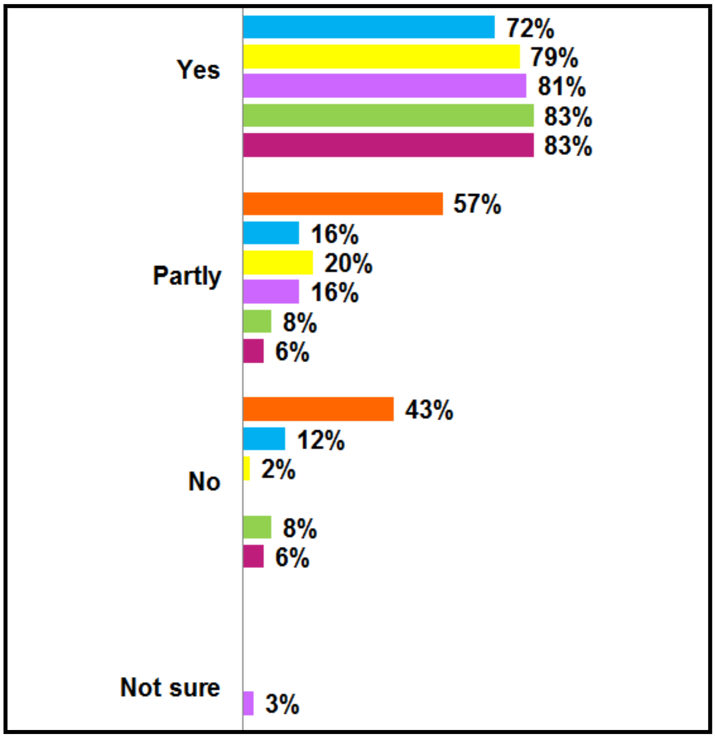
8. Have you read our

9. Do you think the proposals will

engagement document that explains our proposals for future services?

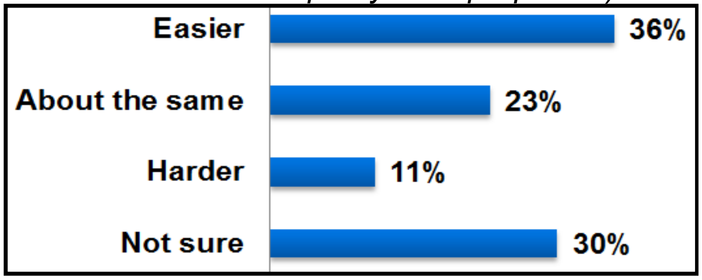
Results for all respondents

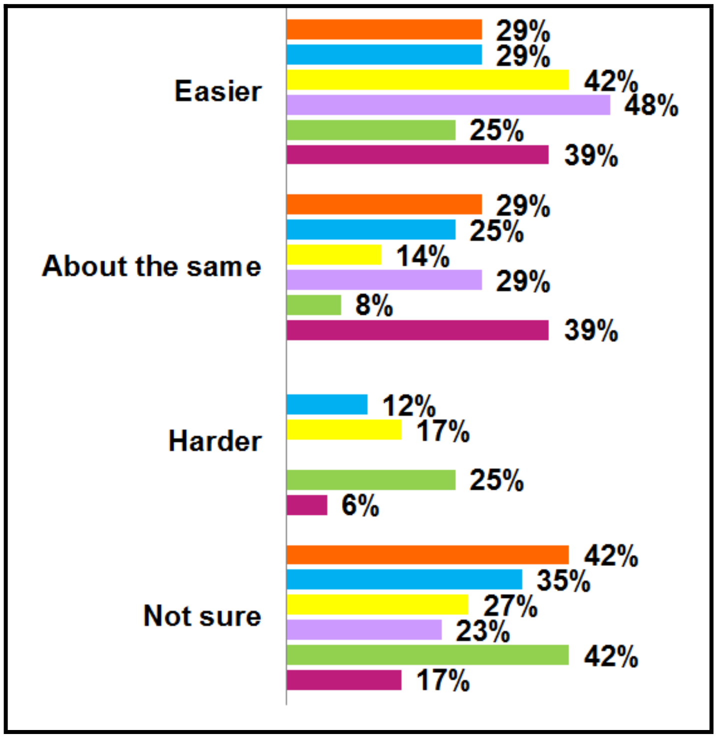




make it easier or harder for you to receive the right support and treatment?

Results for all respondents *(based on 48% who had read or partly read proposals)*





🟧 **Children/young people** 🟦 **Parents/carers** 🟨 **Worker** 🟪 **Worker - other** 🟩 **Children's org rep** 🟥 **Referrer**

Answered by 7 children/young people and 113 parents/carers, 62 workers, 33 workers in related services, 17 referrers and 11 representatives of interested groups/organisations

Of 113 parent/carer respondents, 81 had read the engagement document and 18 partly read. Of the 62 service workers 49 had read it and 12 had partly read it.

(See p.12 for a full description of respondent types.)

Respondents who felt things would be harder made the following comments

69 parent/carers, 62 workers, 10 referrers, 38 workers in related services. *(See p.12 for a full description of respondent types.)*

Parents & carers

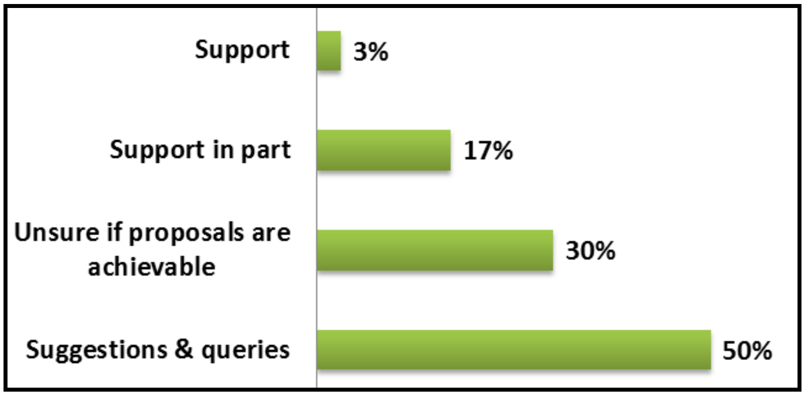
- It all sounds lovely but having been a parent of children with special educational needs and disabilities for 11 years in Devon. I have zero confidence in seeing the benefits of any of it.
- Amongst all the gobbledygook I cannot see that anything changes. It still doesn't address the problems we've had - very little and very poor quality help for middle to late teens. My daughter was passed on to adult services as she was 18, but this/these were totally inappropriate for her and she was left with nothing/ no help. People her age need age specific care and help and not be treated like just another statistic but an individual with very individual needs.
- If a child has a named condition it is easier to point them to the right services. Those without a named condition are pushed from pillar to post across all specialties. There is no emphasis on creating child centred commissioning frameworks that is evidenced at specialist children's hospitals. Rather than giving a child 15 appointments with 15 specialists, the specialists should conduct multi disciplinary team meetings with an intermediator who can liaise with the parents and child. 'Tell us once' should be adopted. Also ASD assessments are still very poor.
- Following assessment and diagnosis have had no support or follow up.
- Endless waiting lists, being passed from pillar to post and seeing numerous people.
- I worry that services will be lost and I won't see the professional I need to see as another. person may be doing that job instead.
- I haven the read it yet but waiting times for ASD assessment and teaching teachers to spot it earlier would help as my daughter wasn't diagnosed until 9.
- Money will rule this service but hopefully it will not as many services are being lost because of lack of funding.
- We need these services in every school. A known face not a string of strangers that you have to repeat the story over and over again. Local face to face is what we like to see.
- My experience was very good with the response from CAMHS professional and timely. What could be improved is better communication between primary care and other health professionals and school.
- Proposals are great but without services working together, listening to parents, it won't change.
- No clear explanation of how things will get better. It's full of soundbites and no real substance.

Workers in other related services

- The service requires a higher level of resources- there is more pressure being applied to the education sector in order to substitute at least one of the above services and we are not the best trained.
- The principles sound good, however I come from a practical point of view re the day to day action of making referrals and this is what I would like to bring up. I feel that there are barriers to accessing the services, which in turn does not help our families and their children.

Open ended comments about the proposals

10. Other comments about proposals for the new service model



Support

- Nothing in it that anyone could disagree with.
- Looks good with the 24/7 crisis and increased primary school workers.
- We should all be doing them already!

Partly support

17% of respondents expressed support for a particular aspect of the proposals:

- **Support for focus on early help and prevention.**
- **Support for using lead professionals and care co-ordinators.**

Support for focus on early help and prevention

The major focus within this feedback was on emotional health and wellbeing.

- How are you going to tackle the issue of painfully long waiting lists (even when you are listed as high priority)?
- It all sounds so very far away from what's actually happening and there is very little in it about identifying families that need help and fly under the radar because they appear to be coping (like mine).
- Current waiting times are dreadful - CAMHS - 8 months and SALT over 4 months - this just makes the problem so much worse for both parents and children.
- It would be helpful right at the beginning particularly with a young adolescent male with mental health issues to speak to someone quickly - preferably referred immediately by their GP. My son saw a GP for nearly a year before they would actually LISTEN to what he was saying. It got so desperate that I had to drag him to the doctors surgery where luckily that last time it was a Locum GP and he realised straight away that my son - who was sick and fed up of being told he was depressed (please can that assumption be stopped) - had a serious anxiety issue.
- Help needs to be provided by Young Devon & CAMHS as soon as possible. We waited 5 months before getting CBT treatment.
- They are not really addressing the challenge of 'early intervention' and /or 'preventative' intervention. Only a model that embraces the addressing of social care challenges (including finance, housing, adult literacy, domestic abuse, neglect, adult mental health

etc.), adult mental health provision and children's 'emotional well-being' - including the very early ante and post-natal experience of the infant and mother - will begin to address these challenges. Just take a look at how Initial Child Protection Case Conferences are facilitated and chaired.

- Focus on early intervention health care services needs to be reconsidered.
- Improved coordination of services and development of support that people can access while they are waiting are excellent ideas.
- Support for children and families whilst they are on a waiting list (particularly CAMHS) is vital so that the child doesn't need to reach crisis point before they are seen by a professional. This could reduce hospital stays too.
- Young adults (17-25) need better access to mental health services quicker
- With the reducing budgets the time scales for waiting for referrals is increasing, I have heard of waiting times to be over a term for speech and language referrals and it is not unusual for a 6 month plus delay for referrals to CAMHS.

Support for using lead professionals and care co-ordinators

Some felt that having a lead professional and/or care co-ordinator to work with service users and their families would be a good thing. Some people qualified this statement by suggesting that time and responsibilities should allow for this role to be carried out well.

- Concerned about blurring of roles and being named professional - while I agree in principle the reality is often one very stretched professional trying to meet needs of complex child/family whilst also managing a very large caseload.
- I fully support the principle of a named lead for each child.
- I am pleased to see that every child will have a Lead Professional - how will this be monitored and implemented?
- A co-coordinator is what is needed - someone needs to have an umbrella view of what is being done for a child with a level of accountability. Schools are not equipped to do this. Needs are not being met.
- The system needs to be much more joined up and a care coordinator sounds like a very good idea.
- Continuity of key staff members is so important. My daughter has had help from CAMHS professionals whose contracts were not renewed. This causes immense psychological trauma to the young person. The proposals are long overdue.
- I think it's really important to have one person who can co-ordinate and manage the needs of the child.
- I really like the idea of there being a lead professional and think it would make a huge difference. I'm hoping my daughter receives post diagnostic support for autism. I'm unsure what some of the services are and don't know whether we can access them?
- Having a 'lead professional' for each young person is ideal, however, not if that 'lead professional' is going to be from education (unless education is the main issue for a young person) as our core purpose is education and there is often disparity in what education expect of staff and what Devon County Council expect of staff. We need to ensure that the correct agency acts as lead professional and currently that is still not happening.
- Having one lead coordinator sounds like a positive move if this can be achieved.

- Firmly believe there should be a lead professional for every child with complex additional needs, especially ASD where a range of professionals are involved. The lead professional should be in regular contact with the family.

Unsure if proposals are achievable

The main reasons respondents were unsure whether proposals are achievable are related to:

- **Capacity and investment**
- **Would require significant culture change**
- **Proposals do not have enough detail**
- **Auditing and benchmarking requirements**
- **Doubt it will happen as it has not happened before**

Capacity and investment

Some suggested that there may not be resources to invest to fully implement a service model based upon the proposals.

- Can you remove all assessments unless there is a service available - don't raise expectations!
- The CAMHS waiting list is too long. Teenagers are our future adults and should be supported more thoroughly during these difficult years. By doing so would reduce non-elective admissions, reduce substance abuse and in turn lead to healthier adults.
- The principles seem sound but the demand will exceed the service's capacity and leave young people without the support they need.
- Whilst it reads very well and I wholeheartedly agree with the sentiment - I do have concerns around how realistic the proposal is within the current climate.
- Yes, there is no mention of continuous service 52 weeks per year and coverage even when the allocated staff are on holiday and off sick.
- In the time I’ve been working in Public Health, we've had a huge increase in the number of managers that don’t hold caseloads, caseloads have increased in size and we have far less staff, services and our ability to provide support for our services users is becoming increasingly harder.
- I think it's important to remember that services are extremely understaffed and under resourced.
- Without investment in staff resources, these simple proposals will not achieve the desired results. So the CCG needs to think about investment in staff resources at all levels and various teams but particularly in mental health teams.
- Working together has always been identified as important in serious case reviews. However, it is common to have to wait days or even weeks for professionals around children to return your calls.
- Not clear enough. Too idealistic due to not enough staff and not enough money in the pot.
- Principles/Key Outcome hopes lack clarity around how they might be achieved.
- There is no longer a comprehensive schools based Tier 2 Torbay Child and Adolescent Mental Health service due to recent education financial cuts and loss of workforce capacity (August 2017), which in turn has removed the capacity for professionals to offer

consultation, support and advice around signposting preventative interventions to address issues such as self-harm.

- How will this be funded as providing services that are more available means more staff or unsocial hours?
- The principles are fine. Wouldn't we all like this level of care? Unfortunately, need for mental health services is rising, yet funding for such care is decreasing.
  Working with young people in crisis is difficult - and despite everyone working together children aren't able to access just ONE worker, to tell their story ONCE. In principle, yes - sounds great. But try working in CAMHS and deal with everything that we have to deal with on a shoe string budget and then propose a new strategy please.
- It highlights the lack of understanding of severe and enduring mental health illness that CAMHS staff are specifically trained to treat and manage as opposed to life events/experiences that can cause distress which would be better managed by more general services.

Would require significant culture change

The majority of respondents saying this were health and social professionals.

- None of the things written in the proposals are new concepts but somehow in Devon we still struggle to deliver these visions/principles on the ground. Our own systems and processes get in the way of truly supporting families in the way we want to, I can't see how these services will change from what has always been provided. We need to enable providers to have more flexibility and innovation and tackle things like information sharing with the wider children's services.
- In principle the proposals are a positive move forward as it will improve front line delivery to parents/carers. My concern however is about getting systems in place/embedded and changing a culture of working.
- All the recent proposals/changes in all areas of South Devon Healthcare sound good, it's the finance and the organisation and then the putting into practice of such changes. Until this happens no one will know if the changes will benefit the patients/clients or make life more difficult.
- It actually needs professionals to actively follow the proposals not just file them away into another unread pile.
- Current service provision is inconsistently managed and lacking the longer term vision. This will need improvement to deliver the proposals set out.
- We would like to see an umbrella 0 - 18 neurodevelopmental assessment service with medical input at the start of the assessment in order to provide a holistic overview and establish a clear differential diagnosis, so that assessments can consider all possible outcomes, not purely pursuing a single diagnosis.
- Intervention post-diagnosis needs to be integral to the commissioning and provided by the same team which has carried out the assessment.
- Any integrated services needs to truly integrated, not just in name.
- My whole career (34 years) has been spent trying to work in a more joined up way with other colleagues working with children/young people, I welcome any ways of achieving this as it's so critical to joined up/quality and cost effective care.
- We already refer to many services via the Single Point of Access, not sure what is to change?

- Whilst the proposals set out are full of good intentions, all too often the working practice is very different and our young children and families experience access to support differently.

Proposals do not have enough detail

- The proposals are very nebulous and although they feel right, they do not specify HOW the principles will be delivered which is key to how we respond to your proposals. If we do not understand what the proposals mean to us the consumers then we are disenfranchised as we do not know exactly what we are commenting upon.
- I think the ideas sound suitable but there are no details as to how it'll work and what services will change and how they will change, will we lose services to enable others to work in a better way? The ideas sound great but there is no substance to how it is going to work.
- I would like more detail, it's too vague at the moment.
- The document is very woolly and non-specific, there are no specifics about wait times etc.
- Not specific enough about the collective responsibility of children's CAMHS services.
- I agree with the principles and the proposals but there is not enough detail to assess if they will make things better. it feels more aspirational than tangible.
- There is insufficient detail to make any meaningful comment. There appear to be largely a series of aspirations with no costing, details, choices or ideas of how services will actually appear.
- The aspirations are laudable, as have all such similar initiatives in the past, that have not succeeded as planned due to lack of a detailed business case looking at the details.
- Fine as proposals but 'the devil is in the detail'. They give no practical clarity about what would change for service users.
- Proposals are unclear within the document.
- Too vague, aspirations that have been repeated before. No clear plans re how any of it will be achieved.

Auditing and benchmarking requirements

- Who is going to audit? How will you know if proposals are being achieved?
- There needs to be a way to measure how well the commissioned service is doing - and consequences if the service isn't performing as well as it should.
- Ensure consultation with parents to obtain their views and experiences whilst trying to obtain services.
- I am unsure how the proposals are to be enforced.

Doubt it will happen as it has not happened before

These comments came mostly from parents/carers.

- I'm not quite sure how this works in practice and the difference it might make in the 'real' world? It sounds good but how will it play out in reality?
- These ideas should already be enacted, feedback has been given over the last couple of years but the same issues persist. Not hopeful this will change anything.
- Sounds lovely but then it always did. Accessing services and getting the information that is needed will be the acid test. I have a nasty feeling that nothing will change in reality. Too much talking, not enough action and restriction of services will continue.
- It would be great if this actually happened.
- It all sounds very good, but will it really happen?
- I have so little faith at this point in our family's life, that I am doubtful any changes will happen that will be useful for us.
- The ideas seem great, but from what I have seen of certainly CAMHS, I don't care about the others, these aims just won't be delivered.
- What I would expect is more detail not bland 'motherhood and apple pie' statements.
- From what I’ve read and from what I’ve experienced first-hand I’ve no idea how all this is achievable. They are completely poles apart.

Suggestions and queries

The remaining 50% of comments came in the form of suggestions and queries.

- **Integration and information sharing.**
- **More services are needed.**
- **Being patient centred and focusing on individual outcomes.**
- **Consistency across services and geography.**
- **Links to education.**
- **Workforce considerations.**
- **Health visiting – continuity of relationships.**

Integration and information sharing

- I want to see records being shared across the providers. When we’ve been to one provider then visit another there is always a huge delay because they cannot easily share information. It’s frustrating.
- Ensuring emails are answered.
- Can you provide a clear care plan with clear outcomes to be achieved so we don't waste our time engaging in 'nonsense' which often serves to meet the needs of the system or professional but not the child.
- How will you make communication better so you're not left feeling like you've been forgotten?

- One central point of information about the client/child would be good - on reviews we went over all the same information for each service which was frustrating and time consuming. Each review had to be started from scratch, no continuity - with or without the same professionals involved.
- When there is an urgent problem there are often emerging issues as well, the help needs to be holistic and assessment of different conditions need to be within set amount of time, so that the help provided can be as required. Not partly helping and waiting for 12 months plus for assessment of condition. Plus there is little information for parents provided surrounding help / support which is available for them i.e. DIAS, Devon carers, etc. - it takes a long time to dig around and find this support. It has been suggested to me to draft a booklet for this.
- I'm interested to know how this is all going to be stored electronically so we all have access to the information. I'm wondering who the co-ordinators are going to be and how this is going to be managed because at the moment there is no communication, timescales are shocking and trying to find someone that knows what is going on is pretty impossible.
- Sounds very similar to early help/ single point of access that in reality create more hurdles to provision as funding grows ever tighter.
- There is an emphasis about online support. This is good as long as it compliments face to face interaction and is not a way of replacing it.
- Triage of referrals is essential to ensure the correct response.
- Not enough about engagement, communication between services. Access to one safe IT resource to gather, share information between all professionals/organisations working with children.
- Particularly like the 'no wrong door' principle and that intervention not contingent on diagnosis.
- I fully support the principle of a single point of access for referrals.
- Super hubs are not working. We need better communication for children services but each specialty delivers a different service. Better communication is needed rather than mixing services together.
- Families and professional need to be better informed about how the system works and need to be kept informed throughout the process.
- I think one of the ways the offer can be improved is a greater integration with adult services sharing resources and support to families and YP.
- In addition a service that is easily identifiable to families and especially adolescents within a drop in type of resource.

More services are needed

- Extra services.
- Highfield House nursery, Barnstaple, was a fantastic combination of services when we first used it 11 years ago. This should definitely be brought back as it was to support children and babies with special educational needs and disabilities.
- We never have any services offered for children who are wheelchair users.
- It might be good to include the hospital paediatric provision - supporting communication and co-ordination across providers.

- There should be a triage ward or additional staffing for adolescents with self-harm within Devon.
- Aspirations for adequately resourced out of hours must include Mental Health Act assessment, integration with police and POS and better response to the general hospital's paediatric wards.
- I also would advocate building on the CAHMS crisis resolution and Home treatment Team to deliver a more robust assertive outreach model to families and YP or to use existing centres such as Youth centres schools colleges etc. etc. to meet and work with YP in the community.
- There is need for additional CAMHs support out of hours to children admitted to hospital
- I was saddened to see that psychology was not included in the integrated therapy section.

Being patient centred and focusing on individual outcomes

- Listen to the parent / carer what might work on paper in reality with a child with special educational needs might not actually work.
- Can you ensure that it is clear on a child's health records that they are adopted and hence when we are sitting in front of another health professional we do not have to explain why we are unable to provide family history?
- Can you not assume that every parent with child with special educational needs and disabilities doesn't work full-time and offer school holiday clubs which can meet needs?
- There is not a one size fits all, so the offer should be flexible to meet the needs of the young person and their family.
- Listen to and respect parents as experts on their children. Involve parents (and children where appropriate) at every step of the process as part of the MDT.
- Please streamline appointments so as we don't have to spend the first chunk of appointment timed repeating the history of our pregnancy, Labour and early years of our children.
- Please consider the impact of a child with mental illness or emotional difficulties on the rest of the family (parents, siblings etc.).
- Treating everyone as an individual case with individual needs it important everyone is different - live in different circumstances etc.
- I think that it is important that families are supported and enough people are out there to do it well- otherwise it won't be effective.
- I am concerned that families will not only have to tell their story once. At the moment some families have no consistency whatsoever.
- It's full of jargon and not centred to the child. Ask the children not a company.
- Pragmatic. Need to ensure YP voice and views are central to service design.

Consistency across services and geography

Some felt that it was important to prioritise consistency so that equitable access is available across Devon as far as possible.

- You have not said where the specialists will be based. Will they travel to East Devon where we have no help for 0-13yrs old with mental health issues?

- I feel that there is great benefit in keeping the services described under one employer with expertise in health services to maintain and develop an integrated approach, ease of access and effective efficient care pathways for children young people and families.
- It sounds great, but not sure how it will all work and come together. Devon is very rural and spread out.
- Services working together has always been the aim within the NHS and all other agencies. Having these under one organisation will hopefully reduce barriers further. Concerns currently regarding criteria to meet referral for e.g. portage in Plymouth is different than Devon clients already notice a postcode lottery. We cover a large area and planning on how to be realistic regarding doorstep services will be difficult. No referral is inappropriate will require some boundaries and there needs to be a way to stop families from being bounced between services.
- The overview looks good, so the question is does the proposal for services fully support this in all geographical areas?
- From experience I feel the triage for cases is very variable between services, what one service classes as a high need another says it's a low need.

Links to education

- I am concerned that school nurses no longer are allocated to schools and that at a drop in my child if she or he were likely to attend would see someone different each time. This would not be good as I want my children to access the service if they needed to.
- Would be useful to link with schools when it involves older children (not under health visitor or school nurse) as we struggle to get the secondary school to understand our difficulties.
- There is no mention of education links. The way health works with education needs to be very clear. Teachers should not be expected to provide the therapy. Specially trained therapists or therapy assistants should do this. If family support practitioners are expected to do this, they should also be provided with specialist training.
- Don't see Educational Psychologists/counsellors/therapists/family therapists involved or the CIT and other school based services. Doesn't seem joined up.

Workforce considerations

- How will you provide help when required and as early as possible when there is not enough funding and not enough employed staff to deal with need? There needs to be more training provided for grass roots staff, perhaps an additional role where a staff member with allocated time (not manager / senior etc.) has the opportunity to put in to place early help for all children and for staff to realise mental health strategies are about more than 'positive' thoughts.
- Keep specialised services specialist with the most qualified doing the triaging.
- Staffing levels always appear low and never feel anyone has the time to actually see to your needs.
- New professionals need to be brought in - ones with different skills which may help.

Health visiting – continuity of relationships

- The health visiting service is very reliant on who you are allocated so there should be more choice and specialist health visitors, at the moment they are giving very general advice which isn't appropriate for some children and is very unhelpful and actually does more harm than good.

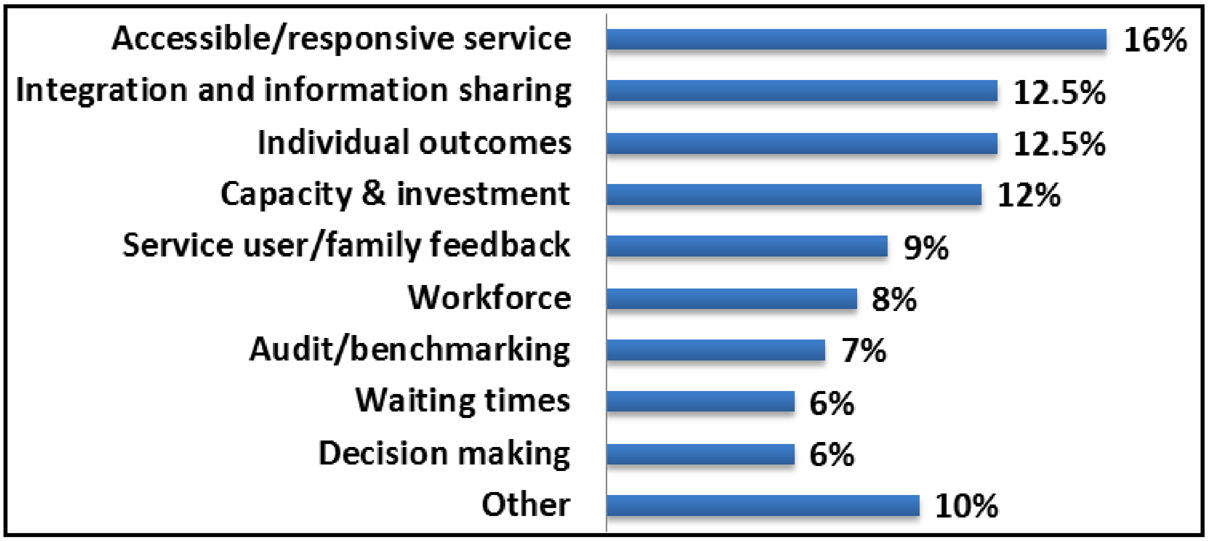
- I want to know my health visitor. They are being pulled out from community services such as clinics.
- Centralisation of health visitor services makes it difficult for families to access their health visitor. It hinders timely communication between GPs and health visitors.

Other

- Help with transition to university.
- All guidelines and legislation state, early intervention is key to achieve positive outcomes for the child and family. In my experience, early intervention does not exist. 1 year to get a referral to CAMHS which then ‘does not meet criteria' and a further year of challenging behaviours escalating to crisis. Please 'look at the bigger picture' as all research states.
- Educate doctors nurses on special educational needs and disabilities and how things like a social story can help, how waiting around & getting to appointments can be difficult. Don't delay treatment.
- Don't stereotype a child with special educational needs and disabilities if you've seen child with Autism you've seen one child the next autistic child could be different.
- How will 0-19 tie in with 0-25 for young people with special educational needs and disabilities? Is there a service gap for vulnerable young people 19-25? How will transition to adult services be managed?
- We will need the resources to enable us to deliver the proposals.
- Nutrition & Dietetics is not included in Children's Services but we would like to maintain good relationships with all services (we work closely with health visitors, school nurses, schools, special schools, other allied health professionals (e.g. therapists) and CAMHS) and perhaps link websites and share resources to keep our service in line with good practice across Devon.
- Is there any indication of how long the provider would have the contract for?
- Thresholds are continuing to increase and therefore families are not meeting threshold. We are in a situation where we are fire-fighting. The preventative strategy is now very low on the agenda, so we are not stepping into support families early enough and they end up being higher need cases when with earlier intervention and Early Help they may not have such a high dependence on services.

Monitoring future services

11. Ideas and suggestions for assessing suitability of potential service providers



Accessible/responsive service

16% of comments suggested that organisations should be asked how accessible and responsive they consider themselves to be. Comments suggested:

Parent/carer

- Children and young people should be able to attend help sessions for as long as required, not be set a specific amount because of funding.
- Telephone assessment at point of referral.
- Find out how their appointment structure works and how long it takes from referral to making contact with the patient/carer.
- Resources published and interactive website and ability to email a clinician direct as you don't always need to see someone and wait for appointment.
- If they do not feel the child is under their remit should provide full information on where to go. No just ' you don't come under our remit'.
- Will the same professional be available for ongoing needs with this service?

Service worker

- Do they have a flexible and responsive service?
- How accessible are you for advice pre referral? (To prevent inappropriate referral)
- Support to set up useful/accessible websites.
- Be able to signpost when they can’t meet the need.

- Ability to provide a single point of access.

Worker in related services

- How will they target hard to reach or hard to engage young people?
- They need a good infrastructure - ability to be flexible creative and responsive.

Referrer

- What do you do with the information requested in referral forms to put it to good use with the families? How do you know it is good use of the referrer's time and essential information?
- Have they listened to the people who know that child best? Are they basing their assessment on a snapshot? Is there a way to increase observations without increasing appointments?

Integration and information sharing

12.5% of comments related to how organisations approach integrated working and the sharing of information, both within services and across partners, to ensure that services work in a joined up way and service users do not experience gaps or barriers.

Parent/carer

- Plans and examples to show how different professionals work together.
- How they will ensure GPs, hospitals and other services know exactly who the patient has seen, when and the outcome.
- In school services locally driven not outside agencies.

Service worker

- Ensuring all services are joined up using just one system that ensures everything about the child's ongoing care is available and communicated to all professionals involved. There are still too many services still utilising their own patient record systems causing many gaps and breakdown in health and social care.
- Ability to share information electronically (with permission).
- How they would ensure integration with other services to break down barriers.
- Ability to plan for the longer term. Commitment to real integration and the ability to move between services easily.
- How are these services working with others/schools and based with others.

Workers in related services

- Liaison between services to avoid duplication for some families and no support for others.
- Their track record of integrating with adult services.

Referrer

- Their ability to connect services (school nurses to social workers etc.). To be able to professionally blur the lines for a quality service.

Interested group/organisation representative

- Their experience of working collaboratively with range of partners to deliver a no wrong door approach.

Being patient centred and focusing on individual outcomes

12.5% of comments suggested that services should be flexible enough to fit in with the individual service user and their family to some extent, rather than expecting them to fit in with the service. The importance of understanding outcomes at an individual service user level was also emphasised.

One third of these comments suggested 'Positive outcomes for young people/their families' or something similar.

Parents/carers

- How many families they see, how many professionals within the same service each family has to see.
- Ability to deliver holistic care that takes into account social and emotional needs not just clinical/medical ones. How well they consider and involve all the family not just the child. Ability to deliver support groups/services such as learning to use a wheelchair - vital for a child's independence and wellbeing.
- How they will be fully inclusive for physically disabled children.
- How they intend to shape services around the families who use them rather than requiring families to fit in with their organisation. What their plans are for the future of the services they provide. How they measure success and see if their answer includes reference to the people who will be using their services, if they don't include them, then any success measures are based upon the organisation's aspirations instead of families' needs.
- How can they prove that their service is child-centred - the culture of the organisation, not just a few good professionals.
- Can you deliver a service that prioritises a child/young person's safety and well-being?
- The ability to provide personalised care.

Capacity and investment

12% of respondents suggested asking about service capacity, investment and sustainability - how much this was prioritised. Comments included:

Parent/carer

- Are they willing to keep the level of service there is now as this is the minimum, services like portage are a lifeline to parents?
- Will any surplus be reinvested into improving services for children?

Referrer

- What is their capacity? Can they offer a series of appointments not just a one off followed by come back next term if you are still concerned?
- What is their capacity and what will they do when the need / demand exceeds this?

Service worker

- Detailed business cases for all the models of service being proposed. There have been so many initiatives in the past, that have not achieved quite what was anticipated, hence the need for more initiatives, that could have been minimised with detailed modelling hand in hand with a detailed business case.

- Availability and out of hours support.
- Possibly think about their budget and what is realistic instead of promising what can't be delivered.
- Ask for evidence of any quality improvement work they have done to improve outcomes within the given resources.
- Questions related to national policy and future direction.
- Organisation aims ethos and objectives. How they aim to meet all the identified needs in proposals.

Worker in related service

- Detail on what their out of hours proposals are; how they would support clients attending A&E but not needing admission for physical care.
- Their plan for services and how they would ensure the services were effective. Also what experience do they have in delivering these services and what business support do they already have in place.

Service user/family feedback should be routinely collected

9% of people responding to this question felt that feedback from people in contact with the services was important for measuring whether a service is good.

Most comments in response to this question suggested collecting 'Feedback from service users and parents/carers' or something similar. Other comments included:

Service worker

- How important are client's views and how often will you review services to reflect their responses?
- What engagement do you have with families on a random selection criteria to evaluate your service development?

Interested group/organisation representative

- I think you could also ask them how they involve children and young people in decision-making about their care and throughout the organisation. I would also want to see a 'you said, we did' approach that evidences the IMPACT that families' participation has had on the way the service is shaped to meet the needs of its community. finally, I would want to have a live video link up with a panel of current service users, who could answer questions developed with prospective service users about the softer, qualitative experience. This would help to assess the culture of the organisation as perceived by people receiving the services.
- How the feedback from service users makes tangible operational changes to service delivery.

Workforce considerations

8% of comments suggested measures related to workforce.

This suggestion was equally popular amongst parents/carers and service workers.

Parent/carer

- What relevant qualifications and expertise do your professionals have, in order to respond effectively to specific conditions?
- Enough trained staff and whether they can travel to towns where transport is bad
- How much and how frequently they invest in staff training?
- Expertise in ASC complex needs.
- Will you reduce waiting times and provide more staff and better wages, to attract new staff.

Service workers

- The training offered to staff and the numbers of staff to offer the service without reducing contact time or quality.
- Enough competent staff to deliver care. Good organisational ethos that respects workforce with reduced staff stress and sickness.
- Level of training in risk assessment that professionals working within the organisation have.

Audit and benchmarking

7% of comments suggested that auditing and benchmarking services against similar services and past performance would be a good method. Comments included:

Parent/carer

- Have they delivered on contracts in the past with good outcomes? How do they measure these outcomes?
- Are services evidence based? How do they monitor their outcomes? Are outcome measures relevant to the needs of the individual?
- What is their previous performance measure?

Service worker

- What do they do currently & how do they audit their service?
- I imagine lots of the services already in place provide this care so I would start by asking the services if and how they meet these targets.
- Commitment to delivering assessments and support in accordance with national guidance where available.

Interested group/organisation representative

- I think a lot of it is down to the culture of the organisation; a watertight contract; and the key performance indicators. I would want to know from a prospective provider: complaints data (e.g. where an organisation already operates in another local authority.) If they are willing to submit the information, it shows they are open and transparent.

Waiting times

6% of comments suggested that the organisation should be asked about whether waiting times were reasonable. This was raised but there were not specific comments.

Decision making

6% of comments suggested considering how decision making is done within the organisation. Comments included:

Parent/carer

- Which children do you exclude and why?
- How many referrals they reject and whether they accept all referrals?
- They must guarantee that they will support everyone who is referred, not 'ration' care as is currently the case with speech and language therapy.

Service worker

- Group decisions. Often one service refers to another totally inappropriately.
- Understanding of different tiers of need and support and how choose where to place someone in the system?
- Regular, minuted, multidisciplinary triage meetings.
- What professional group will hold clinical leadership and accountability?

Referrer

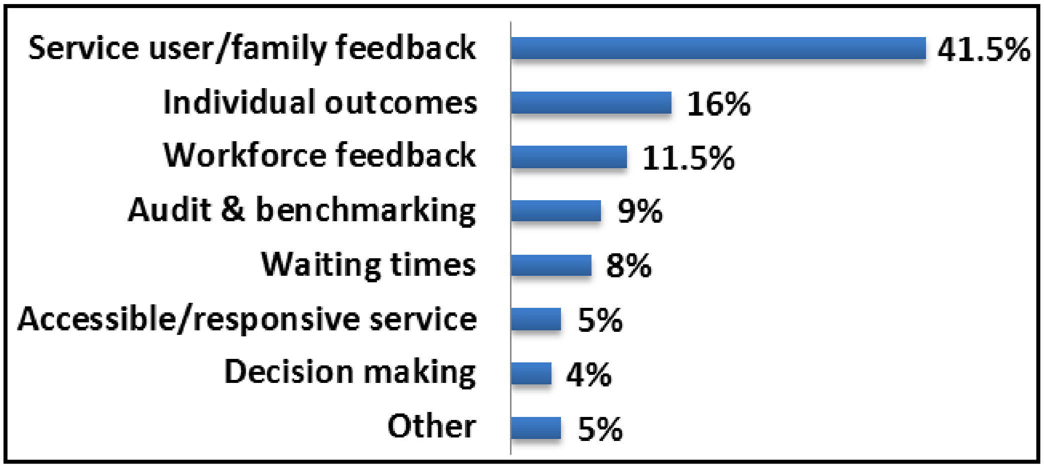
- If GPs feel a child needs to be seen the service must have a really very good reason if they decline to see the child.

Other suggestions (10%)

These included:

- What do they understand about mental ill health in children and young people?
- Serious mental health problems that really are serious mental health problems - how do you get to those? Huge sense of entitlement on part of people demanding a CAMHS service from specialist CAMHS that really need a social worker.
- Post diagnostic support for autism - nothing has been offered to us, we are currently using a private therapist.
- How do you ensure health visitors are based in the community?
- Saturday morning clinics to see the health visitor.
- You are publicly funded to provide these cease and desist hiving services off into private sector where there is even less accountability than from public service.
- Children's Centre workers are often lead professionals for children under 5 and this works well.
- Will they acknowledge their failures and try to amend them to renew the trust in them?
- Our residents have significant delays when transitioning to adult services when they are still struggling to come to terms with emerging mental health and physical health issues.
- Moving and accessing universities help and support.

12. How can we measure 'good'?



Service user and family feedback should be routinely collected

41.5% of people responding to this question felt that feedback from people in contact with the services was important for measuring whether a service is good.

This was the most popular suggestion from parents & carers, people working in children's services, people working in related services and referrers.

84% of the 41.5% of comments in response to this question suggested collecting 'Feedback from service users and parents/carers' or something similar. The remaining 16% of other comments included:

Parents & carers

- Ask for anonymous feedback each time a service is used.
- Actual parent feedback. I haven't ever been asked to feed back.
- Evidence of joined up working which include parents views and experiences as well as that of the child.
- Qualitative measures not quantitative. Measured against practice which supports children and young people as individuals, and therefore practice may fluctuate, we are all different and therefore need help in different ways.
- Whether feedback is listened to and action taken.

Service worker

- Rapid response to complaints with positive outcomes and follow-up with those involved in complaints.

Service worker

- Service experience feedback and partner agencies - mystery shopping - give them support and nurture providers.
- Young people and families should be part of deciding what good looks like for each service
- How much effort is put into engagement on Patient related outcome measures (PROMs)?

Referrer

- How efficiently support is put in place - ask all stakeholders, and how effective the support is in meeting the child's needs, again ask all stakeholders - less waiting and meeting and thresholds and more on the ground support - don't wait for diagnosis or assessment but visit and make early help suggestions.

Four additional comments also suggested that referrer feedback should be collected.

Being patient centred and focusing on individual outcomes

16% of comments suggested that services need to be patient centred, not ‘one size fits all’. Individual outcomes should be measured so that they can be considered.

One third of these comments suggested ‘Positive outcomes for young people / their families’ or something similar.

This response was particularly popular amongst parents/carers and workers in children’s services. Comments were more varied than those made about collecting feedback and included:

Young person

- Successful treatment- did the job get done to a high standard?

Parents & carers

- Whether they prioritise the wellbeing of the children they serve over profit and winning further contracts.
- Achieved outcomes for individual children, meeting their desired need, not those perceived to be required.
- How supported people feel.
- Appropriate care for the individual which in our case seemed to be non- existent.
- Measure functional improvements for the client and the family.
- Outcomes - is the child safe and secure and knowledgeable? Are the parents supported?
- Impact on my child, not just a tick box of interventions.
- How well they engage with us and understand us and how much effort I have to put into persuading them to help?

Service worker

- The outcome for the child and their family - the success will not be the creation of a single point of access, a single website or a team managed by one organisation- but whether or not it helps the child/young person/family with the issue they brought to the request for help.
- Improved outcomes for the child as set at the outset of an intervention.
- Evidence of positive outcomes from children, young people and their families. Are services working together and preventing cases rising to social care/specialist health care/special schools?
- Child/family rating - achievement of client set goals - not waiting time as it just results in 'quick fix' options being used.

- Timely interventions and reaching targets (i.e. healthy child programme).
- Whether the perception of health has improved following an intervention - regardless of the model used and/or the so called 'evidence' to support this. Children, young people and carers (adults) generally feel better when their own emotional distress is first of all noticed and acknowledged; that it and they are then contained and then that they feel that they can 'connect' in a meaningful way so as to facilitate positive change.
- Measurement of outcomes and goals. Evidence of client involvement.

Service worker

- The Early Help assessment should help as this should show distance travelled. Also it is important to use a baseline at the beginning of the intervention, possibly using the same type of worry scale which can then be reviewed at the end of intervention.
- The experience of children, young people and families is key to understanding whether the services are a success. It is understandable that certain elements need to be measured and quantified from a commissioner's perspective but the key drivers should be feedback from service users alongside other KPIs
- Measuring what difference it makes to the family.
- The impact on the child/ young person and how they are functioning.

Interest group/organisation representative

- When the young person is able to maintain and manage their health independently, not when they have reached the specified amount of appointments or time limit.
- Increased ability to self-manage conditions.
- Satisfaction rates, reduction in risk/harm, improvement in emotional health and wellbeing, sustained over time.
- Reduction in crisis interventions /improved self-management.

Workforce considerations

11.5% of comments suggested measures related to workforce.

Two thirds of these comments came from the workforce themselves.

A theme within the workforce was measuring staff satisfaction (6 comments).

Most parent comments focused on workforce levels.

Remaining comments covered several aspects and these are shown below.

Service workers

- Level of training and practitioner caseload.
- Ask the staff on the ground that have contact with the service users how they feel and what should change to enable us all to provide a quality service for the population of Devon.
- Interview employees- ask them would they want their child to be seen by this service.
- Explore with the professional what they think can work and is manageable.
- Meetings with key professionals within team working groups e.g. clinicians within CAMHS, Honeylands under 5 service, ASC assessment team for example. The clinicians have clear understanding of their service and shortfalls within.

- There are assumptions that there will be adequate and sustainable professional staff to make this happen, sadly not reflecting the reality, with the staff increasingly losing morale, while still working hard at the clinical interface resulting in the patient feedback surveys.

Workers in related services

- Staff views about transition arrangements.
- Staff should be happy, similar staff survey as NHS Staff survey to be done.
- Detail - can they realistically do what the fancy words and slick presentations are saying?
- Can they retain staff?

Parents/carers

- Level of job satisfaction in longest serving and so most experienced staff. Number of permanent staff as opposed to expensive poor quality agency staff.
- Up to date training, compliance with BFI.

Audit and benchmarking

9% of comments suggested that auditing and benchmarking services against similar services and past performance would be a good method to determine if services would be considered good.

This was suggested mostly by workers and referrers. Comments included:

Service workers

- We provide outcome measures - we are constantly auditing the service.
- Progress towards identified SMART (specific, measurable, achievable, realistic, time-limited) outcomes.
- Look for audits of service evaluation and outcome measures.
- Care Quality Commission and outcome measures.
- Whether they have a commitment to using the IAPT (Improving Access to Psychological Therapies) core principles of raising awareness, accessibility, participation, accountability.
- NICE guidelines on health and wellbeing for staff to be followed.

Parent/carer

- SEND (special educational needs and disabilities) Local Offer Reference Group developed Family Performance Indicators which could be used to measure the performance of a commissioned service.

Interest group/organisation representative

- My group, the SEND Local Offer Reference Group, has put together some qualitative Key Performance Indicators.

Waiting times

8% of comments suggested that a measure of a good service could be determined by looking at whether waiting times were reasonable. The large majority of feedback came from parents/carers and referrers. No further comment was given.

Feeling informed and supported because service is accessible and responsive

5% of comments suggested that how accessible and responsive a service is able to be would be a good measure of service effectiveness. Comments suggested:

Young person

- Enough communication with service users, as well as giving appointments when they say they will give appointments.

Parents/carers

- If it's actually delivering what it should, putting words into practice and supporting parents and children. Get away from parents having to find all the little snippets of information in order to help their child. Also make sure information is up to date and for professionals to know what support there is in the family's area where they live. That parents can come away from an appointment with a professional and actually feel it will make a difference to their child not that the parents are passed onto someone else 6 months later on another waiting list.
- How quick they respond to any point of contact - even if an answer cannot be given immediately, just to know you are in the system and not being overlooked.
- Whether they are happy with the information they have been given.
- Pre assessment/appointment information to support families so that they can manage their situation and perhaps more self-help.

Referrer

- Speed of reply on referral, quality of referral feedback, speed of seeing family from referral, communication with professionals referring to you.

Decision making

4% of comments suggested that a measuring how good decision making was could be an indicator of a good service. Comments suggested looking at how many referrals are rejected (a high number would be bad so making sure there are no artificial barriers to acceptance) and whether re-referral rates are reduced over time.

Other

5% other individual comments were also received. These suggested the following.

Parent/carer

- Understanding of physical disability.
- Drop-out rate.
- After care after diagnosis.
- I have not yet had access to any services in 11 years so just having one would be a start.

Service worker

- Post-diagnostic interventions offered.
- Value for money.

Worker in related service

- Early intervention resulting in less referral to specialist services.
- Whether there has been an impact on the service deliverers themselves e.g. improved way of working that is reflected in any data.

Referrer

- More practical support for staff in schools (the EH4MH programme has been superb) School nurse team are amazing so maybe use them as the central hub but fund and support them effectively.

7. Meeting diverse needs

The **Equality Act 2010** legally protects people from discrimination in wider society and names 9 protected characteristics that can lead to some people being particularly at risk of discrimination, these are - age, disability, gender reassignment, race, religion or belief, sex, sexual orientation, marriage and civil partnership, and pregnancy and maternity.

Services for children and young people have lots of contact with children, young people and parents or carers that are likely to represent some of the above characteristics. In addition they may be vulnerable due to other factors such as social or economic deprivation, being a cared for child or having a long term physical or emotional health condition and it is important that we give consideration to any additional support that these factors might require in order for access to services to be as fair as possible.

We asked people responding to the survey to let us know if they had any ideas of suggestions about what kind of things we should particularly consider when looking at meeting diverse needs. 50 people responded and their views fell into five main categories which are explained below.

1. Make direct contact with people that have protected characteristics or are vulnerable and ask them for feedback

Some people suggested that going to places within communities to find out direct about service experience from people with protected characteristics would be the best approach. Places suggested included:

- supermarkets
- churches
- school gates
- markets
- faith groups
- libraries

2. Train workforce to be aware of assessing diverse needs and support them to work with families to encourage feedback

This echoes feedback received in other parts of the survey by reflecting the importance of supporting the workforce to deliver services that are as tailored and personalised as possible by ensuring they receive good quality supervision and training, particularly around child protection.

3. Collaboration across agencies and additional investment to build resilience

"Many of our Young People are care leavers and beginning to explore their own choices. This can often lead to risky behaviour, self-medicating with drugs and alcohol, child sex exploitation - this needs a combined effort with other support services such as police, paramedics and drug & alcohol workers."

It was felt by some that further collaboration; wider integration and more investment were needed. Some workers in children's services and referrers suggested using education channels to raise awareness. It was felt that this would reach the broadest population and reach them early enough to do something about meeting specific needs. Views included:

- Working with the 'Seldom Heard Groups' workstream under the Children and Families' Partnership.
- Liaise with partnership agencies that support issues relating to diversity.
- Health visitors and school nurses are essential to support the most vulnerable children. Their numbers should be increased, not cut.
- Increase public health nurses.
- Investment in the services that support these groups within the voluntary and community sector.
- Raising awareness within early help and education to raise awareness reduce stigma and discrimination within the broader population

4. Monitoring and compliance

Again, reflecting views expressed in other parts of the survey, people suggested robust monitoring to ensure compliance and benchmarking against similar organisations and populations to ensure performance is appropriate.

5. Potential gaps

Some people suggested what they felt to be missing.

- There are lots of learning disability groups around but none for physically disabled children.
- More thought needs to be given to parents with low cognitive abilities, particularly those with a learning disability and autistic parents.
- I work with a high proportion of young people with Autistic Spectrum Disorder - an adaptation and support is needed for them to be able to give their views/express their feelings.
- Consider children in care.
- Need to consider 'home schooled' and children in 'private schools.'

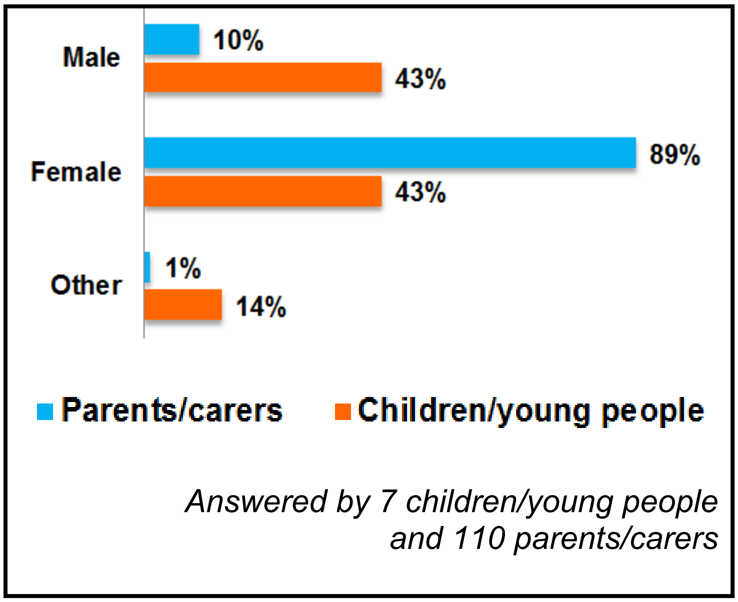
Other suggestions

A range of other suggestions was also received, including:

- Include a member of staff who does British Sign Language in every team.
- UASCs (unaccompanied asylum seeking children).
- Engage specialists in these fields when formulating service specifications.
- Treat everyone equally this shouldn't matter.

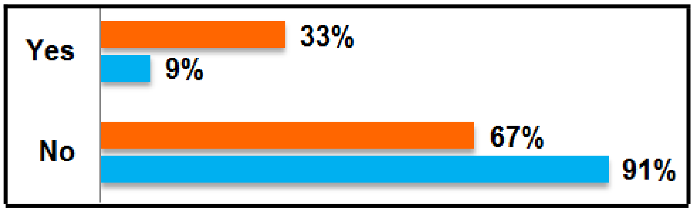
Please note:
Parents & carers responded to the three questions below giving details about themselves, not their children.

Gender of child or young person



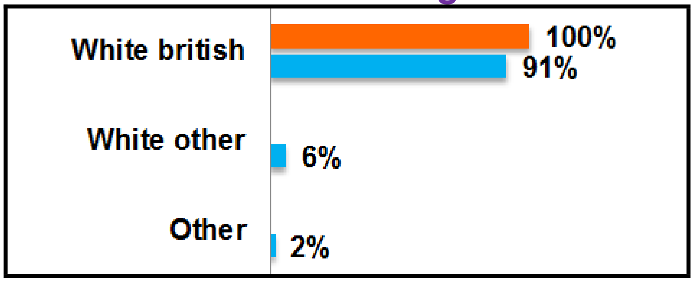
Answered by 7 children/young people and 110 parents/carers

Does the child or young person have a disability?



Answered by 7 children/young people and 108 parents/carers

11. Ethnic origin



Answered by 6 children/young people and 108 parents/carers

Hard to reach groups

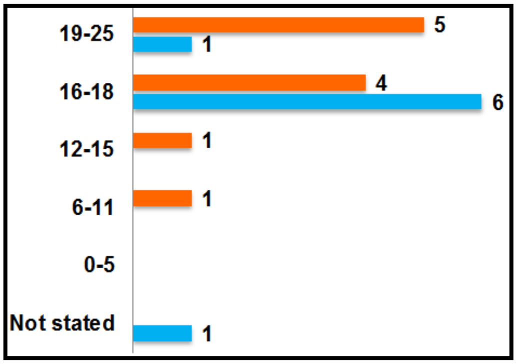
To help us to hear the views of young people from hard to reach groups, we collaborated with Living Options and Young Devon, which are local voluntary and community sector organisations with contact into these communities. Young Devon held focus groups where young people were taken through our survey and a summary of results is below.

8 homeless young people and 11 young people representing black and minority ethnic groups that all had experience of using local services for children and young people responded.

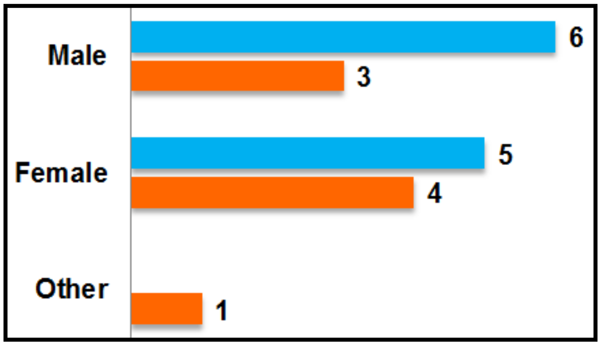
Respondents started that they lived in Newton Abbott, Exeter, Dawlish, Plymouth and Torquay

■ BME person ■ Homeless person

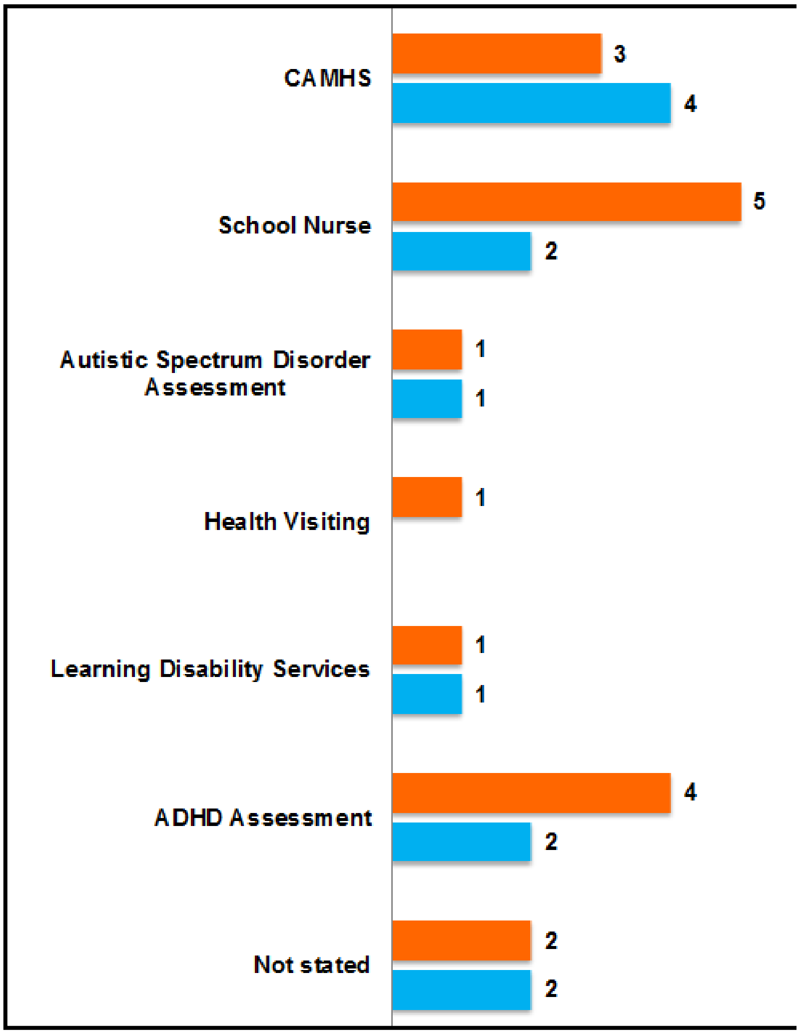
Age of child or young person



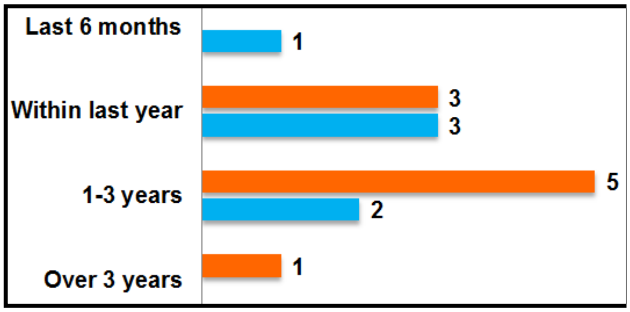
Gender of child or young person



Which services have you had contact with?



When did you last have contact with services?



Top 5 priorities

1 If children/young people need services, they can get them near where they live

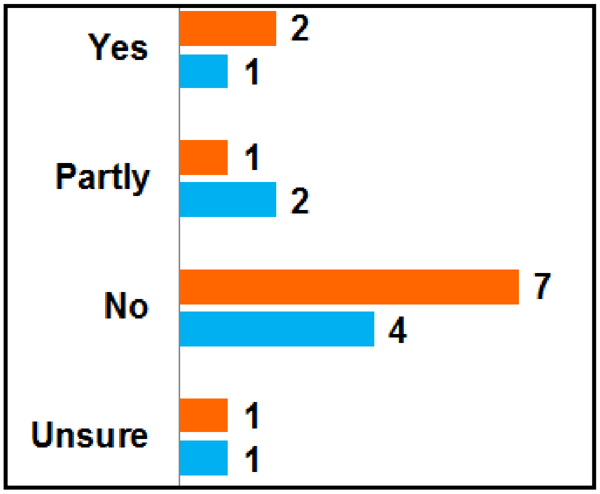
2 One person who the child/young person/family can contact to talk about their care and what they need

3 One website, email and phone number where families can get information about help and support, and services they might need

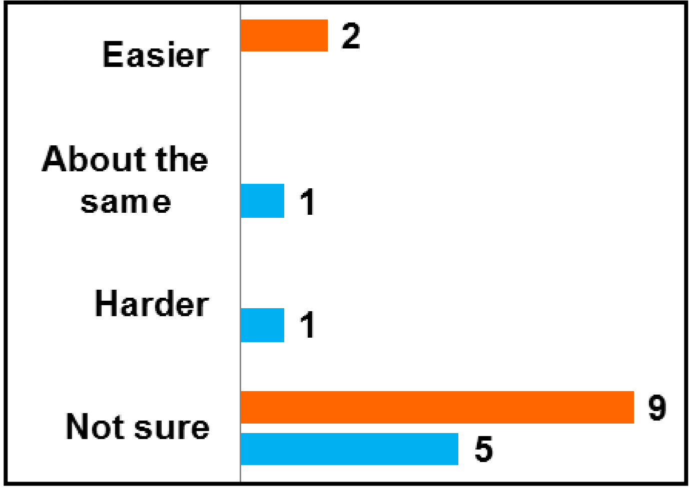
4 Children/young people are involved in setting goals and decisions about their care

5 While a child/young person is waiting for a service, having information about how they can manage, including what to do if their situation changes

Have you read our engagement document?



Do you think the proposals will make it easier or harder for you to receive the right support and treatment?



8. Face to face engagement

As well as running our survey over the summer, we took a number of opportunities to meet with children, young people, parents, carers and people that work with children face to face to hear about and record their views about services and our proposals.

In total, we engaged face to face with approximately 200 people. Some of the feedback is themed by service and some is themed by views about things that could potentially work a little better.

During face to face engagement, the points of view of different respondents varied depending on the type of event being attended. Feedback below is split into what children/young people said, what parents/carers said and what health and social care professionals said.

Children and young people

Face to face discussions with children and young people focussed mainly on two areas:

- **School and college**
- **Emotional health and wellbeing**

School and college

School and college were mentioned in much of these discussions with children and young people. Their feedback about school and college reflected these main themes:

- **The importance of confidentiality and discretion**
- **Supporting the wider family**
- **Peer support**
- **Support with emotional health and wellbeing**
- **Positive and less positive personal experiences**
- **Suggestions for what works well**
- **CAMHS and education**

The importance of confidentiality and discretion

- At my school I used volunteer in a peer support role and other students know this. Kids with behavioural issues that know I used to be involved in peer support sometimes approach me as a friend and someone they trust to talk about their problems instead of someone more official as they know I will not tell anyone else.
- Young people just wanting support worry that things will escalate out of their control if they approach a professional. They worry that a whole process will start up leading to things like having to tell your whole history and everything being looked at, not just dealing with the problem at hand. They also worry that the process will lead to their parents and/or teachers being told and other people being able to guess or find out that something is going on. They don't want something that impacts on their normal life as much as this.
- I wouldn't want to talk to the person in school as they would tell my parents.

- At college information is only in the health area where the nurses are. Lots of kids would not go there to look as they would be worried about other people thinking there is something wrong with them. Posters need to be around the college.
- An app would be really good – it's also private.
- You get worried about people seeing you looking at a poster.
- If you could do online or skype support on a PC or laptop in school or college somewhere private would be good so that people can't see or hear what you doing. Computers are mostly in large rooms all together.
- My school had a room for children to go but we wouldn't use it as it was known as the 'weird room' and you were a weirdo if you used it.

Supporting the wider family

- I have a brother who is autistic. The services that support him are great when there are no issues, but it can get stressful and complicated for my brother and my parents if some extra support is needed.
- Older sister (18) has depression and anxiety. Offered adults group session which she won't take up. Best support was from Young Carers but that funding was cut.
- We need to help parents to understand too. My dad just did the stiff upper lip thing and told me he had been through worse, which was not helpful.
- Family access depends on what child or young person wants
- Need individual working with individual families.
- Parents need support.
- Reassure parents that not a terrible parent.
- Need 'parent communities.'
- Family Support worker role should be for all families
- Parent support should be offered to all. Parents should not need to 'find out'
- Do not assume child doesn't want parents to know: allow for child to change their mind. Revisit decision to include parents.
- My sister needed support.

Peer support

- Peer support can be good, but it is so important to check that the young people offering peer support are actually OK with their own issues and coping with this role and have the right information to help.
- Peer support is good because teenagers often turn to friends their own age anyway for help.
- Peer support is good if you already know the person you are approaching or have a personal recommendation from someone else.

What could be done better in school and college?

- Mental health is not talked about in my school. Knowing how to get help is so important.
- No posters are up at the secondary school and that would be good.
- I think we should have school nurses. Someone said we had one but I've never seen her.
- I attend a private school where it is more traditional that teachers and other staff have a lot more of a focus on responsibility for the wellbeing of the students. For low level things, I think

they react faster and better than state schools. It would be better if they were more joined up with children's services for more serious issues.

Poor experiences from school/college

- Teachers need to understand more about mental health. I was struggling with my mental health and teachers treated me like I was a bad and failing student until it came to light that I actually had a mental health issue.
- My secondary school was awful. I went to see a counsellor and they didn't seem like they wanted to talk to me. They started by saying that if I said anything that made them think I was at risk they would tell my parents.
- I needed help with Autistic Spectrum Disorder – there should have been more support.
- I think you should be able to get an ASD diagnosis at an earlier age then you can prepare better to cope at school.
- I didn't get help for months with my ASD and if I had had help I think I would have done better at school and passed.
- Schools don't understand disability. My younger sister is 5 and her mum (my dad's second wife) has cystic fibrosis. She's a great mum but the school blame her disability for my sister playing up at school.
- At my secondary school I was bullied and it was not sorted out.
- Takes a long time to get help and often by the time you get an appointment either you're better or things have got so bad you're dead. I think its ok but mostly I don't bother with it.
- My little sister needed speech and language therapy and she got a few goes with the therapist and then we were left to carry on. There should be more sessions for each person.

The support is good in school/college

- At my school mental health was never talked about.
- Health and social care at college – there is no information.
- There was a person attending college that committed suicide and I think after that things started to change and dealing with mental health got better and more open.

Positive experiences from school/college

- I think the college is good on mental health issues and support.
- The college is fantastic. The nurses there are great and you can go and talk to them for as long as you need.
- My mentor was fantastic.
- I had sessions on anxiety regulation and stuff via National Citizen Service – it was great.

Suggestions about what works

- Teaching general life skills to cope with day to day life would be good.
- I was in one of the last years to have some training and awareness for mental health. It used to be given to all students. We had a 2 hour session each week on different things, including mental health called 'Learn to Learn' and it was very useful.
- There needs to be more open discussion about mental health issues that is frank, open and sensitive - especially for students that live in less well-off areas that might not get as much support as students from wealthier backgrounds.
- Mental health support should also be in primary schools.

- The approach to mental health seems to be to give medication. It feels the same as with contraception 'Hey, here's some condoms'. We need the preventative stuff as well – there are other choices.
- Need awareness for kids – don't bully children with autism.
- Needs to be more understanding around ASD.
- There should be more toleration for people with different needs.
- My school had a big area where children who were ASD/ADHD were able to go if they needed a break out of class. It really helped and was a very good thing.
- My school also had a break-out room for children with behavioural issues and it was good.
- In our school we have anti-bullying champions and it works.
- There is a part time therapist in school which is helpful.
- Think about something else other than posters as they make you think, but not take any action.

CAMHS

- As a young person that represents other young people, students at my college have told me that their GP has delayed referral into mental health services if they are close to 18 years. They do this because they believe that the CAMHS assessment is not as effective and takes much longer than the adult team assessment.
- Pre-warn about what to expect at an appointment, especially when it is a first appointment or an appointment doing something or meeting someone new.
- Tried to get CAMHS support but this has been delayed mainly due to staff changes.

Emotional health and wellbeing services (CAMHS)

The main experience with children's services for a number of the young people we spoke to face to face was of using CAMHS. We asked questions related to things we wanted to establish to help to develop the service model for CAMHS. The feedback below mostly reflects themes of discussions, rather than individual comments.

- **Transition**
- **What helps transition go smoothly?**
- **When should CAMHS transition happen?**
- **What should happen if someone that chooses not to transition into adult mental health services changes their mind and needs more support?**
- **Monitoring ideas**
- **Crisis care**
- **Being patient centred and focusing on individual outcomes**
- **Early help and prevention**
- **Working with education**
- **Promotion and awareness raising**

Transition

- CAMHS to arrange 1st appointment & introduce me to the new service & worker – see notes from last 3 sessions to enable a discussion and save money and time.
- Community info websites/groups.
- Follow up from CAMHS worker 3-6 months after referral.
- “terrifies me”
- Feel like have to get over hurdle that got over to get into CAMHS
- Children CAMHS should be adult CAMHS – feel like losing CAMHS when transition
- Depends on person as to when to transition
- A transition child worker – a mutual friend
- Alert that may/may not need adult services – start talking about it either way.
- Be flexible as to when to transition
- 0-25 service would be much better from point of view of finding themselves as people and risk
- The biggest problems are waiting times without support and transition to adult services.

What helps transition go smoothly?

- A follow up call from CAMHS 6 months after: checking everything is in place. Follow up from CAMHS worker 3-6 months after referral.
- Being able to contact CAMHS after 6 months if not all in place. Having someone to talk to until transition has happened.
- Before transitioning a meeting with CAMHS and new contact in adult mental health services. CAMHS to arrange 1st appointment & introduce me to the new service & worker – see notes from last 3 sessions to enable a discussion and save money and time. Sessions meetings dependant on young person.
- Being kept updated.
- More connections to the adult services – info on how it’s different – before you leave CAMHS, worker to give you leaflets/contacts of who to speak to in the meantime.
- Start the process 2-3 months before you turn 18 – less waiting time.
- Professionals to be in more contact with each other (not asking the young person what the other workers have said).
- Suggest that CAMHS look at providing a service from 0-21 in which the years between18-21 are dedicated to supporting transition to adulthood and adult services. For instance a proportion of regular appointments would be with adult service, visits etc.
- Ultimately the service needs to be flexible and moulded round the needs of the child so for instance one child might be ready to transition aged 18 another not until they are 24. Added to which, some conditions have their onset between say 14-25 e.g. male psychosis so their age range needs to be fluid.
- How will CAMHS complex ADHD work with the community waiting time with 1200 children on the list?

When should transition happen?

- 0-21/22 (university include) at 18 give them the option to carry on or transition.
- Not CAMHS – YPMHS (Young Person Mental Health Services)

What should happen if someone that chooses not to transition into adult mental health services changes their mind and needs more support?

- Fast tracked into adult mental health if already been in CAMHS – CAMHS worker to support if needed.
- A contact number to the adult services for if you change your mind at a later date.
- Information pack to be given when discharged about adult services and what to do if you change your mind.
- Priority triage on transition so those who urgent get care need
- Could there be a priority referral if are not transitioned but then need help
- Need to know what to do if I need help when an adult (if not transitioned).

Monitoring ideas

- Waiting times being published.
- Website.
- Customer surveys.
- Opinion wall in waiting room.
- What went well?
- Telling us what they have done with the information/feedback we give.
- Surveys during my care – not just at end.
- Don't make me complete surveys in front of you.
- Repeat survey at different times. Be able to 'tick' but also 'explain.'

Crisis care

- Crisis care really difficult ED frightening chaotic, just want someone to talk to at right time, needs to be responsive. Something else other than ED when in crisis but no one had a solution.
- Urgent question from 24 hours to 5 days, routine apt 4-6 weeks, some form of email support when urgent might be helpful.

Be patient centred and focus on individual outcomes

- Need to engage young people on their terms not focusing on assessment or CAMHS workers agenda
- Most had been out of education because of challenges
- If non-attendance is an issue then staff need to be proactive in building relationships with the child and family maybe even having appointments in local youth clubs for instance rather than in the potentially intimidating surrounds of CAMHS.
- Involve youth workers trained in mental health to encourage attendance.
- The service needs to accept referrals and implement them quickly. When children are receiving treatment staff need to communicate with their wider support network e.g. youth clubs staff as they may be able to support treatment in a familiar and comfortable environment

- Parents often feel guilty and felt very difficult not to feel blamed, although this is never intentional.
- Maybe some joint part of session as standard with parent /carer
- Expected to be fully responsible but not given full information because of confidentiality so felt disempowered as a parent.
- With regards to missed appointments there needs to be recognition that families of the child or young person using the service are often chaotic and may lack basic literacy.

Early help and prevention

- Would also like to see an early intervention service building on the well-being practitioner's role.
- My child was offered Cognitive Behavioural Therapy service and then the service withdrawn. We feel let down.
- I was very disappointed when the 12 sessions of Cognitive Behavioural Therapy were cancelled with no reason provided.
- Didn't know they could self-refer
- More joined working with schools, more and early outreach into schools one YP seeing the academy

Parents and carers

We visited a range of community facilities where parents attend with their children. These included parent/toddler play sessions, health visitor clinics, therapy clinics (physiotherapy, occupational therapy, speech and language), and paediatric consultant clinics. Some people gathering this feedback recorded individual comments and some recorded major themes so the feedback below is a mixture of both.

During face to face discussions with parents and carers, they talked about individual services and also what could contribute to making a positive difference to their children and the wider family.

- **Feedback about individual services**
- **What makes a positive difference**

Feedback about individual services

Therapies (general)

- Health says speech and language therapy is not a health need and education say it is not an education responsibility.
- First visit to occupational therapist for handwriting. Reasonable wait, great service.

Speech and Language Therapy (SLT or SALT)

- I do not think that SLT spend long enough assessing and observing the child before jumping to conclusions.
- Episodes of care does not work for SLT - the system needs to be based around the needs of the child not a standard one size fits all approach of 6 sessions

- There are not enough high tech augmentative and alternative communication specialist (AAC) SLTs. There is only one. There are an ever increasing number of children using high AAC in special schools and this trend is only set to increase. All SLTs should be trained in high tech AAC.

Physiotherapy

- Not enough of it. Seems to be once a child is mobile that's it. Need more flexible service and more of them.

Public health nursing – school nursing and health visiting

- School nurse referral but nothing came of it parent heard nothing.
- Need more health visitors and longer input from them and continuity too many changes of health visitor.
- What do health visitors do anymore?

Portage

- Portage is great and would be a huge beneficial use of resources it could be extended to an older age particularly for children with 'complex' needs.
- Our Portage worker had lots of knowledge about our child that could have been shared with the special school as handover took place, but the school did not enable this to happen. It then took the special school over a year to learn about my child.
- Portage was brilliant. In particular because they did home visits, all 1:1 sessions and especially because they had a holistic approach. Very very efficient use of commissioners' budgets!
- The constant review of a child's need for portage service is an un-needed stress for parents.

Learning Disability Service

- Fantastic - just not enough learning disability nurses available. Very efficient use of your resources as specialist in what they do and so good at getting results.

ROVICs (Rehabilitation Officers for Visually Impaired Children)

- ROVICs are fantastic. Deafblind assessments very important for deafblind children. Made a huge positive impact to my child.

What makes a positive difference?

Accessible/responsive service

- Parents report different experiences which imply a lack of consistency around access to services.
- Services need to reflect the balance of family needs with the needs of the child.
- A parenting course for parents of autistic children would be a great help
- More support for families is needed maybe peer support?
- More flexible core hours would be good, especially evenings and weekends, as getting time off work is stressful.
- When Practitioner off sick nothing happened for a while, need better cross cover.
- Getting services shouldn't be about whether a professional helps or not.
- Team are excellent and always on hand for telephone advice.

- Children with challenging behaviours should get parenting support first. Do ‘the incredible years’ before you add medical weight. Discrepancy in parenting courses across the area.
- Families need support with behaviour for children with learning disability and behaviour. Clinical psychology will help with that.
- Staffing is an issue as we often have to wait because of staff sickness or annual leave.
- Transition points are where parents feel least supported.

Equipment waits, provision and maintenance

- The main problem service users are experiencing is regarding waiting times for equipment. Some have to wait months for new wheelchairs etc. I don’t know if this falls into our survey though.
- Wheelchairs. Needed adjustments. Had assessment and 4 months later. Also too small. Back up when power chair is repaired is a regular fold up manual which is ridiculous.
- Delays in equipment. Chairs not arrived, physio bed for school. Planned well ahead and chased. Nothing has gone well with that. Changed company?
- Equipment. Bathroom adaptation great. Wrong bath because cheaper. Same with shower chair. Manager says this is £3k cheaper please consider, and we did, but it didn’t do what we needed so effectively that money is wasted.
- Needs bespoke sling and they keep sending us readymade? The cheap options don't work so it's a waste.
- It all takes months or years.
- We've been far too patient. Service not equitable. Some people have things and others don't. Some people get things quickly and others wait.
- Tubes for feeding. Changed tubes without the fittings being changed too.
- No one seems to chase equipment. I have always given mine back but I think a lot of parents don't which means huge amounts of money must be wasted.

Waiting and referral times

- Delays in getting appointments and equipment.
- Required a 6 week check, couldn’t happen for 6 months.
- Wait to see community paediatrician has been quick.
- Staff are brilliant but the system is broken. If and when you get in things are better but getting in is really difficult.
- Access to services shouldn’t be based on having a specific assessment waiting for these just means we are left without support for way too long.
- ASD waiting times need addressing.
- Open referral systems are better.
- The question of urgent/non urgent needs to be addressed for the person involved whatever is going on will be urgent. In addition, there needs to be recognition that urgency or otherwise is multi-factorial and might include inequality of service provision leaving a child without support.

Being patient centred and focusing on individual outcomes

- All the form filling needed takes time and energy that we would rather spend on our child.

- Child identified as having 'priority' needs in February 2017 not seen for assessment until August 2017. The referral process seems overcomplicated needing assessments at different points before going forward to the next.
- Huge time and energy investment for parents to get the information they need.
- Parents have no faith in the continuity of caring input from professionals as staff move around too much and so they don't want to invest time in working as effectively with them.
- More careful consideration given to age cut offs for services.
- Service provision especially around support should focus on a child's needs not whether they meet eligibility requirements.
- Don't use the word discharge, my child has a chronic condition and will always need input from professionals. To be told they are discharged makes it feel like we have been abandoned.

Clear communication and support with information

- Parents need to understand the process for assessment, they need to understand why they are going to see professionals, they might not know why they need to see a paediatrician etc.
- A mum reported she wasn't expecting an appointment with a SALT, so didn't notice when the appointment letter didn't arrive and didn't chase it, she was therefore marked as DNA. Parents should receive a letter which outlines the process, number of appointments/ professionals.
- Parents not get direct payments because they don't know what they're entitled to. People on forum not know. Too submerged in their life to work out how to organise it.
- Not clear where to gain information about services.
- When my child needed specialist care, the care at RD&E and Birmingham Children's Hospital was great, but there were issues with correspondence being lost and the hospitals just not being able to communicate very well.
- There is a problem with cross organisational communications and communications with parents/carers.
- Information is important but for those without a diagnosis it can be really difficult to find information or to know when to trust what's on the internet.
- None of the services work together.
- All clinicians are seen in one place – this works really well for the children.

Looked after children

- Put nurses in every school able to support this group of children and young people.
- Have assessments at places children go e.g. Youth clubs.
- Where people have not taken up appointments this should be supported through face to face discussions and use of staff able to work with children and their families to explore and understand the issues preventing take up.
- Contacting looked after children nurses is not straightforward unless you work in the system and yet many people working with children would be able to see that there may be a need for this input and so should be provided with information on how to contact them.

Transition into adult services

- Transition support for services should be 16-25. Just because you move into adult services at 18, doesn't mean you are able to cope with this.
- Support services post diagnosis drop off after you reach 18.

- What support is there for parents when your child reaches 18?

Barriers to support for children with Autistic Spectrum Disorder

- For a child with ASD to get therapies outreach support in mainstream school, they need a diagnosis, even if they are already recognised as being ASD.
- Only an ASD diagnosis gets respite and professional input to education.
- On diagnosis you need feedback about what happens next, information about financial services/ benefits you can access. Having access to support services like therapies in the meantime, not only after assessment.

Education, health and care plan (EHCP)

- Worried about funding cuts to schools and how teaching assistants are being used to support whole classes instead of being one to one.
- Need advice on how to apply for EHCPs. With more than one disabled child it is really hard to keep up with all the paperwork on top of their needs.
- Health workers don't understand what an Education, Health and Care Plan (EHCP) document is for. Early interventions are not put in and this can result in criminal justice situation.
- EHCPs are too broad. Need to be more specific. What is happening is against the law. Written on a template doesn't work. Should say level of training needed.
- Teaching Assistants carry too much responsibility like planning for EHCPs.
- Social care and health bit isn't statutory and this seems to lower resources released for these aspects of an EHCP.

Lead professional/ keyworker

- Keyworker should support across different agencies. Not just health.
- We used to have a health keyworker, who was an occupational therapist and was amazing, but the system changed and keyworkers were taken away.
- Access to keyworker to understand family need. Daughters got access to young carers support. Younger children not getting as much attention as they deserve.
- Continuity of practitioner is important
- Continuity important. Not want OT to have to discharge for caseload management reasons if you have long term condition that will always require service. Want to be able to come back to same person in future.
- Need more robust arrangements in place around care continuity in a service that sees staff changes.

Early detection, early intervention and prevention

- Should screen for genetic issues early
- Mum is a teacher in early years. Has seen decline in health visitors and ways to pick up early issues. Children arrive at school with issues that could have been dealt with much earlier. Problem families move around so they get under radar. Exmouth has CPOMS website where all primary and secondary schools can upload all issues/concerns about a child to one place and it doesn't get lost. National thing? Great for safeguarding.
- Support shouldn't be dependent on a diagnosis. Interventional support early on will prevent greater need later.

Suggestions

- Costs more to get continuity of support privately. It would be really good to have a sort of buddy system whereby families are matched to give mutual support on one side from a family who has been there and on the other side allows for reflection on how far that family has gone.
- For speech and language therapy, they should use systems like a learning media assessment that they use in the US.
- Both speech and language therapists and occupational therapists need training in Cortical Visual Impairment (CVI) which is now the most prevalent paediatric eye condition in the western world and has some similar traits to autism or ADHD.
- Better co-ordinated care is needed perhaps with a dedicated care co-ordinator.

Professionals

Integration and information sharing

- Confusion between providers especially school and health about who does what for example doing Devon Assessment Framework Forms.
- Schools need more support to understand conditions and their role as supporters of children with special needs.
- It is common for children in contact with our support service to experience difficulties and barriers to accessing services because they are not integrated.
- Support for a child should not be dependent on a referral and or diagnosis but linked to behaviour and life impact. This will enable a child to be supported earlier and perhaps avoid going into crisis at all. The argument against this approach has always been around who pays for that support so an integrated budget or personal care budgets might overcome this.
- Community nursing team is a very close working relationship. We think it sits neatly with acute. Currently needing to bid for funding on case by case palliative needs, and then build the right team for the child (taking them away from their normal work) for 2 weeks at a time. Not effective way of doing it.
- Some community nurses spend as much time on the ward to talk about the same things with the same people.
- Clinical psychology/ General paediatrics/ CAMHS - different routes with random rationale. Different teams talking about the same children. Should be an expectation that this is all joined.
- Paediatrician should be part of CAMHS/autism etc.
- Piloted joint clinic once in April and paediatricians think it's a great idea but not heard anything further. ‘We're ready and willing and waiting’.
- Early years need psychology. Unpicking early attachment.
- Pilot of transition care combining learning disability complex care team with elderly care team as their processes are similar. It went well but didn’t demonstrate any savings so was not pursued.

What does good look like?

- System wide working – providers working with each other as well as multi agency.
- Communicating and liaising across services.
- Close working with the NHS commissioners (Clinical Commissioning Groups).

- Co-location working model in Devon working well for key working lead professional role and co-ordination.
- Link with acute and paediatricians for rapid response.
- Safe/confidential communication for sharing information.
- Devon wide specialist training team.
- Clear offer around school nursing and specialist school nursing.
- Good pathways in and out of acute care services.
- Consistent policy and practice around decision making for children eligible for Continuing Care or those not but have additional health need or equipment and consumables requests. Decision making and purchasing.
- Understand and prepare for impact of decreasing funding in charitable and voluntary sector which affects the core offer.
- Palliative care working well in terms of meeting family needs and choice – use as an exemplar (although acknowledging not gold standard).
- Transition groups set up to get adults engaged early on in process.

Workforce considerations

- Experiencing more difficulty in recruiting to community posts in comparison to previous years.
- Partnership approach is taken to training community nursing and acute nurses.
- Access to specialist training is limited within South West.
- Capacity in the workforce limits the ability to release staff for training as well as ability to invest and grow your own and developing new and additional roles i.e. advanced practitioner.
- Acknowledge that there is little current published workforce modelling – although NICE End of Life provides model workforce numbers.
- Some caseload modelling has been trialled in certain areas.

Caseload

- Services report increase in numbers of children and young people on community nursing caseloads including those with child protection plans, parents with special needs, and a pattern of babies that die through Sudden Infant Death relating to low social economic background and smoking in pregnancy.
- Complexity of children has increased rather than numbers of children increasing.
- Eligibility for continuing care using the new framework has broadened the criteria impacting on increased numbers needing assessment and intervention.

Special schools

- Recognising more are accepting a wider range of children with less complex needs.
- Issue of the lack of adult nursing provision to Young people over 19 years in reaching to the school.
- EHCP identify the health need but there is limited capacity to deliver. There is a need for DMO and DCO involvement in the quality assurance of plans.
- Need to ensure clear role of generic school nurse compared to special school nurses which are within community nursing teams.

Community nursing

- Want access to a 7 day service for complex children. Not necessarily 24/7.

- 24/7 is needed for palliative care required but not in place everywhere yet.
- Need for step up in to acute and step down in to community pathways as there is some reluctance from families to use hospital based services – confidence of families in the staffing continuity of care. Reassurance required for parents when children just out of hospital that there is skilled staffing and capacity to manage certain procedures in the community.

Autism

- What about Autism service for children with normal intelligence?
- Autism/ADHD with environmental factors. PAEDS needs to sit closer with CAMHS. No other therapies offered.
- Need to get away from diagnosis only. Need follow up and management.
- Autism is the greyest of grey things. Need to have diagnosis in collaboration with therapeutic team. In a way diagnosis is the least important. Shouldn’t be the entry criteria. Should be based on need.
- Autism services need more capacity.

Learning disability diagnosis

- There is no structure for determining if child has a learning disability. Important for transition to adult services. Children leaving children's services not being able to access adults because they have no diagnosis.
- EHCP helps challenge what are other professionals actually going to be doing for this child? ‘As a paediatrician I can't change this condition any further.’

Support to wider family

- Need to pay attention to whole family in particular siblings who need to understand and learn how to cope with the situation.
- Children and their families need support even before there is a diagnosis.
- Praise for services.

Education, Health and Care Plan (EHCP)

- Services report huge impact on time, money and training for staff having to attend meetings and respond to requests for input to Education Health Care Plan.

Personal health budget

- Impact on workforce capacity to lead the Personal Health Budget process and clarity is needed on roles and responsibility in terms of training of Personal Advisors, sign off of competencies, continuing review as part of normal caseload management, clinical oversight, governance etc.

Transition

- Services finding it difficult to get adults services involved in a timely way.
- Transition – early years in to education. More children within main stream settings – service find it difficult to meet their needs with capacity.

9. Feedback from summer events with children and young people

Over the summer, we collaborated with a number of organisations that specialise in working with children and young people to help us gather views. Feedback from these events is summarised below.

Lifeworks

Lifeworks works with local community partners across South Devon and Torbay to enable its service users to participate enjoy and contribute to community life. We commissioned them to support our engagement with young people with learning disabilities, which they facilitated through three kinds of groups:

1. **Kool Club** is an inclusive Youth Club for young people aged 14-25 with learning disabilities who want something a bit different. The club offers a relaxed and supportive environment for young people to make friends and develop life skills through a variety of activities, in a dedicated youth space and out in the community. The young people in this club took our engagement process and designed it in a way that other people with learning disabilities could participate in.

2. Over the summer holidays, they ran a **holiday project** which was developed in partnership with young people age 12-19 plus a fantastic network of activity providers and cultural venues across Devon. This provided recreational and leisure opportunities that enriched and extended experience, offering young people with learning disabilities a sense of community; belonging and independence.

3. They also held two **Breaking the Barrier** events, which enable learning disabled children and young people, with their families, to participate in adventure sport. Their events were cycling and surfing, and they facilitated for all participants to take part in our engagement process.

Many participants of all these points of engagement were at a transition point, particularly regarding education. For example, from secondary to sixth form, or from college to an apprenticeship.

Key themes from the holiday project

- Timely support before and in crisis. Carers are tired and the young people are worried about asking them for more help.
- Fed up that services don’t talk to each other.
- Huge connection for teenagers and emotional health and wellbeing and this is the same if you have a learning disability.
- All our priorities are important but on top of that you need to see me as an individual.

Specific comments were received in relation to this last point, these are summarised below:

- I want to see and understand what professionals do in pictures so I can participate in the process and discussion that is about me.
- Don't group us all together just because we have a learning disability. Anxiety or weight might be our main issue, not my learning disability.
- Places where appointments and meetings take place are often new and strange. Why can't the meetings be at my home? I always have to go to a strange place with unfamiliar people. The only time they came to my house was when I was taken into care 15 years ago.
- It worries me that sometimes professionals are working with a young person that is known by others (e.g. in CAMHS) to have triggers that can cause violent and challenging behaviour in some circumstances and this information isn't shared. This causes stress for the workers and the young person.
- Education, Health and Care Plans are not explained to the young person. How can young people participate? One person I know found out it has been written down that he can read and write but that's not true. He'd actually like more help with that. "Where does that leave me for preparing for my future?"

Key themes from the Breaking the Barrier event – Torbay Velopark

To support the development of future services and some of the things we need to do to **meet future needs**

Three key principles important to these young people (in order of preference)

1. Children and Young people should get personalised support (Scored 28)
2. The system should work together to support me and my family (Scored 27)
3. Services should build upon the strength and resilience of individuals, families and communities (Scored 7)

Other comments that were noted:

- Support matched to ability
- Need help from CAHMS we do not get it because they will not give us the support

Relevant and important to these young people

Common themes that young people felt were important:

- Working together
- Focus on me
- Tell them once
- Earlier support before crisis point
- Torbay and Devon to work closely together to share services
- Tell my story once and give my details once

- Detailed information on all services available from transition from children's services into adult services would be important
- More local activities
- It helps me build my abilities now and in the long term
- Children with special educational needs and disabilities

What makes children's services good?
(In order of preference)

1. One person who you can contact to talk about your care and what you need (scored 33)
2. I am involved in setting goals and decisions about my care (Scored 22)
3. If I need services, I can get them near where I live (Scored 19)
4. Services help me to understand my own health and wellbeing, and be as independent as possible (Scored 17)
5. Appointments are at flexible times and places to suit family life (Scored 15)
6. Children and young people should be prioritised on risk and need (Scored 14)
7. If I don't have the right 'connection' with the professional, I can change to another (Scored 14)
8. If I've got a long term condition, I don't need to wait for another referral to get help again (Scored 12)
9. Crisis services are available out of hours (Scored 10)
10. Whilst you're waiting for service, need information on how to manage (scored 9)
11. Can get quick advice about my situation without needing an appointment (Scored 9)
12. Information in how long you will have to wait for service and what to expect when you get it (Scored 8)
13. If I need services, I can get them near school (Scored 5)
14. Website (scored 3)
15. I don't know (Scored 2)

What do we need to do to make this successful?

1. High quality specialist services that learn from service users.
2. Connected, personalised and working together.
3. It is the best it can be and affordable.
4. Don't mind where the money comes from just that the service is good and there when I need it.
5. Earlier support to stop us needing services in a crisis.
6. Good opportunities for children and young people at transition points in their life.

Comments received:

As the parent and carer of a 23 year old adult with learning disability, I think it is important that he can access regular activities both social and physical to prevent him becoming a couch potato. He does not have work or the ability to undertake normal activities with friends to promote physical and mental wellbeing. When he spends too much time watching TV we notice that he becomes agitated with poor mood.

CAHMS services are totally over stretched the waiting times are ridiculous. We have friends with children's with severe problems that are wanting months for help and are hugely distressed and stressed as result leading to huge problems within family relationships. We have barely had any contact from NHS since daughter grown up. It appears that she is not needy enough so we just make it up as we go along. It would be nice to have a paediatrician that new my daughter and her story so we don't always have to start right at the beginning explaining her additional needs is basically a drag and depressing. Number 5 – services fantastic until 6 years then dwindled now no services.

Would like quality special educational needs and disabilities speech therapy or sign posting. All education teachers in mainstream & special educational needs should believe more in inclusion. If we are aiming for paid work we need to have higher standards of education.

The transition from child services to adult services was a nightmare. We were told on numerous occasions that it would happen automatically and we wouldn't need to do anything. This was absolutely not the case once my son left child services he dropped off the world into a giant abyss and was never picked up by adult services. It was the same with my son's paediatrician, once he got too old to be under a paediatrician he again fell into no man's land. We have no hep what so ever with regard to his special needs. Whenever we go to the GP they look completely over whelmed as to how to help him.

Children's services are very poor; our experience is long delays, being passed around different teams.

OT, physio etc. all in one place at my school. Brilliant environment rather than clinical. Recently support was suddenly pulled back. Not sure if this is due to funding or if they are actually improving. Daughter had lots of support when first diagnosed almost 20 different professionals trying to contact her. She had equipment to support sitting and feeding etc.

Audio feedback with young people - Sound Communities

Sound Communities is an ambitious Torbay-based Community Interest Company that runs radio projects to enhance community cohesion and increase employability. They have a very unique and rich set of skills and understandings, so they were an ideal group to commission to capture the views of young people in Torbay.

They went to youth clubs across Torbay and had conversations with young people who were attending:

- The Edge, Brixham
- Parkfield, Paignton
- PHAB club, Torquay

- Young carers, Torbay

The Edge, Brixham (older teenagers)

- Although it's a good idea to have one centre for people to go, it would depend on where it was and how far away. Torbay hospital is too far from Brixham. Disorientated after having an operation. Buses take ages to get from Brixham to Torbay hospital. Over an hour.
- Is there the funding to do all the things they say they will? Why don't you focus smaller resources in town centres rather than at Torbay Hospital?
- Information should be in pictures and sign language too. Your records should actually be kept like that. It's pointless telling people over and over again. They're wasting their time going over the same question that you have already answered.
- Some people go to an appointment with something wrong with them but don't explain it, so it is a good idea for professionals to check if there is anything else.
- It really annoys me when people don't read your notes before you arrive.
- I find it difficult to say 'yes that's happened', like when I've injured myself. I don't know how I will feel afterwards so I don't want to open up and say anything. I could be traumatised.
- After I had an operation I had someone come and show me how to do things differently and be healthier.
- If you have a day when lots of people are getting injured, do they have the capacity to help them? The new ideas could be expensive.
- Early intervention is far better than firefighting at the end. You spend less on the individual person. That's why we need more services in our community.
- Dealing with mental ill health takes longer and needs dealing with quicker.
- I find GPs are pushy saying 'what's wrong with you'
- I think services should be flexible and fit round each person, but can they afford it? What if they are all booked up? The idea of it moulding around the individual person goes out the window.

Youth leader at the edge, Brixham

- It often takes a long time to get help for mental health problems. Bullying not dealt with quickly enough and this affects mental health.
- When things are not addressed and they escalate, some people taken outside area which makes it so hard for families.

Parkfield, Paignton

- Choice is good in case you don't like one.
- Choice of where it is good so you don't need to go far away.
- Sometimes it can be hard to talk about your health problems so it's good if it can be recorded and passed on so you don't have to say it again.

- Not everyone's problems are the same. It will help you more quickly if they can respond to your needs.
- Carers need to know all the information about your problem so they can help you.

PHAB club, Torquay

- We don't have our own transport so services close by would be helpful. If you get nervous going out on your own, it would be more comfortable seeing someone at home or close by.
- If got so many people helping me with a care manager who works very hard to coordinate. They work really hard. Without my care manager I wouldn't have the opportunities I've had. She's fought my battles. I told her what I wanted and she helped me. I'm in charge of what I want to do. School wanted me to do different things that I didn't want to do.
- Family have really supported me and organised work opportunities for me.
- If you have to say something that makes you worry, you don't want to have to keep repeating it. You only want to have to say something once.
- I'm a young disabled carer, looking after my mum. I get some help with trips and money. I wish they checked up on me more regularly. I get a phone call but I'd rather they came and talked to me. I wish there were more people to visit me and help me. I'd like more help from someone to go through things with me.

PHAB club worker says they provide 2 hours respite for 30 people each week and they are not funded properly for this.

Torbay young carers

- Being able to give a service a quick call or text and ask if they can give you information or advice is a good idea, rather than waiting for weeks.
- There should be more CAMHS. More Checkpoints.
- People with anxiety struggle a few days before they go to an appointment.
- School counsellor sees hundreds of people and has prioritised me and arranged all the appointments I need. Checkpoint could do this better.
- Being involved in your own care is a major thing; it's independence. You need to understand what's happening.
- Half my teachers don't even know that I am a young carer. If they did, they might have treated me differently.
- Teachers just care about your work and your behaviour, not what's going on at home. It's important for someone who is coordinating your care to make sure your teachers know you are a young carer and may have needed to go to hospital with your parents. They don't understand that being a young carer is more than just staying at home and looking after someone. You may not have money; you may need to administer medication.