

# Young Healthwatch event

## 18<sup>th</sup> February 2014

### Key Issues

Mental Health, Young Carers and Transition from Children's to Adult services are top priorities

The Right to be Listened to was most valued

Next steps are to identify groups of young people to work on what needs to change and how.



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## What is Healthwatch?

Healthwatch is a statutory function, funded by the Department of Health and commissioned by Local Authorities with 3 core roles. The first is to listen to the views and experiences of people with their health and social care services. Healthwatch then feeds that information back to commissioners and service providers so they can better understand the needs of the communities they serve and where necessary, improve service delivery. In addition Healthwatch also has a role in information and signposting to health and wellbeing related services, and NHS complaints advocacy.

Healthwatch is a service for all communities and in particular works to ensure the voice of those not normally heard is gathered. The views and priorities of Children and Young people are a key focus within Healthwatch.



## Purpose of the event

Based on the success of the event held in February 2013 to find out whether young people wanted a Young Healthwatch it was felt something similar would be a good way to engage local young people from across the wider area of Bristol, South Gloucestershire, Bath and North East Somerset and Somerset. The aims of the event were to:

- Promote Healthwatch and Young Healthwatch to young people so they have a better understanding of what Healthwatch can do, they know if they have an issue they can come to us, and that their views and experiences are important
- Develop 5 priorities in each geographical area which will form the work plan for the coming year
- Demonstrate to young people that involvement is fun and that being involved with Healthwatch does mean they are listened to and are feeding back on a national scale
- Involve commissioners and other service providers so young people could speak directly with them, ask questions and see that they are being listened to.



## The event

Over 40 young people aged between 13-20yrs attended the event on 18<sup>th</sup> February at The Station from Bristol Black Carers, Mentality project, Barnardo's HYPE, South Gloucestershire Youth Board, Bristol Children's Hospital Youth Council, Young Carers, Somerset Rural Youth Project, Young Adult Carers and KIDZ . The event was publicised through The Care Forum networks and e-bulletins, inviting organisations who work with young people to bring any interested young people along for a days event prioritising issues and concerns with a market place for agencies and arts activities.

First Born studios were invited to record the event, taking photos and offering a diary room experience for attendees to share their thoughts. The results of which will be share on the Healthwatch You tube channel.

APE project and Sounds Delight were invited to run fun arts activities. We also had attendance from Healthwatch England, 4YP, SEAP, NHS England Clinical Senate, Bristol Children's Hospital, Inge Shepherd Programme Manager for Children and Maternity Commissioning, Bristol Clinical Commissioning Group and Denise Swain on behalf of South Gloucestershire Clinical Commissioning Group, observing and contributing to the activities and market place session.

In addition to the event, the South West Medicines for Children Research Network also held a consultation day with some of their members on 18<sup>th</sup> February. The Young Persons Advisory Group (YPAG) and is aimed at 10 to 17 year olds with an interest in child health research, 15 young people participated in the activities for us and the results of the discussions have been included in the findings.

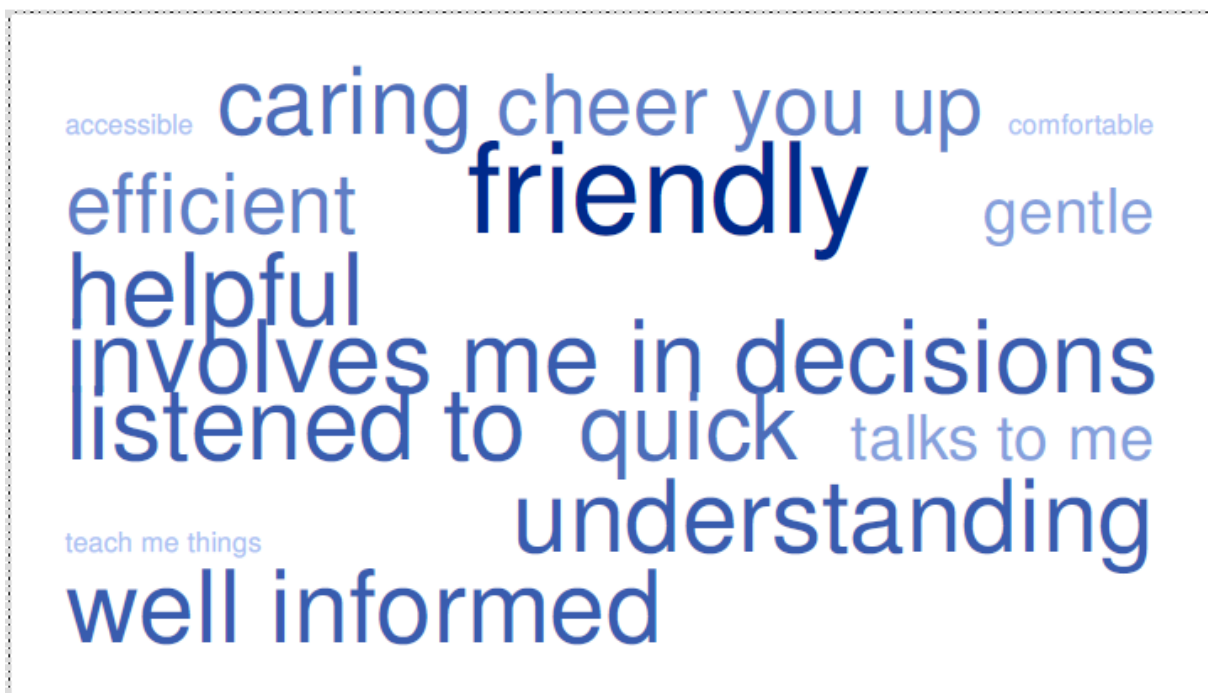


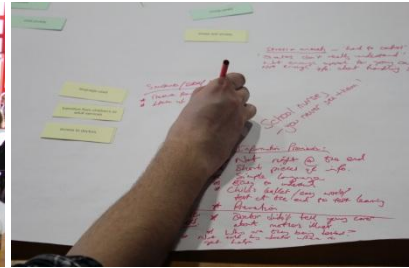
## Findings from Good service washing line

As an introductory exercise for people as they arrived at the event we ran an activity on what makes a good service in health and social care. The young people were asked to write what makes a good service or their experience of a good service on a star and what makes a bad service or their experience of a bad service on a sock. These were then pegged to a washing line.

Being listened to and communication were key comments, see below:

What makes a good service.....





What makes a poor service.....



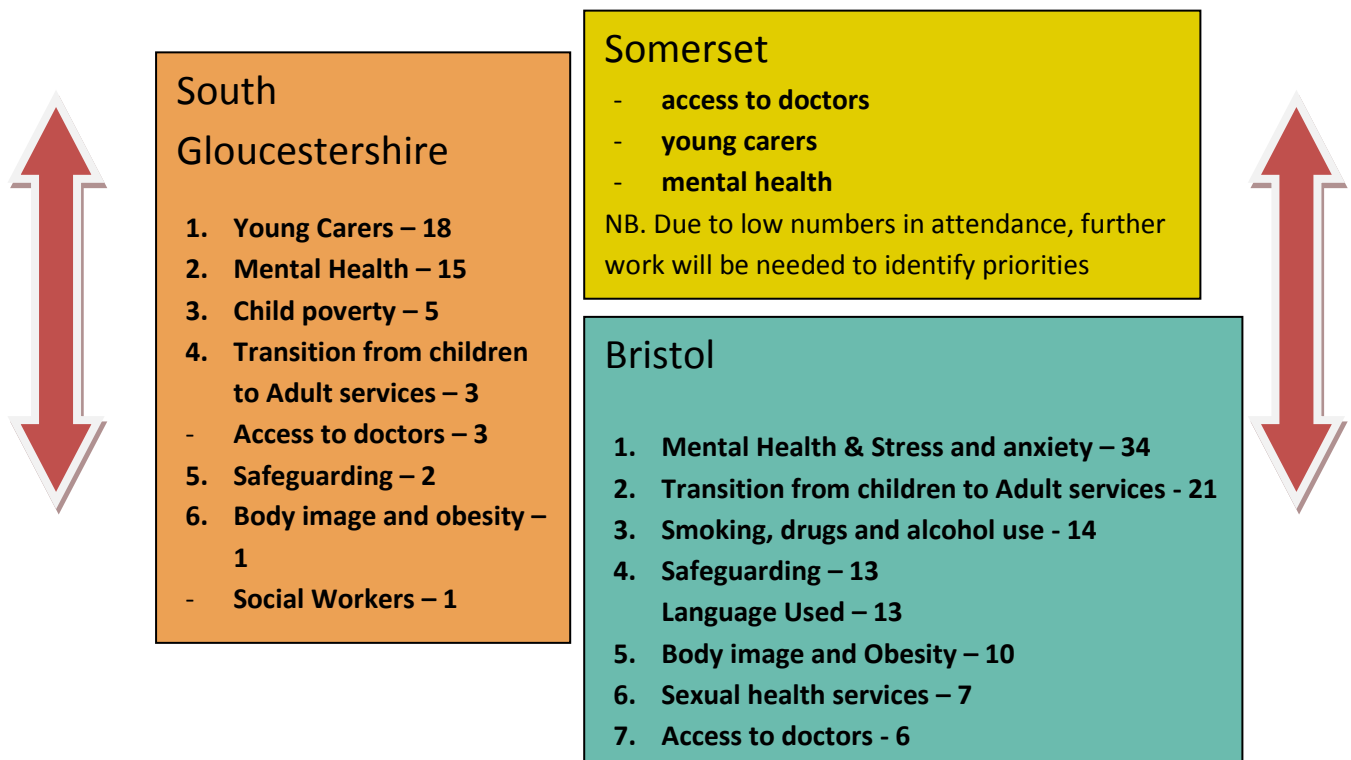
Participants were asked to sit on tables for each area and after a brief introduction to Healthwatch, and Healthwatch England and how this event and the work with young people would fit in, the main activity sessions began.



## Findings from Priorities exercise

The first activity was to priorities the issues and concerns Healthwatch had received and those topics highlighted in various strategy documents e.g. Health and Wellbeing strategy, Joint Strategic Needs Assessment and the Clinical Commissioning Groups commission intentions.

20 cards were given to each table and they were asked to discuss the topics and prioritise their top 5 based on what they felt were the biggest issues for young people in their area. Later in the day the results of the morning session were placed around the room and young people were given 3 sticky dots and asked to vote individually for what they felt were the priorities. The results were as follows:



Paper table cloths were used so young people could record any thoughts and comments during the discussions.

A key discussion was had around the confusion of what the term safeguarding meant. They felt safeguarding is a term often used and accepted but they were not sure if all young people really know what it means and how it can impact them. There was a similar discussion had around confidentiality and whether young people really understood what is kept confidential and how .

See the appendix for complete notes, below are some key comments from the top issues

Young Carers need support and to be able to get out of the house on activities, to meet other people like them and be reassured that the person that they care for is in good hands.

No/ineffective hand over. Turning 18 doesn't magically change things overnight. People die when transitions aren't managed effectively.

Transition from CAMHS to AMHS really bad. No services to bridge the gap. Few 16-25 services, only early intervention psychosis. Have to meet such a high threshold to be passed over. Results in people suffering and becoming really ill before they can access help again

Mental health not looked after every well and schools don't always know what to do.

Gets ignored as teenage behaviour

Doctors and other health professionals need to be aware of their use of jargon, and different languages including sign. Especially have interpreters available

Body image - Influence from the media – girls to be skinny and its not made clear the photos are photoshop'd, puts on more stress

Safeguarding - CYP vulnerable and need to be protected holistically with all aspects of their wellbeing considered

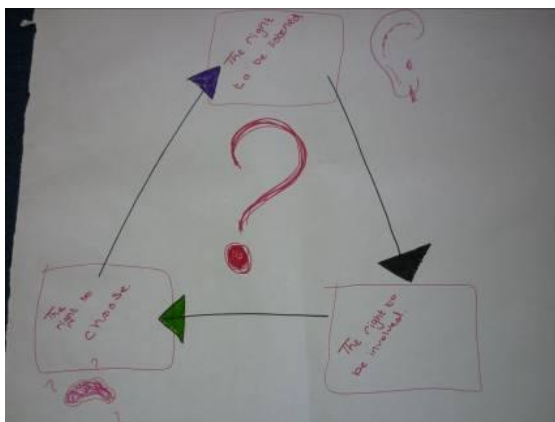
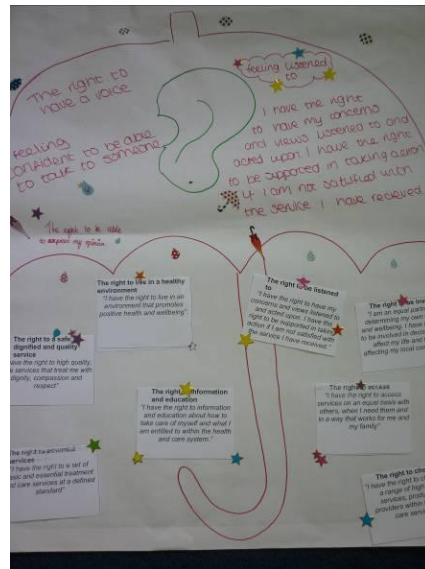
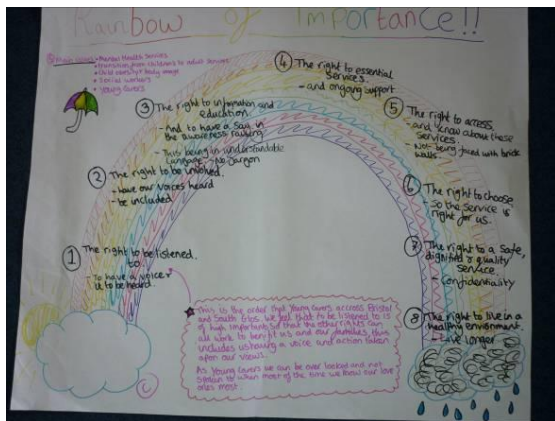
## Findings from Rights exercise

Healthwatch England have proposed 8 consumer rights to put the public voice at the centre of health and social care. They are consulting with all people across the country to find out what the rights mean to them and their importance.

The young people at the event were asked to talk about the Rights and record what they thought of them and produce a poster of the one they thought was most important.



The **Right to be listened to**, the **Right to be involved** and the **Right to Access** came out strongly as the Rights the young felt were most important. With 2 of the groups feeling that confidentiality was a gap. See appendix for the complete notes from this activity



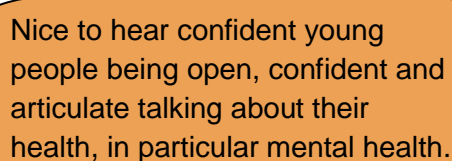


During this exercise the young people highlighted that they should have a right to choose/freedom of choice with regards to whether they receive healthcare and from whom. In particular they wanted more choice where you get healthcare from and from whom. They discussed the age at which they felt a young person would be able to make decisions about their own treatment, which ranged from 6 years upwards. The general consensus was that each young person should be treated as an individual and that the young person and their family should be involved in discussions and decisions regarding healthcare. They felt that young people should not be forced into something they are not happy with, except if is deemed life saving. Discussing all options was felt to be very important and having a voice.

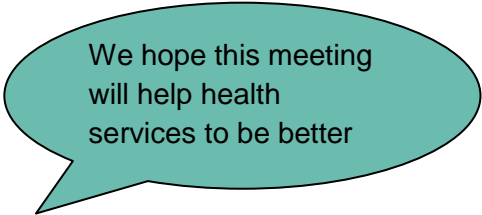
The young people found difficulties in putting some of the statements in order as they felt they had similarities or links with another statements.

## Feedback and evaluation

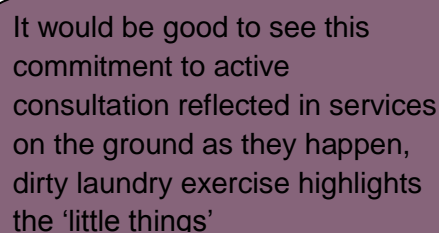
An evaluation of the event was collected with the feedback being very positive for the event itself giving young people the chance to influence and be listened to. The venue and lunch also came out positively. The question about activities had a couple of negative marks, but it is assumed this is because Sounds Delight were unable to come which did leave a gap in the market place session.



Nice to hear confident young people being open, confident and articulate talking about their health, in particular mental health.



We hope this meeting will help health services to be better



It would be good to see this commitment to active consultation reflected in services on the ground as they happen, dirty laundry exercise highlights the 'little things'

## Next steps

- ❖ Further prioritising work needs to happen in BANES and Somerset
- ❖ The identified top priorities to form the work plan for action with children and young people
- ❖ In Bristol and South Gloucestershire detailed discussion needs to happen to draw out what are the issues behind the priorities and what needs to change.
- ❖ Healthwatch should link in with any relevant strategic bodies to ensure the views of young people are heard
- ❖ Healthwatch needs to identify groups of young people to work on the priority issues
- ❖ Healthwatch could assist the Bristol Clinical Commissioning Group to set up a reference group for young people to have their say on the recommissioning of children's services in Bristol and South Gloucestershire
- ❖ A follow up event will be held next year to update on progress and gain the next set of priorities



Thank you to everyone who took part and made the event such a success.

## Appendix

### Bristol

#### Table 1) notes from the discussion over top 5 priorities

##### Smoking/drugs/alcohol

- Pressure from school/socially
- Lack of education
- Continuous education as we get older
- Would go to the internet for information on these
- Peers and family members smoking  
.....family – not good to smoke

School nurses – you never see them

##### Information Provision

- Not right at the end
- Short pieces of information
- Posters in school but little reference to them
- Simple language
- Easy to understand
- Child's leaflet/easy words/test at end to test learning
- Prevention

##### Young carers

- Doctor didn't tell young carer about mother's illness
- Why are they being tested?
- Not told by doctor where to get help
- Not comfortable talking to GP (Beechwood Medical Centre)

##### Mental Health Services

- Unaware of what's there
- Too many posters in GP surgery
- Doctors don't know these things themselves
- Good support via Bristol Black Carers

##### Rights

- 'Right to be involved' – not clear!
- 'Right to be listened to' can result in you being able to change an unhealthy environment!
- 'Right to be involved' sounds better to one person than 'right to be listened to'. But could be similar things?
- Confidentiality...can you be sure about it? Not clear from the rights

## **Bristol Black Carers - Young and Caring**

### **Bristol Table 2) notes from the discussion over top 5 priorities**

#### **Mental Health Services**

- Accessibility
- Not enough of them
- Have a comments box
- Should be able to choose your own counsellor
- Not being involved in any decisions about you
- Being passed between services e.g. not meeting criteria
- Waiting lists
- They make decisions to help with the thing they think you need help with. Won't listen to anything else
- "Do you really think you need mental health services?"
- A say in care plans
- Only get help when in crisis
- Not really an option to go anywhere else
- CAMHS is difficult to get into

#### **Child Obesity and Body Image**

- Don't talk about poor body image until it impacts physical health or at crisis point
- "Obesity is always due to laziness/overeating"
- Only helped with body image problems once they get serious eating disorders or other stuff
- Only get help when in crisis

#### **Language**

- Very diverse – not uniform
- Too patronising or too technical
- Not enough communication
- Blame
- Be careful of triggers
- Making assumptions and not listening to explanations

#### **Stress and Anxiety**

- Often just told to 'deal with it'
- School
- Treated/assumed to be simply attention seeking/over dramatic
- Few preventative measures
- Not taught about places to go/coping mechanisms until it has got serious

#### **Transition from children's to adult's services**

- Not clear

- Not fully informed
- Too big a jump
- Not a child but not an adult at 17 years – where are you?
- Some adult services are ‘very adult’

### **South Gloucestershire Table 3) notes from the discussion over top 5 priorities**

#### **Mental Health Services**

- GPs having an understanding
- No one picking up the signs (until crisis)
- Stigma and discrimination
- No access to services
- Short services (time limited)
- Home support (lack of)

#### **Transition** (young carers, mental health, hospitals)

- There not being a smooth transition
- Being in a bubble with children’s services, then it being popped!
- No funding! Or services

#### **Young Carers**

- Discharge – not being made aware
- Young carers not being recognised as next of kin
- Health professionals not speaking to us
- GPs being aware of young carers so they can be more helpful as see them often
- Health professionals have a lack of awareness
- Not all bad

#### **Social Workers**

- Not listening or understanding
- Not spending time with the young carer
- Take control/all of a sudden
- Only coming in crisis

### **Bristol Table 4) notes from the discussion over top 5 priorities**

#### **Obesity and Body Image**

- Pressure on young people to be thin from the media
- Fat people being bullied

#### **School Nurse**

- Unapproachable

- Not there very often

### **Language**

- Not high tech
- Not jargon

### **Safeguarding**

- Confidential
- Feeling listened to
- Trust
- Safeguarding is important but the word is not always understood by young people

### **Services**

- Young people are not taken seriously
- Scary/difficult to make appointments
- Feel able to ask questions and feel listened to
- Doctors/GPs can be intimidating
- Some stigma accessing services at school
- Important for young people to know healthcare professionals will keep confidentiality unless needed to be broken
- Importance of being listened to

## **South Gloucestershire Table 5) notes from the discussion over top 5 priorities**

### **Young Carers**

- Rewarding
- People act differently
- Young carers have a different perspective on situations which may give less a priority to others but being listened to and being involved is important

### **Mental Health Services**

- Anxiety and stress
- Hits a crisis point then they want to know

### **Transition from children's to adult's services**

- Becoming lost in the system

### **Child Obesity and Body Image**

- Too much pressure on young people in appearance
- More stress to worry about
- Become anxious around people
- Peer pressure
- A cause of bullying

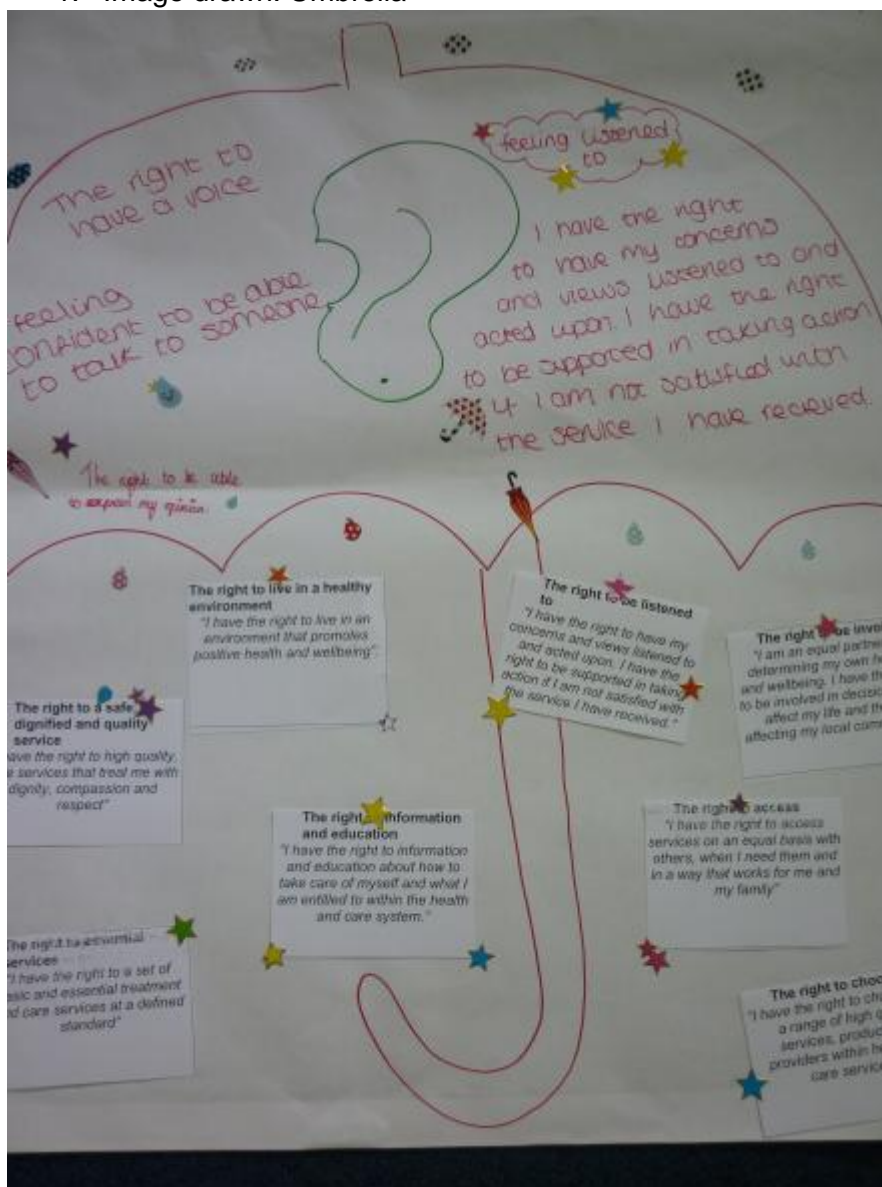
- Self conscious because of other people's views

### **Social Workers**

- Not having one
- Some social workers – being assigned to the family – but often concentrate on the disabled person not the young carer
- Talking too much but no actions
- How do you get one?
- Stigma attached that they will take me away from the family

## Table Notes – Rights Statements: Young Healthwatch event

### 1. Image drawn: Umbrella



Areas: Bristol and Somerset

The following statement was listed as most important: *The right to be listened to.*

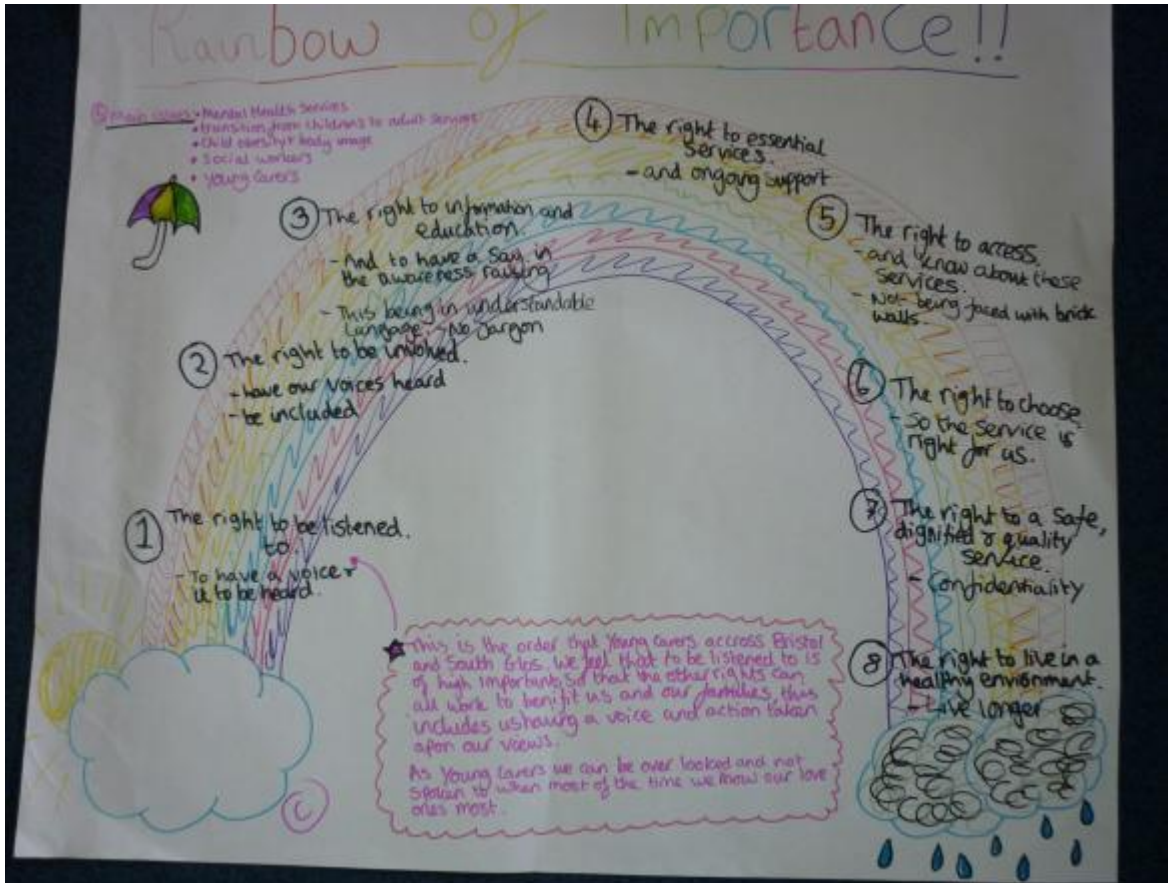
The following statements were also listed as important:

- *The right to have a voice*
- *Feeling confident to be able to talk to someone*
- *The right to be able to express my opinion*

### 2. Image drawn: Rainbow of Importance

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Areas: South Glos and Bristol

The statements were ranked from 1-8 as follows:

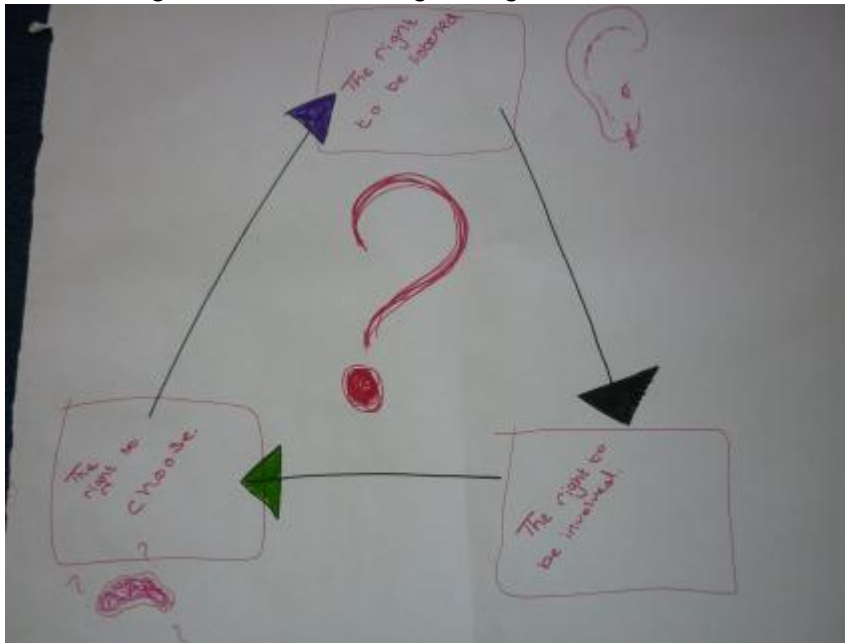
1. The right to be listened to – to have a voice and it to be heard
2. The right to be involved – to have our voices heard – to be included
3. The right to information and education – and to have a say in the awareness raising – this being in understandable language, no jargon
4. The right to essential services and ongoing support
5. The right to access – and know about these services – not being faced with brick walls
6. The right to choose – so the service is right for us
7. The right to a safe, dignified and quality service. Confidentiality.
8. The right to live in a healthy environment – and live longer.

Additional Comments:

This is the order that Young Carers across Bristol and South Glos. We feel that to be listened to is of high importance so that other rights can all work to benefit us and our families. This includes us having a voice and action taken upon our views.

As Young Carers we can be overlooked and not spoken to when most of the time we know our loved-ones most.

3. Image drawn: Interlinking Triangle



Areas: Bristol

The following 3 statements were listed as important, and interlinked:

*The right to be listened to / The right to choose / The right to be involved*

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4. Image drawn: Stars



Areas: South Glos

The following statement was listed as most important: *The right to access*

The following notes were made:

- The right to ask questions and be informed about your own health
- The right to see your doctor when you want to, instead of waiting long period, usually waiting a week or more just to see them – “hurry up!”
- I would like access to education, mental health services, health services, substance misuse and sexual health services
- Chemists can be hard to access
- The right to complain
- I would like access to a healthy environment including access to nature, leisure, social opportunities and a family life free from abuse
- I would like access to multi languages including: interpreters, use different languages including sign language, different forms of information in many different layouts and formats
- Access to education, higher education, like college
- The right to have a complaint because they don't do anything

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5. Image drawn: Artist and Ear



Areas: Bristol

The following statements were listed:

- Communication: listening to your concerns
- Chance to feed back
- Genuine change and action

6. Image drawn: People Building a House



Areas: Bristol

The following statement was listed as most important: *The right to be involved*

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two groups felt that a potential gap in the rights was that confidentiality should be more explicitly included.