

## Summary of young people's evidence

### Why the Children, Young People and Education Committee needed your help

The Welsh Government has lots of plans and policies in place to try and make sure that children and young people get help with emotional and mental health problems when they need it. These services are called Child and Adolescent Mental Health Services. Sometimes these are called 'specialist CAMHS';

- The Children, Young People and Education Committee decided to take a look at whether these plans and policies are working.
- We wanted to meet with children and young people to ask what they thought.
- We've also asked lots of adults to tell us their views – some of them wrote to us and some of them came to meet with us face to face to tell us what they thought.

### We heard from more than 20 young people aged 12-24 from different parts of Wales. The main things we found out were:

- Most young people we spoke to were very negative about specialist Child and Adolescent Mental Health Services (CAMHS). A few said they had a good experience.

### Some of the things which young people told us which weren't good were:

- Young people not getting the help they needed
- Young people waited too long to get any help - this made their mental health problems worse
- The rules were very 'strict' for which children and young people got help from CAMHS
- Being given medication without other types of help (like talking therapies)
- CAMHS services not helping young people to be safe
- CAMHS services not helping young people who have lots of things to deal as well as mental health issues



- When young people reached 18 things didn't work very well to link up children's and adult services.
- Some young people who had been in special hospital units didn't get the help they needed when they were there

### **Some things which young people said did help were:**

- Help from the voluntary sector and projects run by charities
- Having a good relationship with staff and that it's really important to build trust with people who are there to help
- To be given help which makes young people better able to deal with things by themselves

### **A bit about the young people who helped us**

- We met with more than 20 young people aged 12-24
- One young person made a DVD to tell us her views
- Most lived in different parts of South Wales and some lived in North Wales
- All the young people had mental health problems (either now or in the past) and all had some kind of service from or contact with Child and Adolescent Mental Health Services ('specialist CAMHS')
- We didn't ask young people about the details of their medical circumstances but some young people shared their stories. These include lots of different mental health issues.
- Some examples were severe anxiety; autistic spectrum disorder; asperger syndrome; sudden onset bi-polar disorder; depressive disorders and eating disorders.
- Some of the young people had been involved in self-harm, including some young people who had made several suicide attempts.
- Some of the young people had stayed in a specialist hospital unit in the past (an inpatient unit'). A young person (now living in the community) had been an inpatient at various mental health units for 9 years.



–Lots of the young people had other things which might make their lives more stressful - like having been in care; being the victim of sexual abuse; experiencing the death of a parent; being a young carer; being the victim of violence within the home; having a parent with mental health problems; having a disability. One young person told us she was pregnant and happy that she would now be able to focus on her baby.

## What did we find out?

–Most young people were very negative about specialist Child and Adolescent Mental Health Services.

–They said they either hadn't got any help at all - or if they had, it had been from what are called voluntary projects. Voluntary Projects are not the same as councils and governments – lots of them they are paid for by charities.

## A few young people had good things to say

–Some young people said that it would cost the Government a lot less to give them the right help when they needed it.

–One young person said: **'if we thought about what people needed – it would end up saving money'**.

–Young people told us they had felt scared, embarrassed, and unsafe.

–Some young people said that CAMHS services are too structured and 'strict' for young people who might have a lot going on and 'chaotic lifestyles'. Those young people said that services should be set up around what children and young people need - not between the times of 9 and 5 in a clinic or hospital.

–Some young people told us how they had lots of problems to deal with all at the same time – like having more than one mental health issue; being victims of domestic or sexual abuse; being a victim of sexual exploitation; having problems with substance misuse; not many qualifications; no money; and not being given enough help.

–Other young people had done really well at school in the past but their mental health problems were affecting their education. Some schools had been really good in helping



young people with their mental health problems but others were not so good or had not 'picked up' that children needed help.

## Some of the things young people told us were:

'CAMHS is rubbish'

'CAMHS is useless – to make it better you need to start again'

'Why is the Government funding CAMHS like it is now? Let's just give up on these mental health services – they ain't no good'

'Why fund statutory services when other services work better'

'CAMHS needs a lot more staff and a lot of reorganisation of their policies and procedures'

'CAMHS were not very helpful – they were more interested in what my mum had to say than in me'

'They just passed you on to other people'

'CAMHS is just about ticking boxes'

'They are not meeting young people's needs'

'Don't treat us as freaks'

'You just need to help young people understand their minds'

'I wanted help to understand why my childhood sucked'

'Therapy helps – like mindfulness and emotional wellbeing help'

'CAMHS didn't really make a difference'



**'Politicians should extend the period of time for young people to access services – they should fund things better'**

**'Why do we need to have scars on our arms to remind us?'**

**'The way I was treated made me angry'**

**'CAMHS asked lots of questions but didn't listen'**

**'I self harmed at the CAMHS session'** and the young person said they also self-harmed and drank heavily after every contact with CAMHS

**'[CAMHS] told me I am supposed to be getting therapy – I don't trust that it will be delivered'**

**'CAMHS should work with you how you want to work'**

**'Waiting lists are too long – they need more staff'**

**'Your childhood is gone'**

**'Some schools just seem to want to get rid of difficult kids'.**

**'I want help where there are no hoops to jump through – high quality help and people who can work with my family'**

Young People from one project were more positive about their experiences with a specific psychiatrist and with the help they had received from a voluntary project.

**'My psychiatrist is good. I didn't have to wait long to be seen because I was a high priority'**

**'I've had a good experience of CAMHS – it feels like going to the doctors'**

**'CAMHS help you understand and deal with a condition'**



**'Getting into CAMHS is hard – but once you are there it is completely tailored to your needs'.**

## Getting help when you need it

–Lots of the young people we spoke to found it very hard to get any help from specialist CAMHS. One young person told us that CAMHS support is not flexible. Another told us that times for group therapy were very strict.

–They thought there were very 'strict rules' (criteria) for people to get help. Some had gone to their GPs many times asking for help.

–Others felt their mental health problems had got worse because they hadn't had any help when they first needed it.

–Lots of young people had waited a long time for help. Some young people told us they ended up having to go into a hospital mental health inpatient unit because they didn't get help when they first needed it.

**'I went back and forth to GP for years but got no real help'**

**'It's too long to wait to see CAMHS – why can't they help you from the start'**

**'I've been told I don't meet the threshold for CAMHS'**

–One young person said she had told the GP she was suicidal in May but had to wait until December for a CAMHS appointment and by then she was nearly 18 so needed to go to adult services.

–Some young people who had been in care told us – 'we've all seen things we shouldn't have seen and got no help with it'

## Trust in staff

–Some of the young people spoke about adults who had helped them a lot with their mental health.



- Being able to trust and have a good relationship with professionals was really important.
- In one project young people had been given a lot of help by a clinical psychologist who worked there. They felt that she had helped them a lot – when CAMHS services had not.
- In another project, young people told us about how important it was to have good relationships with people who helped with their mental health – and said really positive things about project staff who they felt had helped them a lot.
- They also explained they didn't always trust some staff they had met through CAMHS – because they didn't do what they said they would - or because they were just 'ticking boxes'.
- One young person referred to needing more help from school and for them to understand.
- One young person talked about the time her project support worker had taken to get to know her. This was a lot more time than she had from CAMHS.
- One young person who had faced lots of difficulties in her life including sexual exploitation and a parent misusing substances told us it takes a long time to trust people. She said **'I am not good at talking – they expect you to chat straight away' [...]** **'then they send me to a different person – I have to say it all again'**. Her support worker explained that she had four different CAMHS workers in the past 6 months.

## Crisis / Accident and Emergency

- Many of the young people had been taken into hospital accident and emergency (A&E) more than once after self-harming or overdosing.
- Some young people told us that they had attempted suicide but that this didn't seem to make them eligible for help from CAMHS.
- Some young people had their first contact with CAMHS after being taken to A&E but some had been sent home from A&E with no support.



'CAMHS are here in a crisis and then they are gone'.

'It's all 9-5 and you can't get any help outside these times'

## Whether CAMHS make sure young people get services

–One young person who had experienced trauma after an already difficult childhood had received one phone call from CAMHS and had not heard from them again, 'even though they promised to call back'. The young person said **'five years on and I am still waiting for them to call me back – even though I found my dad dead on the floor – it's not right'**. She had since received support from a project which provides mental health support to young people leaving care.

–One young person told us that they had missed appointments: 'I didn't go to CAMHS as my mum never took me'.

–Another young person told us **'If I don't keep appointments I get struck off'**.

## Prescription medication

–Some of the older young people felt they had been given prescription medication and nothing else when they went to their GPs for help'.

–Quite a few young people told us they were offered strong prescription medication by specialist CAMHS rather than 'talking therapies' or other things that might have helped.

**'My GP put me on medication aged 14 - when I wanted to try talking therapies first'**

**'I was put on medication aged 13'**

**'Take time to build a relationship with us – don't prescribe medication'**

**'They just give you prescription drugs'**



## Inpatient units

- A few of the young people we spoke to who were now getting help from voluntary projects had, in the past, been in-patients in mental health units.
  - Two young people had been sent to units outside Wales.
  - Some of the young people had been on adult wards or general paediatric wards.
  - One young person we met had been in hospital for 9 years. The young person was now getting a lot of support outside hospital and said **'if I had had it sooner I could have lived in my own community'**.
  - One young person reported a very bad experience of an inpatient unit saying **'some of the staff spent the whole time chatting in the office – saying they couldn't wait to get home – it didn't make me feel they wanted me there'**.
  - Of the young people who had been inpatients, some told us they felt they were being 'institutionalised' and being 'held' there until they were old enough to leave.
  - Two of the young people had experienced 'unplanned recall' where they had been moved suddenly to a different unit. They thought this was because it would save money not because of medical reasons.
- 'Instead of getting help we were just given a false sense of reality in residential units';**
- 'They just 'hold you' in inpatient units until you are 18'.**



## Voluntary Sector

- Voluntary Projects are often paid for by charities and some of them are set up to help children and young people. They are not the same as councils and governments.
- All the young people we met said very good things about the mental health support they had from the voluntary projects. Lots of the young people felt they had been given the right help with their mental health in this way.
- Young people told us that it was important to have the same support worker to help with mental health issues.
- In one project, the young people had lots of help from a clinical psychologist. She had run programmes to help young people and they were now able to help themselves much more when they had problems.
- In two of the projects we visited, the five year funding from the lottery was coming to an end. The young people were very upset that these projects were closing or parts of them were closing. They said that the only services that had helped them were coming to an end. Some of the young people were very angry about this.

**'It wasn't for Skills for Living Project we would have got no help';**

**'[Voluntary services] help you to make friends with people who are in the same position as you'.**

- Moving from children's to adult services: For the young people who were nearly 18 or close to that age, they told us things didn't work very well to link up children's and adult services.
- One young person who was reaching 18 told us she kept asking CAMHS what would be happening next – but she told us she still didn't know. Other young people told us they had contact with CAMHS for over 10 years and suddenly 'dropped out of the system' at 18.



## THANK YOU

Thank you to the office of the Children's Commissioner for Wales for helping to organise the meetings.

A big thank you also to the organisations that helped us to meet with the young people:

- Hafal
- Action for Children Skills for Living Programme
- Action for Children Family Intervention Team Caerphilly
- Barnardo's Cyfle - Children and Young People Substance Misuse Service (Conwy and Denbighshire)
- Barnardo's Cyfle – Young People's Advisory Service
- Barnardo's Caerphilly Young Carers Service

Some Assembly Members also visited Ty Llidiard Centre, Princess of Wales Hospital.

Most of all we're very grateful to the young people who gave their time to speak to us – **THANKS!**

