

A summary of evidence from parents and carers

Below is a brief summary of the informal evidence sessions held with parents and carers. Over 25 parents and carers self-selected to take part in the informal sessions after being contacted through organisations that had already submitted written evidence to the inquiry.

Where relevant, we have directly quoted comments that were made to Committee Assembly Members during visits and informal evidence sessions.

Nature of mental health issues experienced

Those attending the parents/carers session and the young people's session were not asked to provide full detail of the child's medical circumstances. We did however learn that they included a wide range of mental health issues including **Obsessive Compulsive Disorder (OCD), severe anxiety, Autistic Spectrum Disorder, Tourette's Syndrome, Asperger, Bi-Polar disorder, Attention Deficit Hyperactivity Disorder (ADHD), Dyspraxia and Eating Disorders**. Many of the young people had been involved in **significant self-harm**, including some young people who had made several suicide attempts. Many of the young people had additional issues which compounded their situation such as being a formerly looked after child; experiencing sexual abuse; experiencing the death of a parent; being a carer; having a parent with mental health problems; or having a disability.

Emerging themes

The majority of parents and carers reported a very negative experience in respect of specialist CAMHS with two of the parents stating they had a mainly positive experience. Given that parents had self-selected to take part in the informal sessions, their evidence is more likely to reflect issues and problems with CAMHS.

Access- referrals and waiting times: Comments included: referrals being rejected 'without explanation'; several cases where GP referrals were rejected by specialist CAMHS without them seeing the child; major difficulties in accessing any support; parents fighting hard to get support; professional parents with medical backgrounds being successful in getting a referral re-assessed and accepted – 'what about parents who can't do that'; having to go through many months of 'box-ticking' to access CAMHS; CAMHS not providing specialist support e.g. to deaf children; 'it all hinges on the diagnosis'; very little or non-existent support. Parents having to advocate and lobby for services – and most of them still feeling in a crisis and not getting the services they need; problems being re-referred back into CAMHS.

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Several parents had sought input from private services. A psychologist working with some young people at one project told us of a 19 month waiting list to receive support from specialist CAMHS in their area. In another area we were told by a professional that the waiting list was 16 months.

Specific quotes included:

- ‘Children and young people don’t get seen until there is a crisis and often not even then’;
- ‘It’s like the process is designed to filter people out’;
- ‘I’ve been back and forth to the GP since my child was aged 5’;
- ‘They are just looking for excuses not to take on a case’;
- ‘CAMHS rejected my son’s referral without even seeing him – it’s very frustrating’;
- ‘The onus shouldn’t be on the parents to fight for services’;
- ‘Everything is crisis driven - we had to do ‘a sit in’ and refuse to leave accident and emergency so my daughter could get help’;
- ‘It’s been a roller-coaster trying to get any help – I work in the NHS and I still find it very hard to signpost my son to the services he needs’;
- ‘Children just sit on a waiting list all the time’;

Support provided: Comments included: very long gaps between seeing psychiatrists; services being delivered through a narrow medical model and a lack of access to talking therapies; children getting a diagnosis but no support; the difference between how physical health issues are dealt with compared to mental health services; One mother (who was not able to attend the informal session on the day) had asked workers at Hafal to tell Assembly Members that her daughter had been placed in Northampton and that this placed a big strain on everyone in the family as the mother could not drive. ‘Clinic based services not meeting children’s needs’, nor the time they are open to help – some mental health conditions have more of an impact in the night.

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Specific quotes included:

- ‘CAMHS say ‘here is your diagnosis – goodbye’ – why is mental health treated so differently from physical health;
- ‘The service is on the verge of collapse’;
- ‘[There is] a significant gap in services at times of crisis’;
- ‘CAMHS seem to ‘wash their hands’ of children and young people’.

Staffing: included many comments about staff shortages; there being no cover when staff go on leave or move to other roles; not enough staff or staff cover; when CAMHS staff are called to emergencies then other children miss their appointments; ‘skeleton staff’ – can’t offer family or play therapy. Because there are no staff and limited resources – parents and carers are bridging the gap. ‘CAMHS staff are not always experts’; CAMHS staff knew little more than the parents about the condition.

Transition to adult services: comments included ‘There is no transition at all’; ‘it’s completely up to me to do it all over again’; ‘my daughter will be 18 soon and I keep asking what’s happening?’

Impact on family: comments that Assembly Members heard included: the ‘devastation’ on the family and the impact on siblings; ‘violence’ from the child towards parents and siblings, and this becoming more frightening as children get older. ‘My child is aggressive because of their mental health issues being untreated and both parents are now on medication because of the stress’. I feel that no-one wants to help. Some parents told us they felt patronised and almost blamed for child’s problems; ‘I’ve been made to feel part of the problem – and I want to be part of the solution’; parents are not given the information they need to help their children and in some circumstances resulting in them unintentionally making the situation worse. CAMHS questioned our parenting and discipline; ‘I despair for the future’. Several parents reported getting no support or respite care. One family had spent ‘tens of thousands’ trying to access services since their child was very young – via solicitors, private medical assessments etc – their child has ended up in an inpatient unit aged 15.

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Parents told Assembly Members: 'Social services only get involved when parents are violent to children - they won't help families when children and young people are violent to parents and siblings'; 'when I restrained my son, social services investigated'; parents worried about the future and what the teenage years will bring; my son is violent to us - his sister is afraid – I have had treatment from my GP because my child has damaged my jaw and has also split my daughters lip – if it was my partner that did it I would get help - 'my son will kill himself or someone else – I can guarantee it'. We are treated by CAMHS as though we are part of the problem. 'I wanted advice regarding whether I should hide knives from my suicidal daughter – CAMHS made me feel like I was just being difficult'; several parents were or had been off work sick. 'There is no support for parents, carers and siblings'.

Impact on children and young people: comments to Committee Members included: our children are missing 'valuable' years of their lives – school, friendships (social isolation); impact on physical health (weight loss); long waiting times to get help – wasted years e.g. from 5 to 12; parents 'pushed from pillar to post' and in the meantime 'no-one is helping my son'; because my child was well behaved in school, she didn't get help – even though she was suffering in silence and ended up in an inpatient unit after several suicide attempts'; when young people are admitted into a specialist unit whether for children or adults, they are just 'held there' rather than receiving treatment; children are told their 'self-harming is not bad enough' to qualify for a service.

Funding / Preventative spend: Several parents noted that their child's care could have 'cost a lot less' if they had received the services they needed earlier – both emotionally and financially. 'My daughter was recalled abruptly from a specialist unit in London for financial and not medical reasons'; 'We have spent tens of thousands as a family' and the cost to the health service would be substantially higher in the end as the young person has ended up in an expensive placement outside Wales.

Schools: There were mixed experiences on the effectiveness of schools and educational psychology services. In the main, families felt their experiences were negative. Parents/carers felt that schools did not have the skills, experience or understanding in respect of children's mental health issues or accessing CAMHS. 'Teachers don't have training', '[my son was] treated as a naughty boy'; 'the secondary school is amazing, but the primary school were appalling'.

Social Services: Comments included: CAMHS don't have any social work support; there is a battle going on between Social Services and CAMHS as to who was responsible for my child; I had to take my son to Social Services aged 15 and leave him there before I got any response or support.

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Voluntary sector / wider support services: Several parents/carers had received very positive support from parenting support groups, but many said that they had found these themselves and there was no signposting had been offered by CAMHS. 'Families have to find this out for themselves'. Third sector projects outside specialist CAMHS were felt to have 'really helped' a number of parents. Many of these voluntary sector courses / projects had either ended or were about to end due to lack of funding.

Communication/ Co-ordination: Comments included that there was no inter-agency communication and it needs someone other than the parent/carer to co-ordinate the care. 'You need a multi-disciplinary team'; 'there is a lack of communication'.

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