# From Seb's mum and the parents of the Children First Coffee and Connect Group

## DEAR DECISION MAKERS

**We stand here today because of parent power. Not the loud, political kind. The quieter, life-saving kind that happens at Children First, where mums – and sometimes dads – share their stories and somehow keep each other going.**

Imagine the scene. We're in the kitchen of a family home, it's the early evening and a mum is sat at the breakfast bar with a cup of tea… gearing herself up to make a start on dinner.

Her son appears, and suddenly, he's in front of her holding a knife to his throat. Asking if she has any parting words for him, as he's had enough. He can't go on.

My child had gone from being bright, funny and full of life to a young person who had suicidal thoughts, anxiety and autistic burnout. Every time I left the house, I returned holding my breath, bracing for what I was walking into. I had to turn down work. I lost clients. The impact was emotional, physical, financial. It was a lot.

We did what most families would do. We went to the GP and we were referred to CAMHS. Many autistic young people are not even given a place on the waiting list.

Thankfully my son was put on the waiting list but we waited years and years. In that time, Seb deteriorated, his anxiety became debilitating. He couldn't leave his room. He stopped going to school and couldn't see a way forward.

Our story is not unique.

Many of the parents at our Coffee and Connect peer group have similar stories of self-harm, neurodiversity and emotional based school absenteeism. A number are supporting children navigating grief after the loss of a parent.

Esme, one of our kids, is autistic, grieving the loss of her father and was also suicidal… and yet was knocked back from CAMHS twice.

Complex trauma, mental health, neurodivergence, grief – navigating these challenges is incredibly HARD.

Our homes become clouded with fear. Each morning you feel sick, your stomach turning, because you don't know what the day will hold. You walk on eggshells constantly.

It rips through the family. The impact on siblings. And the weight on parents' mental health as we watch our children in distress.

I told myself: "Once we get to CAMHS, then it'll be better." But we waited four years… and it didn't work for us. The medical model didn't work.

Seb has an analogy for his CAMHS experience. When he finally met his key worker, his main symptom was anxiety – but there were many other things happening too. He said it was like being in a kitchen with ketchup splattered everywhere: on the tiles, on the walls, across the floor. CAMHS wanted to scrub one tile – anxiety – but missed the fact that everything else was still covered in ketchup.

## AND SO WHERE ARE WE NOW?

Well, Children First has given us a fantastic, trusted advisor who facilitates Coffee and Connect each week. It's consistent – they open their doors every week without fail. For some parents, Children First is the only support as parents they have received.

As parents, we share our experience and learn from each other. One mum shared recently: "the only people that can teach me is you." Meeting other parents who can understand and empathise is very comforting.

Neurodivergence is lifelong and trying to navigate it without support is lonely and exhausting.

Medicalising our neurodivergent children should not be the goal. Children First offers support in a homely, family environment, delivered with an instinctive, sensitive and professional approach.

**You can't help a child in isolation – you have to help the whole family.**

We've all benefited from the whole family support Children First provides: one-to-one sessions, Coffee and Connect, summer activities, Dungeons and Dragons groups, crafting sessions. Children First meet us where we are and shift us from helplessness to hope.

## AND SO, WHAT'S NEXT?

Well, it's baby steps.

Seb said to me the other day: "this feels weird, I'm actually looking forward to things."

And I feel like a more capable parent, who can guide my child instead of fearing for them.

One of the children from the group is now at college – growing in independence and confidence.

These children need time…

**But here is the thing I want you to hear most clearly today:**

We didn't get better because we finally got into CAMHS.
We got better because of early, relational, whole family support.
Support that was compassionate, flexible and built around our real lives.
Support that prevented further crises.

Families do not want to be passed from service to service. We do not want to navigate systems that ask us to fit into their boxes. We do not want to prove we are in crisis before anyone will help us.

We want an approach that sees us as human beings.
We want help early, not after we've reached breaking point.
We want services that work together instead of in silos.

If we do not invest in this type of support - properly, sustainably and consistently - we will keep sending families back into the same cycle of distress, crisis and long waits for clinical services that were never designed to carry this load on their own.

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## WE'RE ASKING FOR A FEW THINGS:

A commitment to sustained investment in whole family support. Not one-year or pilot programmes that disappear when families begin to trust the system.

We want more Children First parent peer support groups and we need to be mindful of the timing of groups to allow working parents to join.

A recognition that CAMHS cannot and should not be the first or only door. Non-clinical, trauma informed and relational services must be available and accessible.

We need an approach to funding and policymaking that puts prevention on equal footing with treatment. Because for every young person supported early, we avoid years of avoidable distress, missed education, family breakdown and escalating cost.

We need more training for teachers and clearer pathways for support that do not leave families lost.

My son is bright, articulate and capable – but now at 16 he has no education or qualifications. And many of us parent carers around this table are in a similar situation. We are not getting it right for every child.

We are all very passionate about this. I know we could talk about our experiences for a long time.

But the reason we are here today is simple. Someone walked with us, not ahead of us or behind us, but beside us. Families heal faster and stronger when we heal together.

Parent power changed our story. Now we need the political power in this room to help us change the story for thousands more.

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**Names anonymised to protect the privacy of the families involved.*