
Stronger Together

Family Event June 2017



Funded by NHS England

Created by families

Background:

Stronger Together is a working group of parents and professionals working in partnership with Bringing Us Together and Respond.

We received funding in February 2016 from the NHS England Engagement Team to organise and run an event for parents who have loved ones in, or who have been in Assessment and Treatment Units.

It was critical that this event was led by parents and the agenda set by the families.

In February 2017, we received further funding, again from NHS England, to run a further event for parents who have had loved ones in (or still in) and Assessment and Treatment Unit.

We sent a flyer to our family networks advertising the event through social media and email. Again, we had an overwhelming response from people interested in attending. Parents applied on line and we contacted each person prior to the event via phone calls, emails and Facebook to ensure we got to know everyone. This was important in holding an event that was going to be an emotional roller coaster and where people would be encouraged to share their hard hitting stories and experiences.

This was, again, a weekend to support families to network and to develop strategies to help them to stay strong rather than resolving individual issues during the event.

The event on June 4th and 5th 2017 brought together parents from across the country along with a group of facilitators. We also welcomed Sue North from NHS England and Dame Christine Lenehan and Mark Gerraghty also came along to discuss their current review into Residential Schools and how the families could engage with that.

We used the event to listen to each person's story and provided guidelines to ensure that everyone had the opportunity to share their experiences. We were able to include themes determined by the families' agenda and NHS England that had been set prior to the weekend.

During the weekend there were tears, laughter, emotional support, bonding, networks and sharing of information. Some parents had never met another parent with similar experiences, many had come feeling isolated, angry at the system, and some were not in a good place emotionally.

Themes:

The main themes gathered throughout the event included;

- What were the issues in parents attending an overnight conference
- What made them smile about their child or young person
- Why their child or young person was admitted to an ATU
- What they expected or hoped for when their child or young person was in the ATU
- What actually happened

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Attending

What were the issues families faced

- Life follows you here – not easy to get away from things
- Reminders and calendars way in advance needed
- Staying one night would have been a dream but no way!
- All the planning went because of the terrorist event in London
- Difficulty in sorting out PAs
- Lots of instructions left for PAs, partner and family
- Had to ask my son to return to the hospital where he is early and having to try to explain why
- Incident yesterday and was unsure of where my priorities lay – feeling guilty
- Family commitments including elderly mum to care for
- Very difficult – needed to ensure non disabled daughter was home to help out
- Make sure my son and everyone had a good day the day before I left to make it easier to go
- Not going to hospital to visit son and feeling guilty
- Child care of other siblings with needs
- Reassurance that the event would be possible and would have an outcome
- Logistics leaving everyone at home overnight
- Very difficult needed extra help to go, planning an overnight stay here is stressful
- Organising care for son
- Emotional worry in leaving him and the risks when I am not there
- Usually visit my son each weekend but not going to this time
- Organising support for my son and siblings
- Sneaked away this morning and had to be very organised to leave
- Ensure that all the meds were ready when I left
- Change in routine for me, catching the train on my own, losing family time, travelling here

Our children

What makes you smile about your child?

- His smile
- He says it as it is
- Never loses his sense of humour
- His “literal” world
- His energy
- His lust for life
- Comfortable in his own skin
- His passion for music
- He still tells me he loves me
- When his progress is acknowledged
- She’s a mini-me!
- He’s incredibly handsome
- He has the clearest gaze
- Great judge of character
- His love for food
- His love for socialising
- He gives the best hugs
- His adoring smile
- His gift of being non-judgemental

Going into an ATU

Why was your child or young person admitted?

- Lack of support
 - Told to call “999”
 - Told to go to Accident and Emergency
- Psychiatrist was old school and recommended a unit
- My lack of knowledge and information at the time
- Child going through puberty
- Anxiety at high levels and receptive language difficulties
- Unwillingness of LA to set up bespoke package for adolescent
- Psychiatrist involved began medicating anti-psychotic drugs
- Tribunal ruled he should go to the unit even though the CTR recommended a bespoke package
- Parents ignored
- Self-harming and at risk
- Breakdown of support
- Challenging behaviour linked to missed physical illness
- Intransigent manager
- Insane systems
- Lack of support from CAHMS
- As a parent I feel like I have a huge lump of guilt inside me
- We asked for a referral to a local hospital bed but told no and had to go to an ATU
- Unknown to services
- Huge crisis and sectioned
- Chucked around on a Section 2

- Lots of triggers caused a crisis to happen – rise in anxiety
- Service provider “wobble” and could not cope
- Very inexperienced staff working with young person
- I was afraid to speak out
- Hospitalised for 3 weeks locally and then due to no specialism in the area ended up in an ATU away from home
- Absconding away from home and train hopping
- Limited input by CAMHS
- Groomed due to his vulnerability and autism
- Crap support and no help as a child
- Little help with behaviour and anxiety
- Chronic anxiety around noise
- Psychiatrists ignorance and neglect
- Care home inability to support
- Lack of legal advice
- Social services unable to help
- Not being listened to by the consultant psychiatrist when we eventually did see someone
- Not supported in the community
- Severe reluctance to diagnose autism by the arrogant professionals
- Being offered medication that probably made the situation worse
- Individuals writing Sections in receipt of bonus payments
- Not to belittle patients with mild LD who are forensic, but our boys with more severe LD and no capacity are a different kettle of fish
- Lack of housing available
- Lack of expertise in package
- Being ignored as a parent
- Not having expert solicitors available

What did you hope for/expect?

- That they would realise it was the support (or lack of) that was the problem, not him
- That they would be person centred and autism friendly
- That he would NOT be traumatised by the experience
- I was told he would get therapy and it would be short term
- Happened so quickly and told that this was what our son needed
- Told he would be assessed and treated
- No hope and a situation that was damaging for my son, the only hope was to get him out
- Help around issues caused by abuse – the self injurious behaviour to stop
- That he would get the right support
- That we would get our boy back
- To find out why he had seemed to change so much
- That they would keep him safe whilst he was assessed
- The Cavalry!
- A proper informal assessment so we could get him home quickly
- Short term stay and therapy and to come home asap
- In depth analysis of incidences by service provider
- Treatment of anxiety and emotional regulation
- Intense therapeutic input
- Development and progress with intense support
- Support close to home
- Accountability – and responsibility (No accountability – when will they actually do the job they are paid to do)
- Service level agreement
- Observation of the problems we were describing
- Being believed
- Support to help him leave

What Actually happened?

- No visible support
- 18 months of hell for him and us
- Introduction to a world we did not know existed
- Deterioration massive in all areas
- More unsettled
- Locking up his things
- No food
- Locked himself in his room and too scared to come out
- Rooms raided nothing dangerous in which was scary for him and no privacy
- Not following his strict gluten free diet
- No therapies promised
- Adult unit and he was only 18yrs
- No support for his communication eg doing diaries
- No symbols or any alternative communication support
- Kept locked up for 9 years
- Over medicated
- Self injury behaviour resulted in physical restraint
- Communicative and distressed behaviour seen as Challenging Behaviour and ignored as communicating his health needs
 - After much fighting admitted to hospital – induced coma, swollen testicles, none of which were noticed during his personal care. Now out but dying tragically of testicular cancer at home.
- Abused, physical and mental neglect, over medicated and lied to
- No resolution – my son is still there
- Overdosed on Lorezapan – regular occurrence
- Comes home weekends without the drugs as doesn't need them with us

- Police conviction
- Heavily medicated
- Stayed longer than was promised
- Mental Health Act failed to support
- Promises and nothing
- Restrained
- Prison mentality
- Every Friday we would have to wait by the phone to see if he had behaved enough to come home for the weekend
- A lot of the time I wanted him to stay longer but they only sent him back with the 3 days medication
- Put on weight and feeling ill with the meds
- Mum unable to see child
- Child diagnosed with depression
- Heartless and dehumanising
- F**k All
- Placement was paid for to attend 7 days a week by NHS however, when he came home for 3 out of those 7 days there was no funding to pay for any support at home.
 - What happened to the funding for those 3 days he wasn't there?
- A specific programme was promised with psychological input –nothing happened
- Daily restraints
- Overuse of medication
- Assaulted daily by peers
- Sectioned and emergency admission – assessments were then done which could have been done in the community, physical illness because of crisis and being in general hospital
- Family not consulted so treatment was inappropriate
- Lost the house he needed to get out 10 months into the process
- Service manager disengaged

- Everything grinds to a halt and no one seems to care how to get it moving again
- Containment
- Loss of skills and two years of nothing
- More anxiety and learned behaviour
- Over medicated
- We were not believed – he was abused by staff member, little happened and severe reaction to drugs
- Over medicated and developed epilepsy
- Financial strain on us the family
- Stress on relationships
- Husband had to give up his job in our fight to get son home
- They took our higher mobility off us and we had to give back the car
- No DLA
- Carers Allowance stops
- If over 18yrs no expense
- If under 16 years no expenses because he was not a looked after child
- Professionals lack of information and knowledge
- Lessons not learned

Top Tips for Other Families

- Benefits when your loved one is in hospital:
 - DLA – may lose Motability car
 - PIPs – care component stops after one month (despite still having to pay for clothing, petrol costs to visit far-flung hospitals and hospital asking for money weekly)
 - PIPs – mobility component continues, so you don't lose their car
 - Employment Support Allowance – does not stop
 - Entitlement to and benefit knowledge usually gained from other parents.
- Have a spare phone for when the hospital demands you leave your phone at reception
- CCTV at home enables independence, low-arousal monitoring, alerts if crisis is looming
- Have a “low-arousal” safe space at your home for your child/young person
- Having a personal budget – but it needs to be flexible
- Decent respite
- A safe room for crisis management
- PAS, staff well trained in Positive Behaviour Support
- Pas, staff paid well and feel valued and supported
- Books & Approaches
 - Phoebe Caldwell – Intensive Interactions
 - Andy McDonnell – Low Arousal
 - Intelligent Kindness
- Support from friends and family
- Trust your instincts
- Always get a second opinion
- Get help from those you trust
- We are stronger together – help and guide others in your situation
- Keep speaking up

- Keep a diary, include promises made, conversations, meetings, behaviour, etc
- Apps are available to record phone calls – helps your child to have a voice and also means promises made on a phone are available

Feedback:

- Thank you for organising another amazing event!
- i appreciate all the effort you all put in Again thankyou to all involved xxx
- Thank you so much for all the effort you put in to today i enjoyed today so much made some great connections esp sue north from nhs england what a lovely lady she is thank you for inviting me xxx
- Thinking about the experience – there is hope!
- Having the opportunity to speak to someone from NHS England
- Individuals here today who have inspired me
- The parents' bravery, dignity, energy and tenacity
- Good facilitators
- Hope
- In awe of the Bloody Awesome Parents here today
- Meeting lovely people
- Keeping each other brave and resilient
- It keeps me going
- Meeting new people
- People are listening more to us
- Catching up with those who support me via social media
- We know more than we than we think we know
- I was moved
- People understand me here

- Thank you to the facilitators and Stronger Together team
- We are not alone
- Sharing our knowledge
- We share the same feelings including our anger
- This event has made me stronger
- We are all fighting for the same thing
- I am just going to carry on fighting and know that I am now not going to do it on my own
- The stories are really sad and depressing but by all of us being together and seeing so many feisty, clever, articulate and strong parents in one place we are taking steps in the right direction
- Before I used to leave home and go to Birmingham to see Josh. Now I am leaving Birmingham to go home and see Josh!
- Genuinely and collectively we can turn this around!
- So good meeting so many like minded people face to face
- The strength and being with so many amazing parents blows me away
- It is so special to be in a caring and supportive environment
- Hearing the stories from one another gives me strength
- We are heading in the right direction
- There is actually support! From one another!
- Getting practical ideas and top tips from other parents
- It has given me the opportunity to be with others and to think about the future
- Managing to laugh between the horrendous stories
- I am determined they are not going to get away with it.....
- I have got fire in my belly now!
- We are definitely Stronger Together
- Seeing some of the same faces as last year and welcoming the new brave families attending
- MAKE THE MOST OF NOW!

- All of you are amazing and I am fortunate to know you all
- It is a privilege to be here
- Parents are the ones who will make the change
- As a mum who is not where you are but could be in 5 years you inspire me.
- Believe in myself again, had started to question myself.
- So nice to get together – it is lovely for me
- Bloody darn sure we are going to have ACTION
- We are going to continue to help individual families
- Planning for Dame Christine Lenehan to come to Oxford to visit families and see what we are doing
- Hoping that Christine will make the link with disabled adults and families
- What a great meeting of wonderful strong inspirational people these past few days in Birmingham. We have all connected through these last few years because of our children and their journeys. The best medicine for us parents is to come together and try and change things. I'm proud and privileged to have you as my friends.
- Bringing us together, stronger together for our Children.
- Starting to feel like a tribe!
- Thank you for another outstanding event!