
Stronger Together

Families talk about their experience
of independent hospitals

Justice Together Project



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Experts by Experience November 2016

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Background to event

Meeting with families on 30th November 2016 held at National Children's Bureau, London.

We have heard so many heartbreaking and horrific stories over the last few years from families who have loved ones held in inappropriate in-patient settings. We decided to focus on two in-patient settings – Hospital X & Hospital Y. Due to the number of people we have met with similar experiences we felt the bad practice their sons & daughters were subjected to was far more than coincidence.

The anonymity of both hospitals and the young people and families involved has been preserved throughout this short report.

We liaised with Challenging Behaviour Foundation and Respond to send out our invitation to as many families as possible. We shared the information through social media and through our networks including Choice Forum.

We had a number of responses from people unable to attend due to personal circumstances. Many of the parents and family members are unable to travel long distances and face incredible amounts of stress. Many have tried for a long time to challenge the system and have put in formal complaints, serious case reviews and are now thoroughly despondent, lacking energy and can no longer “fight” back. Their individual battles and experiences have led to their own post traumatic stress, anger and tiredness. Some of them have had huge expenses as a result and many are unable to work.

We received a small grant to pay for travel costs and expenses and are very appreciative to The Experts by Experience Programme through Choice Support for enabling this to happen. Kim Arnolds was able to attend our meeting and we value her support.

Three families attended have had personal experience of Hospital X and two parents attended with lived experience of Hospital Y.

The wide-ranging discussion was necessarily limited by the short length of time we had together. The topics that arose reflect the most pressing concerns of the five families attending. There are many other concerns we were not able to discuss within the time constraints.

Each of the sections below gives a summary of the main topics of conversation, illustrated by direct quotes from family members, & followed by recommendations relating to that particular topic.

The main themes discussed include:

What goes wrong to ordinary children loved by ordinary families?

Being sold the placement

Accountability

Medication

Human rights issues

Care Quality Commission

Parent issues

Transition

Best Practice Award

What goes wrong to ordinary children loved by ordinary families?

The main question haunting families is that of how they have ended up in the situation they find themselves in. The burning questions for all participants was: “How do we prevent children and young people ending up in independent hospitals such as Hospitals X & Y?” “What services are there in our local communities that could have helped prevent the admission?” and “How can we prevent this happening to others.”

There was a sense of despondency and frustration at the enormity of the task in hand if we are to make a difference and halt the trend of sending young people to such hospitals. And the shortage of funding in children’s and mental health services gave further fuel to the general despondency.

There is a commonality of things going wrong around the point of transition from home to hospital setting:

“Our package of Direct payments didn’t prevent a crisis as it was not enough – it went from £180 a week on a direct payment to a placement costing now £8,000. Could we not have tried something in between?”

“We had access to a voluntary organisation sports club which was very successful due to their person centred approach. Then he went into an expensive institution with professionals who can’t manage him and who are trying to fix him”.

“My son was ill – he had undiagnosed epilepsy and started having seizures at 6yrs old. It was not until he was 9yrs old that he had an EEG. The wrong medication led to challenging behaviours and the school struggled. At 12yrs old he moved to a school with good autism input and the seizures stopped, he was enjoying life, doing sports and mixing well. At 16yrs old the seizures started again and he ended up being excluded from school and going into a residential placement. His medication was going wrong and his behaviour got worse. At 17yrs old he moved into a home and was having psychotic experiences which made him really ill. They ignored the epilepsy and did not know about his fits. In 2012 he was finally diagnosed by a private neurologist and it was disgusting by this time what high levels of medication he was on. He was physically abused and it was medical negligence.”

“My child was gentle and non-challenging. She is deaf and the school she was at had no signing and no understanding of deafness. I was ignored. She was expelled at 12yrs old and sent to a special school 5 hours away. They paid in those days £12,000 a year but would not put in any support at home. At 13yrs she was on medication and drugged to fit the environment. They would not have her there without the medication. I never saw her mobility allowances as that went into the residential placement funds.”

“I hadn’t slept for 16 days. We then hit a crisis that lasted 3 months. Parents worst enemy is exhaustion”

“My child was not known to adult services, non-existent transition and a quick fix was sectioning. I had no idea what that meant or what the consequences would be”

“For the rest of my life I will never forgive myself. I made that call for help. I said I can’t manage any more. He was 18yrs old.”

“ There is an expectation from parents that if you go to an autism specific hospital, there will be a range of therapeutic options. At Hospital X, my son had his anti-psychotic medication tripled in dose. When he left Hospital X and went to a new hospital on this horrendously high dose, it was reduced by two thirds within a very short space of time. And yet, nobody seems to care about information like this.”

“ They told me to leave him because he was so ill and would never get any better. He is now out and about in the community & has a good life. He is not on medication any more.”

Recommendations

Raising families' awareness is vital to prevent young people being taken to places like Hospitals X & Y. Most parents and family members have little knowledge of their rights and what might happen in a crisis. The information and training for families needed includes:

1. **Training and guides on being placed on a section through the Mental Health Act – find out who is already doing this and what is available eg Mencap and CBF. Can this be on the seven days of action website?**
2. **Courses for parents such as the new Expert Parent Programme with a focus on children with learning disabilities and autism**
3. **Courses for foster parents around crisis and prevention**
4. **Raising awareness with families through parent forums**

Being sold the placement

Families told us that it was all too easy when they were in a crisis situation to put all their trust – naively and blindly – in professionals who they assumed had the knowledge of placements and programmes that might meet their child's needs.

"I was naïve – I had no awareness when he was in children's services. I trusted the professionals. At 18yrs old we struggled with his transition – no one knew where he fitted. The Learning Disability Team didn't know him. They suggested he went to a local assessment and treatment unit and that it was set up for adult life. They would do an assessment with experts such as an OT, psychologist and his medication would be looked at. I had no experience and never doubted. But it was a bad culture from high up."

"Social worker is responsible for the transfer. Often they know very little about in-patient settings and are "sold" the institution through the marketing, often heavy in propaganda."

"My son was supposed to only go in for 6 months but ended up being there from 1.7.14 to 5.5.16. They made him too ill for him to move on."

Families told us that the experience was akin to social services dumping their loved ones and then washing their hands of the situation:

"I was sold the inpatient placement. I had no option, he was just sent there, I had no advice. He was sent by the social worker to a residential placement that had already been shut down and then was allowed to re-open with the same staff. When I went to look round they only showed me the best bits and the staff were "charming". It was under investigation and I didn't know. I would visit him and take him out. He was drugged and would come home looking like a tramp with no haircut and stinking."

“It was a new place sold on lies. It was glossy marketing. Social services were glad to get rid of him and to sign the cheques. They told us one thing and sold us another. When he was transferred staff weren’t allowed in from the old place to the new house. They took him miles away on his own and told him he was going on holiday!”

And family members told us how disappointed they were to find that the expertise they had been told about simply does not exist:

“Hospital X removed my son’s diagnosis of autism. But since he has left, he has had that diagnosis reinstated. Hospital X said our son didn’t have epilepsy. My son got so ill with epilepsy, no-one wanted him.

“Hospital Y is not fit for purpose for people with autism. The approach at Hospital Y seems to be – leave the young people to see what happens, and then say how bad they are and make restrictions.”

“Some of the staff at Hospital Y treated our son more like a prisoner than a patient. We wonder what training they have had. We noticed a high use of agency staff. An 18 year old boy was left in charge of our son’s unit (10 people in that unit). The charge nurse (who was the 18 year old’s dad) was in charge of another ward at the time.”

“We weren’t told about advocacy. And then when he got an advocate, the advocate wouldn’t talk to parents”.

“The psychiatrists were not autism specific, and there was no accountability or transparency. X’s psychiatrist was an expert in forensics!”

“He lost a lot of weight very quickly. Hospital Y told us it was due to healthy eating. But we then discovered that he wasn’t getting up in the morning, and wasn’t eating meals. Staff told us they couldn’t re-heat meals due to health and safety.”

“We showed parental concern and staff at Hospital Y thought we were being hostile and left the room”

“2.5 hours of education provision was planned in a week! He didn’t get up in the morning, so missed them all. He had been doing course work for GCSE maths, but came home with exercise books showing that he was matching numbers to words.”

“Behavioural systems in place to try and regulate behaviours. No personal motivation. And, in any case, a behavioural system is not appropriate for our son.”

And finally, when a young person is admitted, all participants found it incredibly difficult to get their loved one out again:

“There is a lack of incentive to get young people out of Hospital Y”

Recommendations

1. **Discuss the trip advisor ideas on in patient settings, hospitals with comments on 7 Days of Action website**
2. **To work with transforming care partnerships to help define what a good placement/support looks like**

Medication

A common theme amongst the family members in the group was around the concerns of the use of medication. Loved ones were exposed to one or more antipsychotics, antidepressants and benzodiazepams. Some on high dose, high use of PRN and on these drugs for many years. There was a definite message coming through the accounts people gave that medication was being commonly used as a method of containment.

Further concerns were expressed around the lack of monitoring and acting on side effects of prescribed medication. Family members described how they had tried to voice these concerns to the Responsible Clinician and were commonly met with little empathy or compassion, especially around the use of depot injections.

There was a lack of verbal and written information given to family carers explaining the use of medication, alternative interventions and choice. Family members reported several drug errors and loved ones found over sedated when visiting. Family carers who attempted to challenge these findings were seen as challenging, being difficult and problematic.

Caregivers raised concerns about the increase in blood sugars, liver function levels, weight gain, emotional bluntness, reduced cognitive performance whilst an inpatient and physical needs not met. Again, the family care giver was perceived as been difficult. Interestingly, some carers in the group reported once their loved one was discharged home or to community supported living setting that a marked improvement was noted. Improved cognitive functioning, and once medications reduced or stopped the blood sugars and liver function tests returned to normal levels. Clearly, inpatient environment combined with multiple, often high dose medications proved stressful for loved ones and difficult for carers to challenge as loved ones were detained under the mental health act.

It is clear that carer involvement is important to ensure their loved ones remain safe and receive high quality care.

With respect to CQC inspections, it seems that pharmacists are not necessarily included. Family members felt it is important that pharmacists scrutinise past and current prescription charts; quiz clinical staff about the medications they administer; and take note of side effects by monitoring any contraindications etc.

Families told us that it seemed to them that staff knowledge about medications is often minimal. It was reported that this general lack of knowledge in relation to medications was worsened by the high use of agency staff administering these drugs. Families want assurance that drugs are not administered by poorly trained agency staff.

Accountability

Parents report how they struggle with the lack of transparency and accountability. They told us this makes it difficult for them to try and make things better for their loved one. The constant need for accountability and the lack of response is not acceptable and leaves young people vulnerable and at great risk of harm. Families asked us who holds the ring for each individual child?

“Commissioners refused to speak with us when we tried to take our concerns to them. They told us it was ‘our policy not to speak with parents.’ When I was trying to report what was happening in Hospital Y.”

“The social workers and others who make the decisions don’t actually know my child.”

Human rights issues

Family members told heartbreaking stories showing how their loved one was being treated as sub-human:

“Disabled people are seen as a set of behaviours and not as a person.”

“We have to prove that our children are children and have a right to a valued life”

“My son had never been restrained in his life before entering into Mental Health Services. At Hospital X he was subjected to numerous lengthy floor restraints during which time he was pinned to the floor by up to 10 people. This was never questioned by social care. His longest period of restraint was for 11 hours. During this time staff were relieved of their restraining duties, but my son had no such relief. In the 3 years since he has been out of Hospital X, my son has not had to be restrained once. This evidence has been taken to CQC, but not seen as significant.”

Care Quality Commission

There was a great deal of scepticism about the role of the CQC:

“Who are they? What is their vested interest? Visits from inspectors are not independent. No spot checks and in patient settings are given plenty of notice.”

“Are they protecting the people or provider?”

"Freedom of information does not apply to private establishments."

"Those ATUs and independent hospitals that have been investigated are still believed. Why?"

"How can an institution get a "good" when there are people who have had serious case reviews against them?"

"I find it astonishing that a mental health unit would be more equipped but in fact they can't cope at all"

"My son was in an ATU run by [name of group] – I was under safeguard. He was in real crisis and very sick and was in hospital loads of times. Medication was increased and he was transferred to Hospital X for 6 months. We were ignored by NHS and social care. Our own social worker left. The responsible clinician at Hospital X put in a complaint about the neurologist to get rid of him and was not interested in following the neurologist's plans. NHS and social worker/nurse agreed with the responsible clinician which made me and my daughter so upset as we had not backing from anyone to help us."

"The responsible clinician has been referred to GMC but still practices and destroys people's lives. How can CQC not do anything about that?"

"Hospital Y had a report saying it 'required improvement' but it was still allowed to open a new unit'

"Responsible clinician lied to us and told us the hospital was going to get an 'outstanding' from CQC"

"Hospital X gets good ratings by authorities – how can this be when our sons and daughters have such awful experiences there?"

Parent issues

A common sentiment within the group was the way the views and wishes of parents were marginalised. Family members reported they were completely at sea, and often felt they were treated badly:

"Only the professionals valued not the parents"

"I didn't know what a 28 day section was. Sold in a positive way and that he would have had more rights"

"Supposed to be protected in section 3."

"Parents are told that you are the nearest relative but that means nothing"

"We said NO but were told we did not have a choice"

Best Practice Award

One of the hospitals families had experience of has recently won a national award. We were shocked and in disbelief that this award was given at the same time as disabled people and their families were being traumatised by the treatment received there. It raises the question, once again, of the differing views of those on the receiving end of services and those running those services. Families concern around such awards being given out with no reference to their experiences comes from their dismay that other families might be drawn towards a specific hospital as a result of the award. And then may experience trauma similar to their own.

Conclusion

This report is a short summary of a discussion between a small number of parents with experience of two independent residential hospitals specialising in the treatment of people with autism and high anxieties. Although the numbers of participants are small, we know from our previous work (<http://bringingustogether.org.uk/reports/>) that the issues resonate with and reflect the concerns of many more individuals and families across the country.

We are looking forward to the publication of Dame Christine Lenehan's report on the care, support and treatment provided to children and young people with complex needs (and behaviour that challenges) involving mental health problems and learning disabilities and/ or autism. We hope that this report will open the door to new ways of working based on the needs of children and families. We also hope that the messages from families outlined in our short report will be listened to and taken into account as new developments emerge.