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# Stronger Together - Family Event

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Justice Together Project with Bringing Us  
Together and Respond



Event funded by NHS England  
June 2016

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# Executive Summary

How do children with Autism and/or Learning Disabilities described by their families using words like “loving, kind, caring, funny, gentle giant, sense of humour, makes me laugh” end up in crisis and within the setting of an Assessment and Treatment Unit?

What goes wrong and how do our children, young people and families end up going through these traumatic, confusing, debilitating, disempowering and, occasionally, fatal experiences?

We know there are strong feelings of resistance amongst the disabled community and families who have loved ones with experience of Assessment and Treatment Units. We know that professionals, services, social care and health are working together through the Transforming Care Agenda to decrease the number of beds used and to enable people to live within their communities.

However, the change is too slow for individuals and we hear far too many horror stories of the abuse, dehumanisation and maltreatment. We believe passionately that this cannot go on. Families are saying that there is an urgent need to stop medicalising learning disability and autism and stop sectioning people under the Mental Health Act who have these conditions but are not mentally unwell. Parents, families and their supporters are becoming increasingly vocal across social media in relation to this issue and are coming together as a community in order to challenge this.

It is time that our communities had strong person centred values and a shared understanding that young people with Autism and/or Learning Disabilities have the same rights to lead a fulfilling and meaningful life as everyone else. This is a matter of human rights.

Justice 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. Using our national networks and knowledge we contacted a group of skilled, compassionate and experienced parents of disabled children/young people to facilitate the weekend. It was critical that this event was led by parents and the agenda set by the families.

We sent a flyer to our family networks advertising the event in February 2016 through social media, email and NHS England’s Contact bulletin. 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. During direct contact with parents we were able to clarify how the event

would run so we were clear on meeting needs and expectations over the weekend. This was 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 5<sup>th</sup> and 6<sup>th</sup> 2016 brought together 29 parents from across the country, 12 parent facilitators, a local NHS psychologist and the Chief Executive from Respond. 12 parent facilitators were critical to ensure people remained safe and well supported whilst sharing their emotional stories. 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 Engagement Team 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;

- The crisis happening in the first place,
- parents not listened to,
- lack of autism understanding,
- imbalance of power,
- sectioning,
- police involvement,
- Accident and Emergency services,
- the Mental Health Act,
- medication,
- complaints,
- Clinical Leads,
- Care and Treatment Reviews, and Discharge
- Parents being blamed rather than seen as a resource.

## Recommendations:

After listening and asking questions over the weekend and continuing our consultation with parents over social media we recommend that:

- Families are involved with further work with NHS England and the Transforming Care Partnerships to inform future policy and practice
- Families are involved in having a voice to highlight the impact of early years, as well as the family journey through education, health and social care
- There is a need for linking in early prevention and crisis happening with young people being in Assessment and Treatment Units
- Investment in early prevention rather than expensive indefinite incarceration
- Use results of the recent "Avoiding Crisis – A Parent Survey on Support Needed 2016" to develop solutions to feed into work from Building the Right Support a National Plan (<https://www.england.nhs.uk/wp-content/uploads/2015/12/build-right-support-ant.pdf>)
- Support continues for families through:
  - Bringing families together for peer support and to share stories and experiences using models that are already being used by family leaders. Families will need support to do this.
  - Parent led training early on for parents such as empowerment and resilience courses
  - Social media and website support for campaigning
  - Crisis helpline run by an organisation with experience of dealing with crisis that can offer emotional support as well as practical
  - Justice Circles as a co-ordinated model of support (See attached).
  - "Go to Place/hub" for information, signposting, top tips, legal advice and resources for families going through crisis and those with loved ones in ATUs
- Up front investment in community care and ring fencing of money allocated to "Mental Health" and accounted for
- Appointment of ASD/LD Commissioner or Autism/LD Tsar, either nationally or regionally

- Personal Budgets to be in place for families and support provided to make this happen including Personal Assistant recruitment
- Awareness of NICE Guidelines amongst professionals, services and shared with family members
- An acceptance that Assessment and Treatment Units are rarely the answer and should only be used after all other options have been tried and with the full support and understanding of what this means
- Discharge planning should truly start on admission to ensure minimum stay in Assessment and Treatment Units and secure units. These should be supported by Care and Treatment Reviews every 6 months
- More evidence needed to be gathered where Assessment and Treatments actually work to ascertain what makes the difference
- Understanding of the impact the ATU has on both the adult and their family – we feel that both experience post-traumatic stress and that this is a huge mental health issue that is not treated as important in a successful discharge
- Urgent need for in-depth training in Autism, behaviour that challenges and learning disabilities
- Independent advocates needed
- Regular reviews of use of medication
- And finally: an analysis of the overall system and the key pressure points to enable more effective targeting of money

# Background to Stronger Together

The campaigns 'Justice for LB' and 'Justice for Thomas' have touched the hearts of many people both involved in the ATU and secure experience and external to this. The two young men, Connor Sparrowhawk and Thomas Rawnsley, both died within the health and care systems of our country. An increasing number of people and supporters have joined their families to seek answers and fight for justice.

## Justice Together

Bringing Us Together ([www.bringingustogether.org.uk](http://www.bringingustogether.org.uk)) and Respond ([www.respond.org.uk](http://www.respond.org.uk)) have been working together since 2015 on the Justice Together project. Listening to families and supporting them to achieve their aspirations is a key component of the work of Justice Together; as is providing evidence of parents' experiences. We know that families are desperate for support, advice and information. They want their voices and views heard; they want their loved ones to have voices too, and they want to be listened to, asked questions and to have commissioners and NHS England responding and feeding back to them. They want to be equal partners in the journey and experiences of their relative.

Within Justice Together experienced parents and individuals work together to ensure that families are supported to address their current crisis issues and to prevent further crises happening. Justice Together is absolutely passionate about disabled children and adults leading meaningful lives in their own communities, near to their loved ones, supported by compassionate and skilled community members and support staff.

Social media activity and connections between parents and families has led to a growing awareness of the apparently increasing number of very worrying stories. Examples include young and vulnerable people – often with Autism and/or learning difficulties - being detained under the Mental Health Act; young people being physically restrained, resulting in deteriorating behaviour; excessive use of drugs to control behaviour; parents, carers and family members having to travel the length and breadth of the country – sometimes for very short and controlled periods of contact. Parents are often struggling financially, finding their own mental health affected through chronically high stress levels. They face confusion, uncertainty, isolation, exclusion and exhaustion.

Fortunately, we do also hear about the success stories of young people coming back into their communities and being close to home. However, as we hear more and more family stories, it has become increasingly apparent that this desirable outcome is often very difficult to achieve; almost elusive.

## Stronger Together:

Bringing Us Together and Respond formed a working group to apply for funding from NHS England Learning Disability Engagement Team. The aim was to invite parents to come together to share experiences and to identify actions that will help to make things better for them and ultimately for their loved ones when going through the experience and process of Assessment and Treatment Units (ATUs). This we called the Stronger Together event.

We also wanted to consider the fundamental question - **what can be done to prevent young and vulnerable people – often with Autism and/or learning difficulties - being placed in such institutions in the first place?**

To advertise the event, we sent out information through our networks across social media and to organisations we connect to, as well as the NHS Learning Disability Engagement Team bulletin. Within days we had emails and interest from a number of organisations and parents of disabled children and young people wishing to attend. Due to the high levels of interest we agreed that we would prioritise the parents we invited to the Stronger Together event primarily on the following two criteria:

- They currently had loved ones far from home in hospitals and/or Assessment Treatment Units
- They had recently experienced their loved ones being far away and who are now back in the community

Below is the promotional leaflet that was distributed:

**JUSTICE TOGETHER**  
WE ARE STRONGER TOGETHER

- ★ For families with children and young disabled people who are or have been in Assessment and Treatment Units.  
Families attending will help to set the agenda for the day
- ★ Le Tour Hotel, Birmingham      ★ Arrive 11am - 5 June 2016 (12pm start)  
★ Depart 11am - 6 June 2016
- ★ Refreshments, lunch, evening meal, bed and breakfast provided, plus travelling expenses
- ★ Meeting one another      ★ Sharing & collating tips for survival and moving forward  
★ Sharing Stories  
★ Staying connected  
★ Having a stronger united voice  
★ Next steps  
★ Ways forward
- ★ Gathering themes, feedback and heart felt messages for NHS England

This is a joint project between Respond and Bringing us Together. Funded by NHS England. For an application form please email [Katie@bringingustogether.org.uk](mailto:Katie@bringingustogether.org.uk).

Places are limited and early booking is advisable.



The majority of those going through the assessment and treatment process are young people and adults with learning disabilities and/or autism (including those with a mental health condition), who display behaviour that challenges.

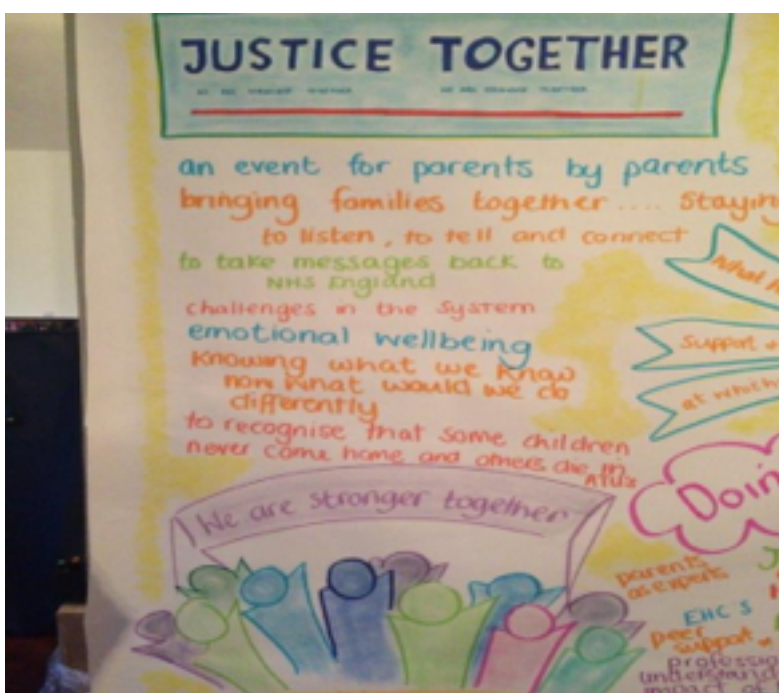
We felt a strong group of facilitators were needed over the weekend and, thanks to a great deal of insightful networking by our organisers, we were able to have the support of 12 skilled and experienced volunteer parents.

The content and process of the event was planned by these experienced parents, and a small select number of professionals offering support and advice to ensure that the weekend would meet expectations and needs of the families attending.

Twenty-nine parents - including couples, single parents and dads - from across the country attended the weekend at Hotel LaTour, Birmingham. Each of the parents had been contacted several times via email and spoken to at length on the phone. Careful clarification was given regarding why we were facilitating such an event, who the day was for, and what we would and would not be doing.

On the day, we had the wealth of experience of Pippa Murray to facilitate the event. To commence, we had the group come together with an introduction and carefully agreed ground-rules. In groups, we had a parent scribe, a parent facilitator and up to 6 parents on each table. We had guidelines on telling our stories, offering everyone an uninterrupted half hour to share their experiences within their small groups. Parents received small welcome presents on the table to help make them feel important and valued.

We also had an experienced parent graphic facilitator with us for the weekend, who is also an Expert by Experience on the Care and Treatment Reviews.



# Who are we talking about?



We asked parents to bring photographs of their loved one to help with the story telling, a selection of these are included below as are the words families used to describe their relative.

One of the hard hitting observations was that so many of the children were described in a similar way when they were younger such as “loving, kind, caring, funny, gentle giant, sense of humour, makes me laugh”.

## Before the ATU



## During the ATU



## After the ATU



# What goes wrong?

How do our children, young people and families sometimes end up going through these traumatic, confusing, debilitating, disempowering and, occasionally, fatal experiences?

Direct quotes and written statements from the families helped us to start identifying some of the main challenges:

“K. spent 6 yrs in college. At age 25 yrs as college was coming to an end (final year) he became more controlling in his behaviour.

On holiday K. pushed his Dad for the first time and became more aggressive which led to K. crying for a full hour which was very much out of character. Dad was worried and called an ambulance. In the ambulance K. was OK. Family decided to return from home holiday early. K. punched Dad at the airport. K was sedated at the airport.

Police were called by family and they sectioned him for 28 days and taken to a mental health unit. K. copied the behaviour of others so was moved to a Learning Disability Unit after 11 days. Dad received non stop phonecalls. After 3 weeks K. said to Dad 'don't come and see me'. Hospital saw family as a problem.”



The challenge is sometimes the young person with Autism Spectrum or Learning Difficulties hitting either a crisis time in their life, or something happening that could not have been prevented or predicted, which then triggers a behaviour that quickly escalates.

For example:

“M. has autism and finds transitions very difficult to deal with. His admission to the ATU followed an acute reaction to stress.”

“R has autism and LD. His mum got ill and was unable to care for him, R was sectioned under the Mental Health Act

(even though he didn't have a mental health condition) so that he could be looked after. The reason that R was sectioned was because school had made a referral to social services (in support of mum as they recognised that she couldn't care for him when she was ill) and the social workers did not look for respite.

Whilst the social workers were working out what to do, school was told to take R to an adult mental health facility. Whilst school staff were explaining the situation to staff at the unit, R was in the minibus and getting increasingly distressed. The facility decided they couldn't take him. Because R had spent so long waiting in a state of uncertainty, his anxiety and behaviour had escalated.

The escalation in behaviour was the 'final nail in the coffin' and R was sectioned."

## Our findings

We asked families what the main challenges are in the system and came up with the following themes.

There are 14 themes covering a range of issues families raised from their direct experiences and recommendations based on the solutions they identified.

Many of these map onto NHS England's own priorities of working to Improving Healthcare as well as the specific Transforming Care targets. Changing culture, shifting the balance of power as well as partnership working with people with Learning Disabilities and their families that feature so prominently in their recommendations.

We understand the national partners leading Transforming Care are committed to implementing the service model and 'Building the Right Support'.

The recommendations cover these 5 key areas:-

1. empowering individuals
2. right care, right place
3. workforce
4. regulation
5. data.

## Social Care and local services

- ★ Austerity hitting families and the withdrawal of preventative services impacting on families and schools
- ★ Families not eligible for direct payments and not fitting into the criteria for social care
- ★ Lack of respite care
- ★ Feelings of being let down by social workers who are more interested in funding and resource implications rather than lives
- ★ Families not asking for help and fearful of having their children “taken off them” from social care – this can then build into a crisis
- ★ A complete lack of Carer’s Assessments needed to support the family emotionally and financially, especially when their loved ones are out of area.
- ★ Waiting lists and pressure on Child and Adult Mental Health Services
- ★ Vital family support services and behavioural support services cut

## *Recommendations*

- Personal Budgets to be a recommendation for families and support provided to make this happen including Personal Assistant recruitment
- Person centred values foundations built into all training and used in practice

## Special Educational Needs Issues

- ★ Families unaware of the importance of the Education, Health and Care Plans and lack of really good support to complete the plans
- ★ Educational needs not being assessed properly
- ★ School unable to support the behaviour and to understand triggers of distress
- ★ Young person leaving education triggering distress
- ★ Lack of understanding and support regarding major transitions; for example, problems can be triggered when starting secondary school

## *Recommendations*

- Bringing in lessons from inclusive education - many are trapped in the system because the resources designed for rehabilitation of offenders are not accessible to people with learning disabilities. Bring in experts from education to create differentiated materials for a wide range of learning and communication styles
- Social communication seen as key early on

## **Personalisation**

- ★ Lack of person centred plans/health passports/positive behaviour plans
- ★ Decisions made by Responsible Clinicians who have behaviourist approaches, rather than more holistic and person-centred models of practice
- ★ Lack of personal budgets used as alternative and employing own staff not seen as a positive way forward. Lack of support structures for people employing their own staff.

## *Recommendations*

- Training for staff in specialist units and commissioners by those with lived experience in person centred thinking and values
- Staff and professionals to understand what "good" looks like and not to accept the unacceptable – families need to understand this as well
- Families to have a voice in Integrated Personal Commissioning and Personal Health Budgets
- Families supported to be proactive around co-ordinating a Personal Budget or Personal Health Budget paid as a direct payment to the person or nominated other. This should be a right to all people other than when there is a legal restriction
- Personal Budgets/ personal health budgets to be in place for families and support provided to make this happen including Personal Assistant recruitment, Individual Service Funds, list of good practice providers
- Training around Personal Health Budgets for families
- Understanding that to have a personal health budget families need to already be in control, resilient, confident and empowered through peer support,

networks, courses, good support around their mental health and well being and for this to start as early as possible

- Good practice models such as NHS England South and In Control need to be clearer and readily available

## Legal support and information

- ★ Families unaware of their legal rights, alongside confusion regarding Mental Capacity, the Mental Health Act and Sectioning
- ★ Little legal support or advocacy, and lack of parents' knowledge around Court of Protection, Deprivation of Liberty and other areas of the law. Parents not having access to lawyers or access to funds to employ lawyers when needed.
- ★ Parents not supported to challenge and unaware of their rights and entitlement. A lack of awareness and discussion regarding alternative provision
- ★ At this point families unaware of what a section means and under the impression that their loved one will be in an Assessment Treatment Unit for 6 weeks only

## Recommendations

- One stop parent led information hub of resources, information, signposting, events happening such as Justice Together ([www.justicetogether.org.uk](http://www.justicetogether.org.uk))
- Keep families fully informed of their rights and any support available
- Professionals need to keep up to date with government guidelines and legislation and practice within these
- Legal information such as the new "Disabled Children and the Law" by Steve Broach, Luke Clements and Janet Read available to both professionals and parents
- Codes of conduct for the various professionals need to be available easily to families.
- Continuous professional development and working with families
- A legal expert team to support families



## Parents seen as the problem

- ★ Hospitals and treatment units often see parents as part of the problem. Resulting in parents feeling that they are treated with contempt. Parents also say they are not listened to and experience feelings of helpless, out of control and powerless, often resulting in a deterioration in their own mental health, physical health and emotional well-being
- ★ Too much restriction on parents visiting their young people in hospital settings, or phone calls. Lack of contact with parents adds to the trauma for the young person and distressful behaviour escalates. Distancing of parents. Blame culture on parents
- ★ Parents pushed out of decision making. Little understanding of their perspective sometimes leading to post-traumatic stress as a result of their child being away from them

## *Recommendations*

- Courses for practitioners and providers in the family journey and how the systems and services add to the complexities of life. Rolled out across the country.
- Courses for parents to develop strategies around meetings, understanding of jargon and the law
- Better staff management training in awareness around family life and valuing families as the expert
- Parents encouraged to be Experts by Experience to raise standards and expectations of care staff
- True co-production and families involved at all stages
- Parents having someone with them to attend meetings
- Each provider to establish and support an externally facilitated parent forum to help share experiences and bring voices together

## Fuller (non medicalised) understanding of Learning Disability and Autism/ASD

- ★ There needs to be a less medical approach and a developmental understanding
- ★ It is often not about a mental illness and yet the person can find themselves sectioned and beyond the Human Rights Act
- ★ Trauma history and PTSD are not considered as being part of the issue
- ★ NICE guidelines for Autism and ASD are not referred to and parents unaware of them
- ★ Autism should be understood and treated in its own right – it is not a mental health issue and often there is not a more general learning disability
- ★ Challenging behaviour is often misunderstood and may be as a result of a misunderstood health need, for example being in pain. The behaviour is usually a means of communication, although rarely understood or managed on this basis
- ★ Autism being treated as a mental health difficulty
- ★ Lack of training in Autism for service groups such as GPs, the Police, the Prison Service and A & E staff

### *Recommendations:*

- Early intervention including sensory processing therapy for those with sensory problems enabling those around to understand the individual
- NICE Guidelines for Autism (<https://www.nice.org.uk/guidance/qs51>) followed and adhered to
- Autism must be classified in its own right – it is not a mental health issue and often a learning disability is not associated with it.
- Staff trained to understand the sensory needs and need for structure/understand the way that people with autism learn and take on information e.g. using visual cues about what is going to happen next
- Employing people who are compassionate and care about disabled people
- Training to be offered by people with lived experience and who are on the autistic spectrum. Eg Experts by Experience in Oxford are training professionals giving

them a clear understanding of people with autism. They are also very articulate about the mental health needs of people with autism

## Concern over use of the Police and the Criminal Justice System

- ★ There were several reports of the police being used as a first option in a crisis for containment – this was often felt to be totally inappropriate
- ★ People can find themselves in police cells, charged and going through the Criminal Justice System because no one has recognised their autism or learning disability

## *Recommendations*

- The police to have specific Autism training that includes case studies and opportunity to work on solutions and alternatives
- Alternatives to being held in custody in a cell that will decrease the anxiety caused by being held, and be less frightening, through involvement of a doctor and mental health practitioner with experience of dealing with ASD and Learning Difficulties

## Mental Health and emotional well being

- ★ Lack of emotional and practical support; the need for more support around behaviour at an early stage and how to manage distress and anxiety
- ★ The real life experience was that there is little support for families; we need to empower families early on (at the point of diagnosis). Examples such as the Parent Expert Programme should be used as models.
- ★ Families need support to become resilient – this might be through bringing people together, creating supportive networks, resilience workshops, etc.
- ★ Families need emotional support to facilitate emotional well-being and good mental health in themselves and in their young people and loved ones.
- ★ Families need straightforward access to information and rights and support to use this. Information on websites, helplines, independent well trained advocacy and the justice circle model. Information needs to be available in a range of ways as older people are not as au fait with technology as the younger generation (Ofcom 2015)
- ★ Particular support and attention leading up to education transitions and other life changes

- ★ The recognition that school breakdowns are often the starting point of things spiralling downhill towards ATU admission.
- ★ Families not being offered a circle of support (Justice Circles), parent forum or help line to ring for extra support.
- ★ Lack of services and experienced staff available when family hits crisis. No emergency respite services to offer appropriate help other than just the use of the Mental Health Act.
- ★ Parents reaching crisis point and then being unsupported around the point of crisis. Requesting help and support and then finding that the solution is that their young person is to be sectioned
- ★ A common theme was that parents feel too scared to ask for the help they need to get their loved ones back home; some simply not sure who to ask. And then others say they wished they had never asked for help in the first place

## *Recommendations*

- Investing in early prevention – no one can last long with little sleep and extreme stress
- Proactive support for families long before the point of breakdown and crisis
- Working with families as early as possible in their child's life to build resilience
- Crisis specific helpline offering guidance and therapeutic counselling rather than generic helplines
- Crisis mental health teams that come out and support the family during the crisis
- More empathy for the family members. Better carers assessment to support the family emotionally and financially especially when their loved ones are out of area.
- Resilience courses to empower parents and opportunities for bringing parents together through training, workshops, information sessions, peer support to build confidence and knowledge. Workshops in developing strategies around meetings, understanding jargon, the social model and the law such as Partners in Policy Making
- The need to implement/uphold Human Rights over and above the, sometimes inappropriate, use of the MHA.

Facilitator notes:

“In hindsight would have kept him at home as the last 8 months have had crippling consequences on her marriage. And at the moment Mum hates life and she feels that if things go downhill or the ‘revolving door’ situation was to happen it would literally finish her off. Mum can’t go to counselling as she is not emotionally up to it. She feels like J’s life has been stolen.”

One parent told us

‘If I knew then what I know now I would have fought for sectioning **not** to have taken place’

“Dad wishes he had brought K. home after initial 28 days in the ATU”

## Other Issues:

As well as the general themes emerging from the family’s descriptions of their experiences, NHS England were also interested in the family’s feedback on the following issues:

- The complaints system
- Care and Treatment Reviews
- Medication
- Staffing
- The Discharge Experience

### The complaints system

- ★ Families are mostly not informed of their rights or of any process for complaining
- ★ The difficulty in knowing who to complain to and who has ultimate responsibility
- ★ Families do not know of a clear process for complaining against specific professionals such as the psychiatrist

- ★ Families who do want to complain fear reprisal against their family member whilst they are incarcerated; they sense a huge imbalance of power
- ★ One of the most common themes was that families do not feel listened to
- ★ Families given no guidance or advocacy around the complaints process; they are aware that a huge amount of energy and resilience is needed to go down a complaints procedure and it can be very time consuming
- ★ A Lack of independent advocates to help parents and families through these complex and stressful processes
- ★ Parents having to research how to complain
- ★ PAL's: at first they had little understanding, however once they listened they were very supportive and attended several meetings
- ★ Long processes regarding complaints and having to jump through too many hoops with little support for families already drained by their personal experiences.

This was one direct quote from a parent:

"I started the complaint last September regarding the psychiatrist and lack of care, and using antipsychotic drugs without knowing my son. I have not got as far as the mediation meeting yet, this is next month. They have not agreed with anything I have complained about so I am not sure how far I can take it. Ombudsman?"

## *Recommendations*

- Ensure families are provided with information about how to complain
- Support for families going through a complaints process and guidelines for families developed that includes signposting for legal information, resources and advocacy
- Where necessary NHS should fund mediation

## Care and Treatment Reviews

- ★ Some parents were unconvinced that their young person's history was carefully pulled together and considered as part of the understanding of the person and their current situation (e.g. trauma history)

- ★ Families often felt excluded, or at least unsupported to take a full part in the CTR process
- ★ Some families experienced bias and inconsistency regarding how issues were documented. One described their loved one who has learning difficulties speaking extensively at their CTR about something that was of huge concern to him, yet none of this was minuted.
- ★ Families often felt that they were seen as part of the problem, rather than part of the way forward, and so not listened to as a result.
- ★ To actively include families (particularly nearest relative) in all plans and decisions connected to their family member with a learning disability. This includes making information accessible and clearly explaining any professional language or abbreviations

## *Recommendations*

- Follow the NICE guidelines, the NHS England recommendations and other such guidance available.
- National Valuing Family Forum are putting together Gold Standards to be used
- The CTR report should have a timescale attached to it for actions contained in the report. These timescales are currently determined by the team, families ask that they remember there are vulnerable children and young people involved and three months can seem a very long time to a family in crisis.
- Ensure all Care and Treatment Reviews include an Expert by Experience, a Commissioner and an Independent Clinical Expert
- Clearer adherence to existing protocols on the conduct of CTRs in particular on the recording and communications of decisions made and actions to be taken
- An effective audit approach to analysing CTR and CPA reviews to inform an understanding of strengths and development areas against best practice standards/policy and guidance
- Providers should be accountable for actions generated through CTR and external scrutiny is needed to ensure these are completed.

## *Medication*

- ★ Many families felt that medication was introduced often in the first instance and not, as NICE guidelines recommend, as a last resort following interventions which were developmentally based and person-centred.

- ★ The Responsible Clinician – often the Psychiatrist – was viewed as having too much power and parents often felt not listened to when it came to views on medication.
- ★ Most felt that medications were over-used and at too high dosages.
- ★ Some felt that medication was being used as a restraint (inappropriate) and needed more careful monitoring and reviews.
- ★ Parents wanted support to challenge this use of the 'chemical cosh' which goes against NICE guidelines.
- ★ Some said that their young people had never experienced medication until they entered an ATU.
- ★ Medication being used as restraint and as a punishment (see Medication section). Many parents voiced serious concerns regarding the forms of restraint used, particularly around prone restraint, which some said should be banned as an inhumane practice.

### *Recommendations:*

- Alternatives sought rather than medication
- Where possible to have a meeting just about medication with the professionals, young person and the family to talk about the pros and cons. Route to come off the medication clear at the start
- Regular reviews of medication as above
- Awareness of NICE Guidelines amongst professionals, services and family members

### **Staffing and Assessment Treatment Units**

- ★ Various concerns regarding the nature of the agencies offering these assessment and treatment models. Many mentioned a consistent sense of underpaid and under-trained agency staff, working in organisations driven primarily by profit. The whole funding process was seen as being complex and opaque, with little sense of who was accountable.
- ★ A serious inconsistency around the following of care plans; communicating with families on issues and challenges; training on routines, behaviours, Makaton etc.
- ★ One very common theme was the young person being placed in a unit miles from their home and community – as there is no local service available - and then parents having to pay for their own travel costs to see them for often very short periods of time.



## *Recommendations:*

- If a decision is made that as a last resort someone with a learning disability needs to be detained under the MHA a long way from their family. Provision must be made for the family to have their costs for regular visits recompensed in an easy and timely way.

## *The discharge experience*

- ★ Lack of realisation that the person may be suffering from post-traumatic stress disorder and that therapy should be offered by specialist services
- ★ Hospitals should work more closely with community teams and social care; sometimes there appears to be no link-up at all
- ★ Often there is no person-centred plan either to inform the persons care or their discharge. More workforce training in person centred planning is needed
- ★ Individuals leave hospital with a lack of a personal budget or financial control due to the heavy focus on a placement and the step down pathway.
- ★ Lack of information about the possibility of a capital fund if people have been detained for a period of time
- ★ Lack of knowledge by commissioners, professionals and families about suitable providers who could set up the right tailor-made provision
- ★ The discharges that were described in more positive terms did have skilled, independent advocates supporting the family
- ★ One comment was "They go in with autism and come out with personality changes, mental health issues, poor physical health issues, weight issues, no education and with post traumatic stress disorder"
- ★ Some parents mentioned the renewed sectioning of their young people – without thorough reviews – which then delays their discharge further
- ★ Some also mentioned the discharge being regularly delayed because professionals were now highly risk averse, and being in the mind-set of 'hospital being the best place for everyone's safety'
- ★ It was felt that no understanding or priority was given to the young person having regular access to their own home whilst in the ATU, so they remember where they are returning to (if appropriate)
- ★ Lack of action by Local Authorities to set up support ready for discharge.

- ★ Some young people missed the staff and familiarity of the ATU, with no thought given to these kind of transition issues.
- ★ It was identified by some parents that any new providers needed to be involved with the young person and family prior to discharge, although this rarely seemed to happen appropriately
- ★ Funding around housing etc. takes months. Independent person to set up local services.
- ★ A list of local providers, vetted by parents would be useful. Housing officers in LAs who know about deputyship and supported tenancies
- ★ Parents identified a need for properly pooled budgets so that there is no reluctance to discharge into the community because social care don't want to/can't pick up on costs
- ★ Ensuring that for a young person moving into adult services on discharge has education services in the framework
- ★ Potential providers need to be sent a very clear detailed pen picture of the young person and only considered if there is a certainty from all sides that all needs can be met
- ★ The transition plan needs to be very thorough with transport, staff shadowing, visual timetables and staff photos all part of preparation process
- ★ The added major complexity of bringing the young person home suffering from post-traumatic stress, mental health issues and physical health problems due to the time spent in ATU and impact of medication.
- ★ Nothing in the community once the young person is home (see Discharge notes).

### *Recommendations:*

- Make sure the individual has access to their real home on a regular basis so that they remember where they are returning to – if that is what the adult and family want
- Take into account if the young person has turned 18yrs old chronologically but if their development age is a lot younger – and be creative in involving, communication and mood, observing behaviour etc
- Meet the needs of the loved one – then sort out the funding. Parents and carers should not be working about where the funding is coming from. Pay

someone to be responsible for sorting the detail of the funding issues, separate from the discharge/best interest decision

- An independent person to liaise with local housing providers and services to ensure effective timescales
- Potential providers need to be sent a very clear and detailed pen picture together with a Person Centred Plan. Only assessed if 100% sure that needs can be met. Too many assessments are unsettling.
- Consistent Transition Plans to be very concise with transport, staff shadowing, inductions, visual timetables and staff photos all part of preparing the young person using social stories
- New staff spending time at ATU and with family before the move
- Lists of local trusted providers vetted by parents would be useful
- Housing officers in LAs who know about deputyship and supported tenancies
- Much more workforce training in Person Centred Values and planning
- Have organisational budgets that are properly pooled so that there is no reluctance to discharge into the community because social care do not want to or can't pick up the funding commitment

Some further direct quotes from parents on the issue of discharge:

“Everything is too late...diagnosis, support to prevent crisis, CTR that was done 5 months after being detained and not receiving the report until 3 months later. Punishment for unsettled days..home leave cancelled.

CP identified after 7 months of being detained so then a lengthy process of finding the appropriate team to support, training, transition..this all adds to even more time spent in ATUs. Transition process back to the young persons home/supporting living can be lengthy and detrimental to the young persons state of mind when they really want to be discharged.

One of the placements that was set up for my son broke down because there were funding issues over transport and staffing which resulted in my son becoming very unsettled not feeling safe with new people!

He then had to stay in ATU for another year until new provider was found. His anxiety levels increased dramatically as a result.

“Discharge... Coming out under restrictions is also hard on the young person, CTO DOLs...

Alarms, restrictions in the property that could cause distress..

There is more emphasis on risks and behaviours than the person...PCP here isn't recognised as being important enough to add...even mentioned that it was a waste of time!

Lastly not letting the young person live where they want to live..and told where they should live!”

“Just to add, now J is discharged he is ring fenced away from us and now I am not involved as much as I want to be.. Not told anything and meetings are ahead of me arriving, I get to talk to a few people that stay around at the end...not good enough at all.”

“new care staff are inexperienced and have made a lot of mistakes over the last 2 weeks of xx being discharged.. he is very unsettled at the moment ... he spent the day here at home with us today and it took a few hours for him to regulate himself back to being here...”

“What worked for xx was that his new carers at his future placement spent time with him leading up to him being moved.”

“xx been home since December; still no care plan been actioned even with a high court order...”

“If the young person has turned 18 chronologically but their developmental age is a lot younger then this is taken into account by everyone, and there is opportunity for creativity with these individuals and reading between the lines of their non-verbal communication, behaviour and mood”

“Individuals returning to the community are given a flat which is often impersonal, with little thought given to their sensory needs. Bare walls, windows you can't see out of. Perhaps 2 “guards” sat with you, with very little interaction and who are falling asleep with

boredom wearing their protective gear. They are part of the package of cost which is diabolical.”

“Meet the needs of the young person and then sort out the funding. Parents and carers should not be the ones worrying where the funding is coming from. Pay someone to be responsible for sorting out funding issues separate from the discharge/best interest decision”

“A good transition would have meant that there would have been gradual support to go home. There was no plan that they talked about with us, they just did what they wanted”

“They bring him to a school close to home every morning as part of his integration in community and he wouldn't get in the taxi and he told them he wanted to come home for the afternoon, I'm two miles up the road no phone call no nothing they just called police and xxx said that the police restrained him and that they pinned him up against a wall. They wonder why our children can become challenging when their treat them like this instead of a simple explanation of why”

“The transition was not well planned and led to K. sharing space which did not work and after 1 month K. said to Dad 'help me' as another YP had took his diary. Staff were not helpful in this matter.”

“staff shortage now, they are holidays ..today when we good bye with t, normally a staff will deliver him some food for snack ,but no staff, then t said no good bye with mum ...then t melt down since it broke his routine, or maybe t just simply didn't wish to good bye with us .”

Facilitator notes included:

“Mum found a care provider but as they were not on the Approved Care Provider List they LA refused.

LA offered J. a flat which mum does not feel will work but she feels powerless as there are too many restrictions on her as his mum, i.e. restrictive visting and phone calls due to DOL's. Agency staff are used. Mum feels J. may go down the criminal justice route.

“When R was discharged, the support that was promised was not put in place. Because of the lack of support, things became difficult at home again and R ended up back in hospital.”

# Evaluations and feedback

From Social Media and elsewhere:



“Amazing. Thank you for your kindness from the heart. It shines through. You and the other ladies on my table showed your patience, empathy and were so lovely. Lovely to know that there are still genuine people about. Touched me. Love and Hugs.”

“what a beautiful bunch of soul’s lovely emotional positive day and fabulous night now lets put these plans into action and get the beautiful dudes and dolls out and back into community life love you all”

“Lovely to meet u all. Praying will make a change u all fabulous thanks for putting together all involved. Wished cld of stayed over. We talk soon. Thanks for being so kind and thinking of”

“And that's what we are stronger together!!! love u all”

“Hello beautiful ladies. I no longer feel I'm walking alone since meeting you and what fun cant wait to do it again xx”

“Honoured to be part and thank you all for everything x”

“I was honoured to be a part of the weekend too xx”

“Thank you for thinking of me to be involved in the weekend, I can’t really find the words to describe how it feels to have been part of it but was an honour”

“Thank you for such a great weekend. Such a laugh, considering what everyone is going through and has been through. I knew none of you three years ago, now you are life long friends”

“you made me laugh so much. After such an inevitably full-on day it was much much needed and appreciated! So glad to have met you amazing and inspiring people. Xxx”

“Was fabulous some really positive ideas for outcomes slowly making changes for learning and physical disabilities and of course autism xx”

“BIG humungous massive SHOUT OUT to Katie Clarke for doing what she says on the tin.....bringing us together...and for doing it in such a loving, generous, thoughtful and supportive way. A woman of intense integrity, wisdom and compassion who I am proud and privileged to call my friend.”

“I think it gave a much-needed boost to families who are living under the most incredible pressure. Thank you for keeping me in the loop with your initiatives and perspectives. I’m struggling to understand what has happened to my boy and how on earth I can get him home after all he has suffered - so my out of the box thinking (such as it is) is concentrated on him. However if I can help in anyway, I would like to try.”



One parent wrote a poem:

Bringing us together and justice together  
Brought us together at a Birmingham hotel  
We laughed and we joked, we all felt provoked  
As our children are residing in hell  
Our stories all told, and often tears flowed  
As one by one we spoke out the truth  
About the kids locked away and abused  
The professionals all noted as desperately trying  
To stop the truth being used.  
We ate and we drank while our kids locked in the tank  
Somehow we block all the hurt felt inside  
When the truth finally reveals  
We will fight for the rights for our child  
As soon there'll be no place to hide  
We all crave for the day  
When our pains seep away  
And finally again cherish our offspring  
That'll be the day, when all others will know  
Because it's a day when all of us sing  
So they brought us together, and we are stronger together  
To fight for the rights there should be  
So onward and upward we are refuelled again  
When the smiles in their eyes we can see

“Love, friendship, tears and laughter. What could be a better way to spend two days?”

“Well, I don't think I can compete with all (fully deserved) kind words you have already had, except to say that it was a great event (as part of a great piece of work), and I could see how exhausting and wonderful it was that all those people were able to get together. I was honoured that I was able to play a small part in it, thanks for inviting me.”



“I for one am proud and privileged to have played just a small part in what was an amazing event. well done katie, without you it would never have got off the starting blocks. Lets hope we can do more to help support the families and get justice together well and truly underway. Stronger together “



“My energy levels seem to plummet these days. But I hope that my sincere goodwill adds to the energy and commitment

you all bring. Keep me in the loop! Meanwhile. Love all and let's stick together!”

“I wish I had the time and energy to do more. However, together we will move mountains. thank you for such a wonderful message after an amazing weekend.”

“I am really sorry to have not been able to stay till the end of a remarkable weekend but have had great feedback from the Oxfordshire families who attended. The positivity and sensitivity of the event stood out for me”

“I felt very honoured to be involved and only wish I could have done more and would have loved to have seen the hugs too:) What amazed me was the courage of all those families and the resilience they were able to demonstrate from talking and Being with each other. It was such an emotional day and to see mums and dads smiling and laughing at end of the day made me feel so humble that despite all what is going on in their lives they were able to find their own bit of sparkle.”

# Conclusion

In Education, the child is placed at the centre of their provision and parents are placed in the first ring of care.

In an ATU a child is de-humanised (under section they have no human rights) and their parents are marginalised.

The effect of this deprivation is devastating. Words are not enough to explain. Being in contact with lots of families now, we have seen heartbreaking before and after photos of what happens to our children in "care".

Do people whose behaviour (as a consequence of their impairment e.g. sensory overload, communication impairment) challenges others deserve to be treated as undeserving outcasts? Do their families deserve to be punished just because their loved one happens to have an impairment which is difficult for society/us to understand and relate to. Whatever the consequence of impairment we are all human. We deserve to be treated with love and compassion. People who struggle to contain emotions and anxiety deserve the support and understanding that allows them to grow rather than support that diminishes and demonises them.

Illness and impairment are part of our human condition. Whatever the advances in science, technology, illness and impairment will exist in one form or another. In this country we are fortunate enough to expect to be given a wheelchair if needed, we have inspirational role models showing that disability need not stand in the way of amazing achievements.

Children and young people who end up in Assessment and Treatment Units have an impairment which effects their ability to self regulate rather than affecting their ability to walk or see or hear.

We wish for Transforming Care Partnerships and NHS England to not only be providing long term policies and strategies, but also to get those young people who are in the ATUs back home as quickly as possible. These loved ones need to be home where they belong. At the same time we wish for measures to be put in place that complement 'Building the Right Support' and to consult with our parent members on the challenges in keeping the next generation away from institutions be it in the community, out of area schools or out of authority Assessment and Treatment Units.

# Big thanks

Firstly, many thanks indeed to all the parents who attended the Stronger Together Event. Your stories continue to make a difference, even if it feels incredibly slow, and through these we have raised awareness on a national level. Thank you for sharing your experiences with one another and for allowing us the privilege to listen and make notes for this report. We love you all very much and have a lot of respect for each one of you.

Thank you our parent facilitators, Noelle Blackman and Lawrence Moulin who supported the day. Thank you so much to the lovely Kath Broomfield who did an awesome job of graphic facilitating the day, left lots of gaps, went away and finished the graphic after many hours of thinking, listening to us, and choosing carefully what went on.

To our wonderful steering group from Justice Together Liz Wilson, Zoe Thompson, Sam Clarke, Pippa Murray, Jeanette Thompson, Noelle Blackman and Liz Gowe.

Huge thanks to Jo Whalley and her team for giving us the go ahead to run the event and for NHS England's Engagement Team on giving us the funding that paid for all the direct costs associated with the event.

Thanks goes to Debs Aspland and Katie Clarke from Bringing Us Together for giving hours and hours voluntarily to make this work and to highlight the plight of parents who have loved ones in Assessment and Treatment Units.

Lastly but very importantly, thanks go to the two parents and their families whose stories have touched so many of us and have drawn us together in solidarity on these important issues – Sara Ryan and Paula Rawnsley.

May no one else experience their loss.