



FAMILY RIGHTS, CITIZENSHIP AND MENTAL CAPACITY

DAY 104 OF THE JUSTICE FOR LB CAMPAIGN
JULY 1ST 2014



We asked **how** we keep our young people safe, loved, happy, with purposeful lives and in the driving seat?

LOVED

- Developing Circles of Support
- Including brothers and sisters in the Circle
- Being with people who love and care about the disabled person
- Living independently in same area as family and building relationships
- Having family around to support when and if needed
- Being involved
- Ensuring he is listened to – especially when he wants a hug

SAFE

- Being with people who love and care about that person
- Employing a PA co-ordinator to oversee that the disabled young person's life runs effectively
- Information on rights and also what is not right
- Developing Circles
- Rules – predictability to help with understanding
- Information on rights and what is wrong
- Living independently in same area as mum and building relationships
- Ensuring staff are safe and competent "know what to do"
- Appointing Deputies to support decision making processes



HAPPY

- People around to read and understand the signs
- Photographs to record experiences
- Different people involved to agree what happy looks like
- Living in own flat with good PA
- Having the power and being 18yrs old
- Making own decisions
- Decided which PAs to go out with
- Being made Gala Queen
- Good relationships
- Family close by
- Having a fiancé
- Imagination!
- Making own choices around music – accommodating so music can be heard when he goes
- Having fun times and doing what he wants to do and what he likes to do when he wants



PURPOSEFUL LIFE

- Finding an incentive whether it is a payslip, time bank etc.
- Circle ensuring contribution to community
- Being involved in the community
- Being an employer – knock on effect of enabling creative families
- Using people’s gifts and skills
- Ensuring that we investigate a person’s interests and appoint PAs accordingly
- Work
- Football
- School
- Voluntary work – talks to parents
- Achievements – exams etc.
- Having plans for the future
- Having ambitions
- Values part time job – raises self esteem

Being in the DRIVING SEAT

- Being willing to give up your “mum” hat if you want them to be truly happy
- Expect to hear things you don’t like or agree with
- Financial Deputy very helpful in ensuring person retains benefits
- Need for information for families to understand the processes around Mental Capacity
- Cameron Trust using Deputyship appropriately
- Opens own post
- Having his own flat
- Having own front door key
- Having own credit cards



Day 104 of 107 days

#JusticeforLB campaign

We asked what is working well for our families around Mental Capacity and Supported Decision Making?

- Communication Forums with a group approach
- Connecting – supporting families
- Information and learning together for families
- Coming up with our own decision making agreement
- table of major decisions he can make eg moving house
- Daily decision making “Tom Team Handbook” used for induction.
- About Me – written by Tom
- Regular team meetings
- Circles
- Social Worker actually thanked us for helping
- Family stories can help professionals understand without us having to battle
- Families being informed about rights
- Families having a voice
- Respecting families – respecting our choices – knowing what is “silly stuff” and mounting “small things” that add up to quite major issues
- Rebalancing voice and power between families and the system

We asked **what is *not* working well** for our families around Mental Capacity and Supported Decision Making?

- NHS – from 17yrs up – being in adult wards and parents not welcomed.
- Welfare Deputy meant could not negotiate with the ward re private room. Had to involve a solicitor so that relatives could stay
- Lack of training around understanding of Mental Capacity
- Referral happened to psychologist without parents' consent
- “No choice, we had to take a personal budget”- without high quality information on how they work
- Local authorities going backwards not forwards
- Social Workers with little experience and non-social workers doing Resource Allocation System assessments
- No Person Centred agenda – it costs too much £
- Closing Day Centres without alternatives
- Ignoring families
- Being made to feel guilty supporting my daughter into Independent Living
- Having control taken away
- Being dictated to by Local Authorities
- Painful battles – fighting schools, social worker and the systems.

- We were “alone” and it became about him and excluded what we thought or knew he needed.
- Injustice
- Family exclusion
- System that is totalitarian
- Tin pot tribunals
- Life sentences imposed
- Moving family further and further away
- Social work driven
- Misapplication of the MCA
- People find it difficult to hear what we have to say
- People have no concept of Mental Capacity Act and what it means – including big players like the CQC
- Some people choose to ignore MCA
- People not following the Act
- Do professionals leave an audit trail to show decision making processes?
- Big networks and lots of connections: voice of mum/best interest/safeguarding/right to make poor choices – “you can't go out looking like that”
- People with some capacity – complicated and needs thought and planning around decision making
- Finding the balance – choice/best interest
- Choices often made too informally – too quickly
- Worried that in the future the subtleties of MCA will be lost

- Worried that people get “kidnapped” by people/professionals who understand the MCA
- Choices around food/clothes – lack of common sense – support staff scared of MCA
- Problem if one parent “gets it” and the other parent “does not”
- People feeling isolated about MCA – and not knowing about all the good resources and information available for free



QUOTES OF THE DAY

- Bring back Common Sense
- Communication and Consistency
- Control is a hard word to achieve and make happen
- Be part of something that is going to make a change happen
- Listen to stories and gather information
- Not to be alone
- Learn from one another's experiences
- Achieve more in a group
- Learn what things mean to people
- Someone with a label does not have the support to make a decision – however for the rest of us without an impairment we can call on family or friends to help us out
- Our young people when they hit 16yrs now they have a problem with the new Code of Practice
- We feel that Local Authorities want us out as it easier for them without us
- Families need advocates
- Professionals take over then have 101 reasons not to do anything
- We can achieve more as part of a group like this
- Bring people together to support one another
- Families not listened to and disabled people detained
- Stories speak much louder than policies
- It is us the parents who are labelled as “challenging” and then marginalised
- Practical solutions brings us closer together
- Love, trust, togetherness and listening to the voice of our young people and their families
- What happens when I am not here
- It takes an enormous amount of strength and support to continue
- I would feel more comfortable knowing that my young person would die the day before I do
- Sadly true. All the mums that I have spoken to say they hope their young person precedes them
- I would feel such relief if they could die before me. But, we carry on fighting for their rights, to be listened to and to have the best healthy life possible – and to have the best opportunities whilst they are alive
- Who will champion our children when we have gone?
- This is about how family voice needs to be respected and our stories to inform a better way
- Treatment of my own mother was so bad
- It could happen to any one of us or who we love
- Frightening
- What is so hard to see what is missing?
- Family
- They have teams, training, skills, drugs, tech stuff, money, equipment and supervision and cannot enable happiness.
- Most of us are alone – children excluded from “special schools”.
- What do they think we do all day in our homes?
- Decision making can be so subtle – it can be working things out in the head and having the right support from people thinking creatively and flexibly
- Parent carer forums to feed their stories through social media
- Include us – we are marginalised
- Misapplication
- Who has the right to speak
- Services should learn through family stories, learn through experiences and apply common sense
- I would like to know that I am doing ok with way I am moving forward with his life
- I would like advice on how to make the best decisions for my sons future
- I am not alone

FEEDBACK

Meeting lots of new people

Inspiring stories

The honesty amongst those attending

We all talk the same language

Lifting my head after keeping it down for so long

This has helped me an enormous amount – I feel invigorated

It was a perfect day – very person centred towards those attending

Really want to keep in touch

All those who had organised the day and the thought that had gone into it was tremendous. Well done.

Fantastic

Being able to be part of a group of similarly concerned parents (and others) who are keen to make a difference

More positive now about achieving better outcomes

Really appreciated the day and the work in advance to make it so worthwhile

Opportunity to talk to other parents actively involved in change

I feel refreshed

Feeling stronger, more informed, fired up! Thank you VERY much

Given me food for thought

As always having the chance to speak to other family members – get ideas, support, share experience

Feeling stronger, more informed, fired up! Thank you VERY much

Meeting new parents and people. Listening to more stories. Given time to listen

Meeting people on the same road as me

Networking with other families, hearing stories

Feel more positive about where to get help, information in the future

Being with people who talk the same language “my tribe”

Feel I have found some more energy to focus once again on some difficult issues.