

Why do we need the
#LBBill? v2

This document contains the exact words shared with us by the parents and families featured in Day 12 of the #LBBill Twelve Days of Christmas.

We had to edit slightly for campaign purposes, but this is what we received.

We are grateful to all of them for sharing, and you for reading.

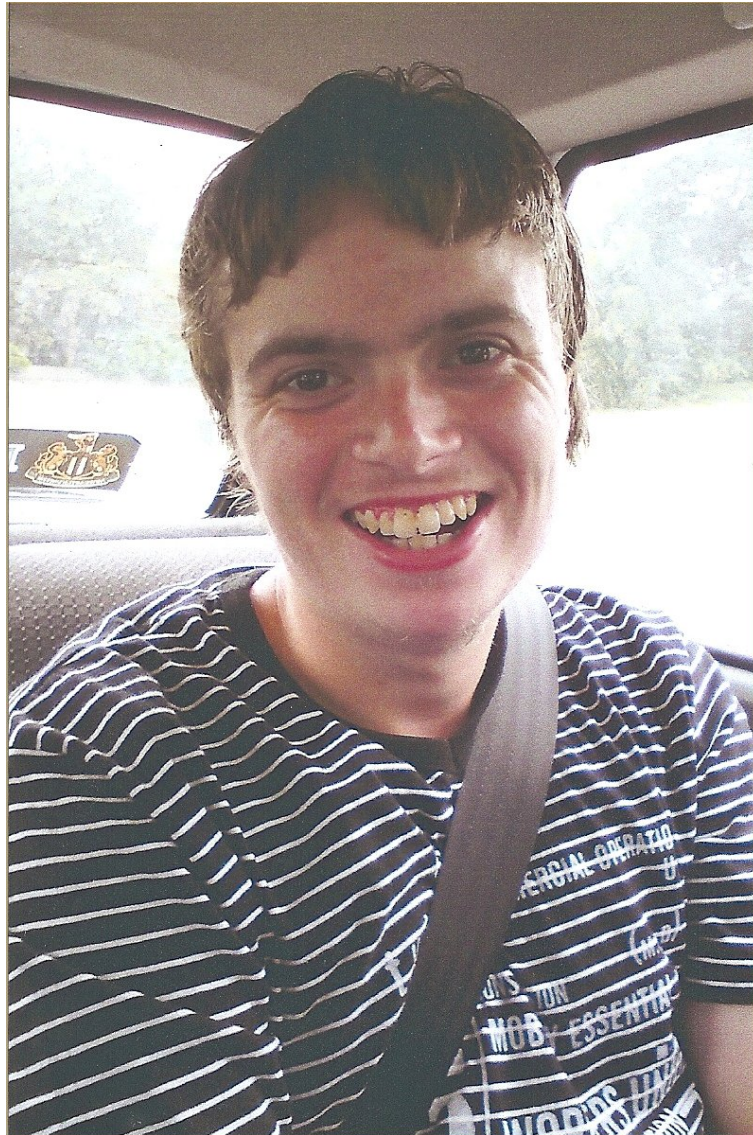
Thank you.



My dude lives with angelman syndrome he is dependent on others to facilitate his life ensuring quality AAC methods are maintainedif he can't speak out and be understood and respectedhe acts out. If those around him see this as his challenging behaviour rather than behaviour that challenges them to listen and understandthen he could so easily find himself on the treatment route.....that's why we need the LB bill..... We are already looking at DoLS issues where he lives.. In a house shared with a mate with team of PAs supporting them.

Am always emotional when I think of LB and Sara, as I do daily. Could so easily be my son.

Wishing you every success.....total respect to you all



As the father of a young man with very complex needs I now count myself as one of the lucky ones. When Adam hit 19 we soon found out that there were no services that could meet his needs as an adult and while he was living with us at home there didn't seem to be any way for him to have a life of his own as no one seemed able to provide any meaningful support or opportunities locally due to his complex disabilities, autism and challenging behaviour.

For nearly a year I searched but there just wasn't anything of a suitable standard that could cope with his level of need. No suitable support, no activities, no day centres, no clubs, nothing. Our modest weekly allocation of support worker hours provided by a local agency continued to offer very welcome respite for us but though the staff tried hard they could not offer him any kind of meaningful activity.

Now getting desperate it was suggested that we look for a local residential placement. This is not at all what we wanted but with options narrowing we decided to consider the possibility. After nearly a year of looking we had exhausted the options in our area but then were extremely lucky to find out about a vacancy in a

small residential home, some way away from us, but which offered exactly the right balance of support, environment and expertise that could help him to flourish.

Without this opportunity I am certain that as a family we would have struggled on as best we could on our own but have no doubt that eventually, perhaps due to a crisis caused by a meltdown, ill health or accident the outcome could well have been an enforced and indeterminate stay in an assessment and treatment unit for our son.

Finding and maintaining appropriate person centred support for an adult with disabilities, no matter what their needs are, should not be a matter of luck. Families must not be left to fend for themselves and vulnerable people must be assured that their needs will be met in full. That's why I support the LB Bill which will provide a legal framework to safeguard the rights of people like my son to have a decent quality of life.



This is 'madam' - severe physical disabilities and complex health needs - but far more intelligent than the so-called professionals who try to control her life.

The LBBill is vital to protect ALL disabled people as current legislation is openly abused by LAs, NHS etc. As soon as the MCA came into force our phone started ringing - and she doesn't lack capacity! The witch hunt had begun - with some awful consequences. The witch hunt still continues now, albeit with failure on their part at every turn - their failure does nothing to lessen the distress they cause. 'Madam' and others like her deserve the protection that LBBill aims for; she deserves to be protected from people who use their positions to abuse current legislation.



This is my fabulous son Michael who is 24. He has Autism and LD.

He lives with us, is happy, healthy and very much loved and valued. He has a father, a sister, a brother and a nephew who love him to bits and without him in our lives every day, our world would be a bleak and unpleasant place to live.

I always want to be my sons advocate. I don't accept that anyone, other than me, Mikes Dad, or his siblings know what's best for him. I will fight for my right to protect him from anyone that I believe doesn't have his best interests at heart in the same way I have since he was born and since his diagnosis. When I die, I know that his siblings will take that role from me with the same courage and determination that they have always shown for their much loved, respected and valued brother.

But I want this right protected in law, in a way that I now know it isn't. I want Michael and his family to have the final say, not the local authority or an NHS trust who's motives I question. Michael is perfectly able to say what he wants. I want that right to be upheld against all comers. I truly have been naive in believing that the dark days of the asylum were behind us...that the law was unimpeachable and its officers not above being accountable. Let's make this bill a reality before another family is fractured beyond repair.



Like many parents one of my fears is "what will happen to my daughter when I die or I cannot support her anymore".

I know the amount of work it takes to keep her happy, healthy (both emotionally and physically), supported well, safe and leading a purposeful life.

It can never be underestimated the amount of unseen time behind the scenes this takes. I am the Mother/Director of Quality in our own small "business" which employs 9 Personal Assistants.

The bill is important to me as, although the fear for her future, her happiness and her safety will never completely disappear, I really wish for the world to be a better place for her to live the life she chooses, with support that goes above and beyond the call of duty, with enough funding to pay her PAs a decent and valued wage, and for her family and those that understand her non verbal complex communication impairments to continue to support her in making informed decisions and that they will be listened to in all aspects of her care.

Although she has very different needs to some of the young people that end up in ATUs she too could be in an institution. Without the good support, without her communication aid, her electric wheelchair, and without her voice she too could

end up extremely vulnerable, and frustrated with a tragic and meaningless existence. The large and beautiful whales that are imprisoned in Sea World centres turn aggressive and violent, develop challenging behaviour due to living in a prison with no freedom and no understanding of their needs and desires. She deserves to have the ocean to swim in, to go where she wants, with who she wants, to enjoy life and be free.

I fear that the same thing that happened to Nico and Connor could happen not only to my own daughter but many other young people out there.
WE HAVE TO JOIN TOGETHER AND DO SOMETHING THAT WILL REALLY MAKE THE DIFFERENCE NOW AND IN THE FUTURE.