



This document contains the exact words shared with us by the parents and families featured in Day 8 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.



Just to say the #LBBill is important to me because the two beauties in this picture have autism.

I want to make sure they are never subjected to what Connor and others have been, when they grow up and out of my care and protection as their parent.

I dont want them warehoused somewhere hundreds of miles away.

I can only begin to imagine how it would destroy them (and me), and to be honest, I dont want to have to think about it. It's terrifying. It should never happen.



This is Michael my Son who is 48 years old. Michael lives in his own shared ownership bungalow, (part rent, part buy). Michael is able to do this through ILF funding and Social Services Direct Payments which pays for personal assistance to have a full social life, volunteer at his local elderly persons home and attend college. Before ILF Michael's funding from Social Services was not enough to keep him safe and well. Michael was frequently attacked by people in his block of flat's. Michael was also financially abused by one of his carers, and a petition was raised locally to try to get him evicted, his crime ? "He should not be allowed to live with amongst ordinary people" "He should be somewhere more suitable" This was over 15 years ago now and not only does he live in his own home so nobody can request his eviction, Michael has the appropriate level of funding, Thanks to ILF to keep him safe and well.

I think with everything Michael went through in his early attempts at independent living, he has earned the right to live where and how he chooses, also to have enough support, regardless of cost, to do so. However, I am deeply concerned for his future support as ILF will close in 2015 and over 18000 people, many with learning disabilities will lose their funding. This is meant to be picked up by LA's but the government are only providing money for the first year. My fear is that unless compelled by law, my LA will refuse to meet the full cost of Michael's support. I am totally behind this bill as I think it will make a huge difference to the rights of those like Michael, who wish to be adequately supported to live independently.



This photo of Joe is a couple of years out of date, but I love it because this is who Joe really is: affectionate, full of joy and energy, and capable of a level of happiness that only those able to live in the sensory delights of the moment can know. He was 16 then, and now he is 18.

Since he was 7 years old, I have fought hard for Joe to be placed in schools where he feels safe and where his peers can engage with him in the humour filled, friendly way he recognises and responds to. This was after two years of having to drag him over the threshold of a specialist placement where none of the peer group could interact with Joe positively, where his hair was ripped out, and he and others were restrained regularly. Joe was so anxious in this environment and social grouping that he had to escape it at any cost, and he learnt along with his peers, that challenging behaviour was the way to be removed from a stressful group situation. This became the way he communicated and I was struggling to manage him at home. Overnight respite in another specialist setting was suggested but I knew this would make Joe miserable and the situation worse. Instead, social services sent me on safe restraint training and we used direct payments to employ staff who Joe liked to do the things he enjoyed in the community.

Once I got him out of the specialist school and into local, more inclusive provisions, Joe started calming down and over the next 7 years, the incidences of challenging behaviour and the need for restraint diminished to none.

But at 16, the always difficult task of finding a local and more mainstream setting to accept Joe became impossible. No local college or sixth form would have him, even though the challenging behaviour had now pretty much

disappeared, Joe was simply 'too disabled' for them. We were forced to go back to a segregated school with a high level of challenging behaviour and little appropriate peer group interaction. Over the last two years Joe has lashed out a couple of times, but mainly his challenging behaviour hasn't returned. Yet.

However, he is not the boy in this photo. No one at his school knows that boy. Joe's eyes don't sparkle like that any more. He doesn't instigate a cuddle or tickle with me or anyone else. He doesn't actually instigate anything. He is anxious and confused all the time he is in company, and deals with his fear by being entirely passive and not expressing any preference or wish of his own. He would comply with anything rather than risk being or doing 'wrong'. I can't tell you how frightening I find this.

Sometimes when Joe is alone in his room listening to music, or on his own on the reinforced swing in the garden at night, the old giggles and exuberance come back, but socially and communicatively his confidence has gone.

We are now looking for a post 19 placement for Joe and this time it feels like we haven't even been given the illusion of a choice. Local colleges have viewed Joe in his special school and written him off as not suitable for them (what about what is suitable for him?) Then we were told that a council panel meeting had decided to place Joe out of area in an independent, specialist college run by the same providers with the same peer group as his first school. No one attended that panel who knew the Joe in the photo, and no one who knew and loved him was invited to contribute to that decision.

This is a very brief history to explain why I support the #LBBill. After 20 years of being a mother of two sons with autism, and 12 years working in the autism field, I still cannot believe that decisions are made for the Joes of this world - the most vulnerable people in our communities - that are not based on who they are; what makes them happy; what makes them feel and be safe; who they enjoy being with, and what they are good at. When any other young person chooses a sixth form, college course, or place to live, aren't these the criteria they use? Who can be happy doing a course that always concentrates on the things they are bad at or unable to do? Who can be happy or learn in a peer group or environment where they are not safe, and do not feel safe? Who can have a quality of life when they have to spend every day with people who scare them and give them no positive interaction or feedback? Who learns appropriate social behaviour shut away from socially able people and the local community? How can we be so inequitable?

I want Joe to have equal rights to inclusion in his family, his community and all other services and institutions. I want decisions to be made on his behalf that use the same criteria the rest of us use to make decisions - in short, will this make me happy, and will I be safe and well? I want to be listened to the most because I know and love Joe the most.

The Joe in the photo. The real Joe. The happy and safe Joe.



This is my son, Jamie. He has autism, LD and schizophrenia. He also has the most wonderful sense of humour and happy personality. People never fail to like him. He loves to be out and about and loves to be with friends and family. In fact he just loves life and, in that respect, he is a lesson to us all. #LBBill would give him the right to choose how to live his life to the full, to make the most of opportunities that come his way and realise his potential.