From Legislation To Family Life – What's In It For Us? A power point presentation from the Living Autism Conference 2013

Introducing Eddie

What difficulties have we faced over the years?

- Difficulties in getting a diagnosis
- Recognition of needs
- Lack of information
- Lack of understanding
- Lack of support
- Poor access to existing services and a lack of appropriate services to meet his needs
- The battle for everything!

What have we achieved?

- We got the appropriate diagnosis – eventually!
- We got his needs recognised – eventually!
- We found the information we needed – largely unaided
- We brazened it out in the community despite the 'goldfish bowl effect'
- We found support where we could and started a support group to help other families
- We got him the services he needed somehow – but at huge cost to our own mental health

IT ALL CAME DOWN TO US!

The Autism Act

What did we hope for as a result of the legislation?

- That things would be easier for Ed as he moves through life
- That we would not have to battle at each stage for what he is entitled to
- That other families would also find it easier to get the needs met of their family member with autism

What has been the reality?

- Not much has changed for the better – how depressing!
- There seems to be a greater awareness of autism out in the community … maybe a greater tolerance and better understanding and acceptance … or am I just kidding myself?
- Families are still having to battle for diagnosis, recognition of need, information, support and appropriate services … and some of it is getting worse …

A global and national crisis!!!

- Economy – tax changes, benefit cuts, wage freezes
- Unemployment – especially for the young - NEETs
- Housing – bedroom tax, dearth of social housing
- NHS – cuts to services for physical and mental health
- Social Care – Winterbourne View, lack of expertise among social workers
- Education – Michael Gove's changes

All bad news for everyone – even more so for autism!

Examples

- A 25 year old young man who lives at home with mum and dad. Diagnosis of Asperger Syndrome, OCD, Schizophrenia. Can't get benefits he is entitled to because he can't cope with going to the job centre and there is no flexibility to help him. Where are the reasonable adjustments?
- An 18 year old young woman in her last year at special school. Parents like the specialist college close to home that she could access as a day student and think it would meet her needs, but places are limited and she may not get one. Why are there not more places or more specialist colleges?
- Another 25 year old who lives in his own flat. He panics when alone but his funding package does not allow for the hours of support he needs so he texts people he knows all the time saying he's so depressed he's going to commit suicide! Where is the mental health support he needs?

More examples

- A 20 year old young man with AS who has the academic ability to go to university but lacks daily living skills despite years of his family trying to teach him. That kind of support will not be available to him because he is too able. What real choices does he have?
- A 34 year old with MLD and autism who wants his own place but hasn't the independence skills so he remains at home with mum and dad. What happens when they are no longer there? Likewise a 27 year old who is so able he gives talks on autism and holds down a job but can't wash his own clothes. Who can help him gain greater independence?
- Our own 27 year old – he needs to move on eventually too, but where to? We can't even find him access to the music therapy he loves and so benefits from because there is none available even though he has the money to pay for it – even leisure services are not there on demand.

What needs to happen?

- Staff across services STILL need better training
- Mainstream services need to be more flexible
- We need more specialist services and a greater variety of services to meet individual need - right across the board
- We need more resources – human and financial
- People with autism need advocacy
- Families of people with autism need continuing support
- The general public needs more awareness of the needs of people with autism, but also of their strengths and the positives they bring to our world
- We have got to get better as a society in recognising, assessing and meeting individual needs – not just tinkering with diagnostic terminology and eligibility criteria to make as little as possible go as far as possible!

If you need help looking for services for an individual with an autism spectrum condition, we can help. Click below for the Autism Placement Support Service.

Click here for our Autism Placement Support Service