

SUBMISSION FROM KIRSTEN GILLESPIE

1. I am writing to show an example (my own) of how the current Mental Health and Social Services are failing to meet the needs of people with Autistic Spectrum Disorders (ASD).
2. I have been in the mental health system for 10 years now. Not once have I received appropriate therapy. All I am offered is cognitive behavioural therapy (CBT) which just does not work for me, or for a lot of people on the autistic spectrum. 6 – 12 weeks, extendable to a maximum of 18 weeks of therapy simply does not work. My disability is life long, it cannot possibly be fixed within 18 weeks.
3. It would be important to note that I was in the "system" for seven years before obtaining a diagnosis of Asperger's Syndrome. This was never suggested to me by any professionals in my dealings with the NHS as a condition I might possible have. It was only after reading about it and realising that it explained a lot of my problems, that I sought a formal diagnosis at the age of 30.
4. I have seen more CBT therapists than I care to remember over the past decade, even though it should have been obvious that CBT was not the correct approach from early on. I believe that I am now labelled with the stigma of being a difficult patient within the mental health centre that I attend. I am told repeatedly that I am complicated and not offered any suitable treatment. I am simply given a short appointment once every 4-6 months in which I am meant to review my treatment, treatment that I am not receiving. I have received absolutely no therapy at all this year despite asking many times for help for both depression/anxiety issues and an eating disorder.
5. Standard therapeutic approaches for eating disorders are inappropriate for people such as myself. Therapists do not understand how particular I am about certain types, tastes and textures of food, coupled with the fact that change is extremely difficult. They view it as avoidance rather than an actual issue. A great many people on the spectrum have extremely particular food habits. This needs to be understood and accommodated.
6. I find going outside a huge challenge. As with many people on the spectrum, I am extremely isolated. I have no friends or family to support me in this. As a result I am imprisoned in my own home. In the past I was given a care worker from a service that was geared towards mentally ill patients. I suffer from certain conditions such as anxiety and depression, but a large part of this is directly due to having Asperger's Syndrome, and attempting to fit into a world that for all intents and purposes is running backwards for me. The experience was a disaster. The service was completely inflexible and unable to understand or meet my basic needs. I was talked to like I was an idiot when we went outside, which only added to my anxieties. I do not class myself as a mental health patient. I cannot cope due to my disability, along with being unable to process difficult thoughts and emotions

out of my head in a timely fashion. As a result I get extremely overwhelmed on a daily basis.

7. The current guidelines for support agencies is that services are client centred. The reality of this is that there is no guidance. I have to instruct a carer what I want and how to do it, then we do it. This seems bizarre to me. If I knew how to do everything, why on earth would I need support? I NEED guidance. I want someone who knows when to step in and take over, and when to step back and relinquish control of a situation, and most importantly know the intricacies of subtlety. Current support services just do not cater for this.
8. I have been granted direct payments, but Social Work has no funding so I am left with nothing. I have not been given any advice on what to do in the meantime. There is a huge gap in services. I was originally given a social worker from the Learning Disability division. I have since been passed to Mental Health. I fail to see the point of this since I am not actually receiving support of any kind, from anyone.
9. I hope this may shed light on some of the failings of the current system, and highlight areas that need and should be changed. The system has made a great many of us feel broken and invisible.

Kirsten Gillespie
3 October 2010