Dear Philip Alston,

I hope that during your travels you will look at the plight of adults with learning disability under austerity. Cuts have meant that too often they are included in policy making and discourse under the labels of ‘disability’ and ‘mental health’ or lumped together with autism. Consequently their own needs are considered less and less e.g. the young man who was recently given a lengthy but standard dementia test with no consideration of his special needs of which the doctor seemed to have no knowledge and did not hold the notes from the previous 2 tests. The result is unnecessarily time wasting and costly.

Just like the blind who need help to walk, those with learning disability need help to find a voice. They also have hopes and dreams and interests just like everyone else.

Local authority cuts have meant loss of advocacy, closure of centres and adult learning, loss of transport, social workers and support workers. More and more family carers (where they exist) are having to step up. Care packages are being slimmed down and opportunities for socialising diminished more and more. The result is increasing boredom. Isolation, loneliness and depression and increase in mental health problems.

As far as benefits go, where parents are still alive, they are forced to fill in time consuming application forms, providing new evidence each time, despite the fact that their children have been in the system all their lives, their condition has not changed and their health problems are likely to multiply as they grow older. My Downs syndrome son is 51. Why should I have to continue to justify his existence as if he’s some kind of figment of my imagination for which I must be punished?

What’s more, in the face to face assessments, carers as appointees must enumerate the things wrong with their child in minute detail and in front of the person whose confidence they have always tried to promote. This is abuse.

The so called ‘health professionals’ who do the assessments do not understand that people with learning disability always want to please and to present themselves in the best possible light. One assessor asked, ‘When did you catch Downs syndrome?’ Questions contain hidden minefields e.g. a person might answer that they can cross a road but lack enough understanding of their own condition to include that they have no concept of danger.

Please ask all those officials you meet, the specific question regarding loss of services to adults with learning disability. Most importantly ask adults with learning disability and their supporters themselves.

Yours sincerely,

Sue Hubbert (Adults First, a group for family carers in the London Borough of Merton).