

Dear Dr de Gruchy

We are both former GPs who are parents of adults with severe learning disability and autism. We are also active in the voluntary sector, supporting people with autism at local and national levels. We are writing to you because of serious concerns about proposals by Haringey Council that would reduce access to services for many local adults who are critically disabled by autism and/or learning disability. In your role as Director of Public Health for Haringey, you have a professional responsibility to promote the health and well-being of these highly vulnerable adults and their carers. We want to ensure that you are fully aware of what is being proposed and the likely impact so that you may represent their interests in advising the council.

We attach various letters written by family carers to councillors and to the chairman of the local clinical commissioning group. These explain the situation. In brief, Haringey Council proposes to markedly reduce expenditure through moving to a new models of care. These are sketchy but seem to rely on moves to supported living with any daytime activity taking place in and assisted by 'the community'. This will apparently be so successful that care packages can be reduced, and existing council-run services such as day-centres can be closed. We are extremely doubtful that these proposals will lead to any cost savings in other than the extremely short-term. Rather, we believe that they will lead to crisis and very costly emergency placements and admissions under the mental health act. The human cost will be enhanced distress to vulnerable individuals and to families that are already on the edge of coping.

Council documents seek to justify the proposals with fine sounding words that are wholly lacking in evidence. They ignore the harsh reality of what can reasonably be accessed in our local community day-in day-out and the nature of the needs of people with autism and/or severe learning disability. They speak glibly of voluntary sector support despite the fact that local voluntary sector organisations are almost on their knees, and at least two have had to make staff redundant in the recent past. They speak hopefully of preventive work reducing need in future whilst not seeming to understand that any gains from early intervention with a younger cohort does not remove the need to support the older cohort.

The people who meet council criteria for services often have: critical difficulty in making sense of their environment and the behaviour of others; crippling levels of anxiety that can escalate very rapidly; poor communication, and behaviour that can seriously challenge carers and any others they encounter in the community. They have great difficulty coping with change and uncertainty and need a highly structured environment and intensive support from trained staff who are familiar with them and their needs. Many have epilepsy and other complex health problems including psychiatric disorders.

We understand that the council scrutiny committee has referred the proposals back to council officers with the requirement that they explain the evidence behind their suggestions. We

would point out that NICE made an assessment of evidence and reported in 2012. NICE highlighted the importance of being “aware of the sensitivity of some people with autism to changes in their physical or social environment and the possibility of very rapid escalation of problems, including risk related problems’. NICE recommended that choice of interventions should be based on past history of care and support in addition to other factors – in other words, there is substantial risk in making changes. In general, studies of care settings and specific interventions for adults with autism have been of poor quality. NICE found one study that met its criteria and this related to the positive effects of a TEACCH approach which uses highly structured planning of activities. Taking into account, advice from their appointed experts, they concluded that effective provision of care included a structured environment with scheduled activity in and outside the home. The bulk of NICE recommendations extrapolated from data are for adults with a learning disability. These generally support small group living settings but it is clear that each type of living arrangement has advantages and disadvantages that may vary according to individual need. We are therefore concerned that the council should seek to impose one particular model of living and have been extremely worried by pressure to reduce care package costs in a way that can only be achieved by reducing carers’ wages. This is not compatible with the trained workforce required to implement structured approaches and the need for consistency of staffing that is crucial to minimising anxiety and challenging behavior.

Yours sincerely,

Hilarie Williams/Gedroyc

Michael Fitzpatrick