

COUNTY COUNCIL LOCAL COMMITTEE FOR CARLISLE

Meeting date: 5 January 2021

From: Christine Bowditch –Champion for Autism

AUTISM CHAMPION UPDATE

I do consider People First to be one of the foremost in being the 'voice of autism and disability' in Carlisle. Their members are truly vocal in describing the issues which most concern them. At the recent Autism and Learning Disability Board meeting they described the continuing difficulties in their lives. Important health check issues, with particular concern over phone checks which are often difficult for people to understand. Over-medication issues, late diagnosis for autism, lack of counselling, reasonable adjustments required by law not being made, lack of support for dental care, mental health problems sometimes assessed as being about disability when it is not and lack of support in hospital.

In response to some of the above, Cumbria Clinical Commissioning Group has set up, as part of the National scheme, the Learning Disabilities Mortality Review 'stop people dying too young'. In North Cumbria, shockingly, people with disability can die 15-20 years earlier than the rest of the population. They outlined support given in hospitals - hospital 'passports' 'relevant medical reviews, end of life care plans, sharing of records with permission, cancer screenings. This is all to the good, however, the review also found that in some cases clients or their families were not included in decision-making, mental capacity tests did not take place, lack of evidence that hospital 'passports' were always used by staff, judgements were sometimes made not to continue with cancer treatment and most disturbingly, a report that having a Learning Disability was given as a reason for non resuscitation.

Families and adults continue to struggle to receive a diagnosis for autism with only 50 people a year being diagnosed. There is a long waiting list for diagnosis with, reportedly, some doctors not taking the requests for diagnosis seriously.

Grim news for autistic children and adults and their families following a grim year but progress is being made and there are some positive, able professionals working towards making life better for autistic people. I salute them.

**Christine Bowditch
Autism Champion**

December 2020