Learning Disability and Health – Obesity, Diet and Exercise (papers previously prepared by James Reid at Rescare)



In summary, statistical evidence (of mortality rates within the UK population) clearly indicates that people with  learning disabilities die much earlier than their peers.  Also, their quality of life will often be adversely affected by the standard of care they receive (including health care) – and that quality of life is *more likely* to affected by obesity.
There is research being carried out into learning disability and health, and indeed it is now an immediate objective of the NHS to improve the health of people with learning disabilities and/or autism (Read on to learn about or be reminded of the NHS 10 Year Plan).  BUT wider public and media attention is now focused on ‘the obesity crisis’ within the general UK population – *and Rescare sees it as one of its priorities to point out that people with learning disabilities and/or autism are part of that general population, and are similarly (in fact more acutely) affected by obesity and its effects.*On 11th October 2018, the writer attended a conference in Birmingham organised by Public Health England (PHE) entitled ‘P*ublic health and people with learning disabilities: national evidence for local action’.* It’s complicated (it always is), but in summary the conference comprised a consultation by PHE on what recommendations it should make to the NHS with regard  to the NHS’s long term plan, aka ‘[the NHS 10 Year Plan](https://www.engage.england.nhs.uk/consultation/developing-the-long-term-plan-for-the-nhs/user_uploads/easy-read-nhs-10-year-plan-discussion-guide-v3.pdf)‘. The Plan  was announced in August, as the NHS celebrated it 70th birthday, and specifically made ‘autism and learning disability’ one of its four clinical priorities. PHE’s CEO, Duncan Selbie [welcomed the Plan](https://www.gov.uk/government/news/local-government-nhs-10-year-plan-and-a-prevention-opportunity) , noting that *“The burden preventable illness puts on public services is also clear. Obesity-related ill health costs the NHS around £6 billion per year, while the impact of obesity on local authority social care budgets is estimated at £350 million per year”.*

I made a few contributions to discussions at the conference: I am awaiting feedback from the conference, and future updates, which I will report on here. I also wrote [a blog post about the conference](https://www.rescare.org.uk/public-health-england-the-nhs-and-people-with-learning-disabilities/).
To save time, and to avoid ‘reinventing the wheel’, I reproduce below two articles which appeared in recent editions of Resnews, and which comprise a pretty extensive overview of the issues involved, and of the results of our initial research.
*Note 1: I include web-links where appropriate, which may prove useful to anyone wishing to explore further the intertwined issues of learning disability, health and obesity.*
*Note 2: I have not yet checked on recent developments in Scotland, but am aware that in 2013 the Scottish Government launched a long-term strategy ‘*[*The keys to life*](https://www.gov.scot/resource/0042/00424389.pdf)*‘ subtitled ‘Improving quality of life for people with learning disabilities, and I report below on the role of the Scottish Learning Disabilities Observatory (SLDO).*

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**The scale of the obesity crisis i.e. the rising rates of of obesity in children and adults across the UK and the rise in the incidence of diabetes and health conditions, is receiving sustained attention in the media.**

There are frequent articles on the topic in our newspapers, and there have been numerous TV documentaries on the consumption and production of processed foods. We have of course seen the introduction,with great fanfares, of ‘the sugar tax’. Within the Scottish Government there is now a Minister for Public Health who will develop and oversee new ‘anti-obesity’ initiatives. In England, this responsibility was assigned to Public Health England. In March 2017 Public Health England posted on the GOV.UK website an new section entitled [*‘Health matters: obesity and the food environment’*](https://www.gov.uk/government/publications/health-matters-obesity-and-the-food-environment/health-matters-obesity-and-the-food-environment--2). This emphasises the scale of the problem, and ends with a Call to Action, requiring the involvement of local authorities’ education and public health departments and of medical professionals. One person backing this campaign is the ever-modest Jamie Oliver. Oliver’s Food Revolution Foundation (see [www.jamiesfoodrevolution.org](http://www.jamiesfoodrevolution.org/)) is demanding change or improvement on six areas: taxation policy, reduction in sugar use, food marketing, food labelling, school food, and education. Another celebrity campaigner, Hugh Fearnley-Whittingstall has fronted the BBC1 documentary series ‘[Britain’s Fat Fight](https://www.bbc.co.uk/news/health-43838655)’
At a recent meeting of Rescare’s committee, the issue of obesity and learning disability became a subject of discussion. Trustees described their experiences of the problem as parents and carers. Rescare staff contributed their own experiences and those of callers to the helpline. The committee speculated that the incidence of obesity amongst people with learning disabilities is far above the national average (and it is estimated that two thirds of all Britons are overweight!). It was no surprise to learn that this speculation is confirmed by the NHS. The opening sentence of a new NHS web page entitled ‘Managing weight with a learning disability’ ([nhs.uk/Livewell/Disability/Pages/weight-management-learning-disabilities.aspx](http://nhs.uk/Livewell/Disability/Pages/weight-management-learning-disabilities.aspx)) states: “*If you care for a person with a learning disability, they may need help and support to stay a healthy weight. People with a learning disability are more likely to have problems with their weight. Some people may be underweight because their disability means they have difficulties with eating or swallowing, for example .Others may be overweight because they have a condition that increases their risk of obesity, such as Down’s syndrome and Prader-Willi syndrome.”*

Rescare’s trustees debated the use and possible overuse of medications. The use of risperidone, frequently prescribed to manage anxiety in autistic children and adults, was hotly debated, especially since any list of its common side-effects is headed by weight-gain. There was a general feeling that, at a time when local authorities’ budgets for social and personal care are under severe financial pressure, health and care staff are too quick to resort to medication to manage mood and behaviours. Some cited from personal experience the failure of social workers and care staff to encourage people with learning disabilities into a healthier diet and especially away from fast- or junk-food. One trustee noted that if there was no day-centre or recreational facility to visit, ‘another trip to the town-centre and McDonalds’ is a severe temptation. Another complained that many recreational facilities are facing closure , or imposing higher fees; and that higher contributions to the cost of ‘non-essential activities within care plans’ were being demanded, giving people with learning disabilities less opportunities to exercise. Ironically , [that NHS web page](http://nhs.uk/Livewell/Disability/Pages/weight-management-learning-disabilities.aspx) states: ‘Exercise is key to managing weight. It helps burn calories for people who need to lose weight… Ask the person you look after what activities they are interested in. Try to think of ones that will fit into their routine and that they enjoy. If you can, organise some regular physical activity and support the person you care for to make sure it happens’.

Ultimately, discussion came down to a debate on the meanings of capacity within the decision-making process, the meaning of choice, and the possibilities of someone with a learning disability making ‘an informed choice’. Do people have the right to decide to over-eat, or follow a poor diet , or not to take exercise, when they cannot appreciate the full consequences of their decision in terms of the risks to their health and their longevity? Rescare trustees and staff cited the reluctance of social workers and care staff to intervene more ‘assertively’ over diet and exercise. They considered the compatibility of the concept of wellbeing (cited in the Care Act) and decision-making rights (cited in the Mental Capacity Act). Are there not contradictions between the Mental Capacity Act and the Care Act? Could there possibly be contradictions within the Care Act? The Care Act Guidance states that wellbeing ‘relates’ BOTH to ‘physical and mental health ’ AND to ‘control by the individual over their day-to-day life including over care and support provided’.

In researching this article we have (belatedly) become aware of the [Caroline Walker Trust (CWT)](http://www.cwt.org.uk/). The CWT is dedicated to the improvement of public health by means of good food. It was established in 1988 to continue the work of the campaigning nutritionist Caroline Walker, who believed that everyone deserved access to good-quality food. In 2007 CWT published a report ‘Eating well: children and adults with learning disabilities. Nutritional and practical guidelines’. This included practical guidelines, which readers may find useful. It is available to download from the [CWT website](http://www.cwt.org.uk/) . It echoes Rescare trustees’ concerns about the effect of medication: *“Many people with learning disabilities take a number of different drugs, both those prescribed by medical practitioners as well as over-the-counter medicines. Many drugs influence appetite, food intake and ultimately nutritional status.”*

● Rescare is committed to pursuing this issue (of learning disability, diet, obesity and health) in the longer term. We intend to contact several of the parties mentioned in this article, to express our concerns. The immediate task is make others aware of how acutely this issue affects those with learning disabilities. We will begin by by contacting relevant ministers in the UK and Scottish Parliaments, and the All Party Parliamentary Group on Learning Disability. We hope to contribute observations based on our many years’ experience of supporting family carers, We will update you via Resnews, and add some dedicated content to the website. If you have comments on this issue, please contact us by post or email.

● A specific concern raised by our trustees was the quality of dietary provision in residential care placements. One trustee wondered what specific questions were asked during CQC inspections. Initial investigations suggests that the CQC has obligations under the Health and Social Care Act 2008 and its Regulations (updated 2014) to ensure that people who use CQC-regulated services *‘have adequate nutrition and hydration to sustain life and good health’*. CQC must also fulfil its duty to ensure that providers conform to current food hygiene legislation. We will write to the CQC for a clear description of how it fulfils these obligations.

●**NICE**. Further to the key finding of the Parliamentary Select Committee’s post-legislative scrutiny report, that ‘the Mental Capacity Act, is not widely and adequately implemented’, the National Institute for Health and Care Excellence (NICE) is currently preparing a new guideline on ‘decision-making and mental capacity for people using health and social services aged 16 and over’. The settings covered will include community settings such as supported living, and ‘care homes of any type’. NICE expects to publish the new guideline this July. NICE has acknowledged that it will need ‘to be aware of other legislation’ including the Care Act. We wait to see how NICE ‘squares the circle’ comprising the concepts of best interests and wellbeing. (**Note:** now published October 2018 <https://www.nice.org.uk/guidance/ng108> )

● **STOMP**. Finally, we must also bring to your attention the campaign [STOMP](https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/) – ‘Stopping Over Medication of People with a learning disability, autism or both with psychotropic medicines’. Launched in May 2017, it has the backing of [NHS England](https://www.england.nhs.uk/2018/04/nhs-england-urges-more-doctors-and-health-care-professionals-to-sign-up-to-national-pledge-to-stop-overmedication-for-people-with-a-learning-disability-autism-or-both/), Public Health England, and many other public bodies and voluntary organisations across the UK.
This how NHS England describes STOMP on its website: “*It is a national project involving many different organisations which are helping to stop the over use of these medicines. STOMP is about helping people to stay well and have a good quality of life. Psychotropic medicines affect how the brain works and include medicines for psychosis, depression, anxiety, sleep problems and epilepsy. Sometimes they are also given to people because their behaviour is seen as challenging. People with a learning disability, autism or both are more likely to be given these medicines than other people. These medicines are right for some people. They can help people stay safe and well. Sometimes there are other ways of helping people so they need less medicine or none at all. It is not safe to change the dose of these medicines or stop taking them without help from a doctor.*”
Public Health England says that every day about 30,000 to 35,000 adults with a learning disability are taking psychotropic medicines, when they do not have the health conditions that the medicines are for. Children and young people are also prescribed them. *“Psychotropic medicines can cause problems if people take them for too long. Or take too high a dose. Or take them for the wrong reason. This can cause side effects like: putting on weight; feeling tired or ‘drugged up’, or problems with physical health.”*
In April this year the NHS renewed its drive to encourage health professionals to sign up to the STOMP pledge. The launch of the pledge campaign last year led to 60 healthcare providers signing up to take action. NHS England now wants remaining clinical commissioning groups, NHS trusts and independent providers to also sign up. John Trevains, NHS England’s head of Mental Health and Learning Disability Nursing, asserted that healthcare providers had a very important role in stopping the over-prescribing of these powerful drugs: ‘It is really important that people only receive psychotropic medication when all other approaches have been considered. Everyone, including the person with a learning disability, autism or both, and their families, needs to be involved in the decision-making and clear about why such medication is needed.’
If you need help or information on this issue, it is available on the websites of NHS England and of several charities e.g. the Challenging Behaviour Foundation ([CBF](https://www.challengingbehaviour.org.uk/)) – or as ever, contact the Rescare office for assistance.

(Article 2 in Resnews edition 2018.1)

**Further to the article the previous Resnews, I have investigated further which individuals and organisations are researching or campaigning on the dietary habits, obesity levels, and use of prescribed medications a) within the general UK population, and b) amongst people with a learning disability and/or autism. It was astonishing how much it was possible to discover with a bit of persistence.**

Summary of research findings:

● Previous efforts within the DoH to address the issue of Learning Disability and Obesity. In 2011 NHS Midlands and East launched a flagship project ‘A Learning Disability and Obesity Charter’. This aimed to address facts which were known 9 years ago i.e. that less than 10% of people with learning disabilities in supported accommodation eat a balanced diet or enough fruit and vegetables; that over 80% of adults with learning disabilities engage in levels of physical activity below the DoH’s minimum recommendation. The aim was to have a range of care and service providers sign up to a charter committing themselves to higher standards and targets. The objectives were hugely ambitious: it has been difficult to find out how successful the charter has been in the last 9 years. Even before 2011, the disproportionate levels of obesity and physical inactivity had been cited in report ‘Equal Treatment – Closing the Gap’ from the Disability Rights Commission in 2006, and in the government’s White paper ‘revamp’ , Valuing People Now in 2009. This problem of health inequality and the issues of obesity, diet and exercise is a long standing one and recognised as such.

● Academic Research into Learning Disability and Health is of course ongoing at various institutes and universities, conspicuously at St George’s University of London Hospital. The epicentre for the collation and publication of such research is the University of Hertfordshire, which hosts a resource entitled ‘Understanding Intellectual Disability and Health’. This is administered by an Editorial Board, and its website, [www.herts.ac.uk/intellectualdisability](http://www.herts.ac.uk/intellectualdisability), though not aimed at family carers, is very informative. There is a useful ‘Links’ page, and sections entitled ‘Family’, ‘Life Stages’, ‘Physical Health’ etc. It is my intention to write to selected members of the editorial board and published authors to make them aware of Rescare’s worries about obesity. Some possible addressees are already familiar to Rescare e.g. Baroness Hollins, and Sandra Dowling , research associate at the Norah Fry Centre at Bristol University.

● Recently, after I had a test of my own blood-sugar levels, I speculated on the levels of diabetes amongst people with a learning disability and/or autism, as compared to the general population. I learnt that in July last year the NHS RightCare Project published a report NHS RightCare Project, subtitled ‘Reasonable adjustments for people with a learning disability who have autism’. The report comprises the latest guidance to commissioners and service-providers. Its Summary confirmed that my suspicion that prevalence rates for both Type 1 and Type 2 diabetes ARE higher. The ultimate aim of the recommended reasonable adjustments are a) to improve diagnosis and detection and b) to reduce complications and emergency visits to A&E and GPs. Adjustments are anticipated at various stages in assessment and treatment, including ‘weight management programmes’ and ‘personalised care planning’ . The key milestones for commissioners were ‘Know your population’ and ‘Increase the uptake of annual Health Checks’. This has been a simplistic precis of a long document , available at <https://www.england.nhs.uk/rightcare/2017/11/21/the-need-for-reasonable-adjustments-for-people-with-a-learning-disability-and-diabetes/> , and well worth a look.

● Birmingham Event:‘Thinking about Health and People with Learning Disabilities’.  One of the contributors to the the NHS RightCare Pathway was Professor Gyles Glover, Co-Director of the [Learning Disabilities Observatory Team](http://webarchive.nationalarchives.gov.uk/20160704150433/http%3A/www.improvinghealthandlives.org.uk/projects/primarycaredata/details) at Public Health England (PHE). By coincidence, Gyles was the lead speaker at an event organised by the charitable foundation, the National Development Team for Inclusion (NDTi), in very close conjunction with PHE (now officially ‘an executive agency sponsored by the Department of Health and Social Care’). This event entitled ‘Thinking about Health and People with Learning Disabilities’ was held in Birmingham in July and was open to people with learning disabilities, parents, carers, volunteers and social care professionals. Being interested in the event’s theme, and as the father of an adult son with obesity-related health problems, I accepted an invitation to attend. The agenda covered three main topics: weight and the importance of a healthy diet; mental health and wellbeing; and flu jabs and flu prevention. Each session comprised: an introduction, a presentation of relevant statistics and data by Gyles Glover pitched at a suitably comprehensible level, a group discussion or exercise, and a ‘recapitulation’.

Chief points that I took away from this event were:

● Many of the statistics used by Public Health England and the NHS are supplied by GPs, who submit data from consultations with patients.

People with learning disabilities visit their GP less than often the general population.

The speakers from PHE repeatedly reminded us that people with a learning disability are entitled to an Annual Health Check (a entitlement which they or their carers should ensure is met).

● According to PHE’s collated statistics, the level of depression amongst people with learning disabilities is only slightly higher than that in the general population (13% vs 10%). This claim was met with some scepticism from the audience, and a heated discussion ensued on the ability of GPs and staff in health centres to assess the mental health of people with learning disabilities. This discussion was rounded off with anecdotal evidence from several contributors as to the (in)adequacy or unavailability of psychiatric services for people with learning disabilities.

● Many of the points raised in group discussions about the specific problem of learning disability and obesity raised concerns and issues already cited by Rescare staff and trustees. Gyles Glover cited statistics that 40% of people with learning disabilities are clinically obese (not just overweight) compared with 25% of the general population. This only confirmed my opinion of how serious this issue is.

● It was alarming to see on screen a list of the clinical problems statistically proven to be associated with obesity: heart problems, diabetes, breathing problems; and mental health problems. And of course there are associated problems that affect the quality of life; difficulties in getting about, in participating in social and sports activities, and in managing personal hygiene and cleanliness.

● Participants repeatedly raised the question of awareness amongst medical staff in GP practices, health centres, hospitals and specialist units, i.e. their understanding of people with a learning disability. I raised the issue of the crisis in the recruitment and training of Learning Disability Nurses (see article on page 11); and of the slow progress of the Adult Autism Strategy, introduced in the Autism Act 2009 , which aspires to have Local Authorities and NHS bodies follow national guidance on how autistic adults can ‘get the help they need’.

● A key phrase, used repeatedly by PHE’s representatives, was ‘reasonable adjustments’. I now know that there is a specific page on GOV.UK (www.gov.uk/government/publications/reasonable-adjustments-for-people-with-learning-disabilities). Worth a look: now covers a range of topics, not just obesity but postural care, dementia, and blood tests and injections

● On the subject of the flu injection, it was made clear that guidance on reasonable adjustments for injections and blood tests has now been issued (see above) re desensitisation, safe-holding and sedation. With regard to the flu injection, the slightly less effective nasal spay vaccine may be considered as an alternative, if stocks are available.

● PHE was anxious to correct its own error. In 2014 the Confidential Inquiry into the Deaths of People with Learning Disabilities (CIPOLD) found that respiratory problems were a major cause of death, and **recommended that children and adults with learning disabilities are a high-risk group and should receive the annual flu vaccination free of charge.** PHE has sent advisory guidance to GPs and Clinical Commissioning Groups (CCGs), in the last three years (another specific letter on this issue has just been sent out), but it is still worried that awareness in doctors’ surgeries is too low – and that immunisation take-up will remain too low. If you have a learning disability, insist on your rights.

● The issues of entitlement and reasonable adjustment prompted one attendee to come forward with some interesting information on eye testing. People with learning disabilities are more likely to have sight problems and should have an eye-test every two years, but less than 50% of them will actually have had an eye-test in that period. And most will be in receipt of benefits which entitle them to free eye tests. The charity SeeAbility wants to change this, and offers specialist advice on the issue ( www,seeability.org), which emphasises especially the entitlement to a range of reasonable adjustments to facilitate an eye-test.

● I was already aware that Scotland has acute ‘public health’ problems (on the basis of published statistics, not just fried Mars bar anecdotes), and was aware that the Scottish Government has a Cabinet Secretary for Health & Sport. With regard to people with learning disabilities, the Secretary is advised by an organisation called the Scottish Learning Disabilities Observatory (SLDO) ([www.sldo.ac.co](http://www.sldo.ac.co/)). Gyles Glover was particularly complimentary about Professor Anna Cooper, an academic who leads SLDO, with a very high reputation for the quality of her research into health and learning disability. Much of her published work is available to view online if you have the time to Google, and covers a range of issues.

**Rescare’s advice to people with learning disabilities and/or their carers:**

● Ask for your annual health check with you GP – you are entitled to it, and you will incidentally contribute to an improved accuracy of the statistics used by the NHS and others.
● Ask your GP or psychiatrist for regular reviews of your medication. It’s your right, and it’s the recommendation of STOMP (‘Stopping over medication of people with a learning disability , autism or both’) See the previous Resnews for details of STOMP.
● Ask for your free flu-jab – you are entitled to it.
● Arrange an eye-test every two-years (If you receive benefits, you will probably be entitled to this free of charge)
● Insist that health staff make reasonable adjustments to enable what may be stressful, confusing or intrusive procedures (injections, blood tests, eye tests etc.) to take place.

**Next steps for Rescare:**

● We have devoted significant time to researching this issue. In doing so we have learnt that:
there is a plethora of ongoing medical and academic research on the issue of learning disability , obesity and its consequences, and
that the NHS is concerned about public health and learning disability. It regularly updates its guidelines to health staff; the problem is with how effectively those guidelines are applied in practice. On 11th October senior NHS managers will attend a national conference in Birmingham ‘National Evidence for Local Action’ with the theme of health inequalities and care planning .

● The issues of public health, obesity and diet is very much an issue of the moment, and will probably remain so. As I write this, news media is reporting on a massive (40%) annual increase in rates of detected Type 2 diabetes amongst people under 25. Rescare must argue for inclusion (in a very specific sense), emphasising that when people write or speak about a public health issue (the obesity crisis, the diabetes crisis) and refer to ‘the general population’, that ‘general population’ includes those with learning disabilities and/or autism, who are liable to be even more acutely affected. And that ‘those with learning disabilities and/or autism’ comprises both adults and children, and people in the spectrum of residential and non-residential contexts.

● In practical terms, we must try to ensure that advisory, supervisory, and regulatory organisations, perform their role to improve behaviour ‘at the coal face’ i.e. that health and care workers are made aware of and follow guidance issued. I am thinking of the Royal College of Nurses (RCN), the Social Care Institute for Excellence (SCIE), and the Care Quality Commission (CQC)

● We can give our our support to other voluntary organisations and individuals already campaigning on these issues e.g. the Children’s Food Campaign, STOMP etc., thanking them for our efforts to date.

● We must ‘grasp the nettle’ of the current legislation, which allows people, deemed to have sufficient capacity, to make ‘bad’ decisions, even decisions which in the long term will have disastrous consequences for their health. Rescare has long and consistently argued that current understanding of ‘decision making’ and ‘best interests’, based on interpretations of the Mental Capacity Act and its Guidance do not encourage or support ‘sensible’ interventions by parents or health workers or care staff. This includes interventions around diet and exercise