



PHE Advisory Board Paper

Title of meeting Public Health England Advisory Board
Date Wednesday 19 June 2019

Title of paper **PHE learning disabilities advisory group: a briefing for the PHE advisory board**

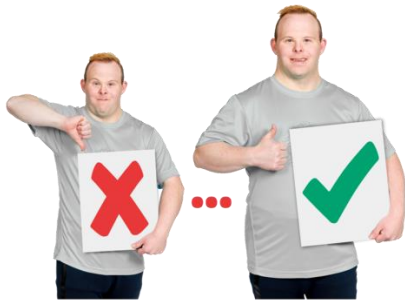


The PHE advisory group are people with learning disabilities, families and carers.



We have advised the PHE learning disabilities work programme for five years.

A small part of this work programme has been about autistic people. Mostly this has been about autistic people who also have a learning disability.



In that time, lots has happened. PHE now have:

- better data about the health of people with learning disabilities
- more evidence
- a network of people to share this information with



How have we worked with PHE?

We have **challenged** – we told PHE that we didn't like being asked to comment on things that had already been decided.

We changed the way we worked so we helped plan work before it was done.



We have **suggested** topics that are important, such as epilepsy, postural care and constipation



We have **changed** things - we helped to make changes to the PHE easy-read information about the flu vaccination.



We have **made links**. We pointed out that dental care is linked to dysphagia and constipation. These are important health issues for people with learning disabilities.



Dentist

We have **raised concerns** about why we don't get the health care we need.

We told PHE that people with learning disabilities were having problems getting dental care. This is because the forms we need to fill in for free treatment are confusing.



Although we have done lots of work, people with learning disabilities still have poorer health than other people.

They die 15-20 years younger than other people. Often, the reasons for their death can be avoided.



We are pleased that PHE promises to work to improve the health of people with learning disabilities in its equality objectives



PHE work closely with NHS England.

We are also pleased that improving the health of people with learning disabilities **and autism** is a priority in the NHS Long Term Plan.



This year PHE have made some changes to how they do work about the health of people with learning disabilities (and autism)



We want to talk to you about how we can carry on working with PHE to improve the health of people with learning disabilities.



We also want to make sure that PHE are thinking about autistic people, especially those who do not also have a learning disability.

Our group are not experts on the lives or health of autistic people who do not have a learning disability.

Appendix A

Publications from April 2018 to April 2019

Baines, S, Emerson, E, Robertson, J & Hatton, C 2018, 'Sexual activity and sexual health among young adults with and without mild/moderate intellectual disability' *BMC Public Health*, vol. 18, no. 1, 667. DOI: 10.1186/s12889-018-5572-9

Baines S & Hatton C (2018). CQC inspection reports for acute NHS Trusts: Are there relationships between the comments in inspection reports regarding people with learning disabilities and CQC hospital/trust ratings? *Tizard Learning Disability Review*, 23, 56-62.

Emerson, E, Hatton, C, Robertson, J & Baines, S 2018, 'The association between non-standard employment, job insecurity and health among British adults with and without intellectual impairments: Cohort study' *SSM - Population Health*, vol. 4, pp. 197-205. DOI: 10.1016/j.ssmph.2018.02.003

Giraud-Saunders, A. & Marriott, A. (2018). Dementia and people with learning disabilities: making reasonable adjustments. June 2018.
<https://www.gov.uk/government/publications/people-with-dementia-and-learning-disabilities-reasonable-adjustments>

Glover G & Mehta H. (2019). Psychotropic drugs and people with learning disabilities or autism. March 2019. <https://www.gov.uk/government/publications/psychotropic-drugs-and-people-with-learning-disabilities-or-autism>

Glover, G, Williams, R, Tompkins, G, Oyinlola, J. (2018). An observational study of the use of acute hospital care by people with intellectual disabilities in England. *Journal of Intellectual Disability Research*, DOI: 10.1111/jir.12544

Hatton C (2018). Paid employment amongst adults with learning disabilities receiving social care in England: trends over time and geographical variation. *Tizard Learning Disability Review*, 23(2), 117-122.

Hatton, C, Emerson, E, Robertson, J & Baines, S 2018, 'The mental health of adolescents with and without mild/moderate intellectual disabilities in England: Secondary analysis of a longitudinal cohort study' *Journal of Applied Research in Intellectual Disabilities*, vol. 31, no. 5, pp. 768-777. DOI: 10.1111/jar.12428

Marriott, A. (2019). Oral care and people with learning disabilities March 2019. Public Health England report. <https://www.gov.uk/government/publications/oral-care-and-people-with-learning-disabilities>

Marriott, A. (2018). Postural care services: making reasonable adjustments. May 2018. Public Health England report. <https://www.gov.uk/government/publications/postural-care-services-making-reasonable-adjustments>

Robertson, JM, Baines, SMJ, Emerson, EB & Hatton, CR 2018, 'Constipation management in people with intellectual disability: A systematic review' *Journal of Applied Research in Intellectual Disabilities*, vol. 31, no. 5, pp. 709-724. DOI: 10.1111/jar.12426

Robertson, JM, Emerson, EB, Baines, SMJ & Hatton, CR 2018, 'Self-reported smoking, alcohol and drug use among adolescents and young adults with and without mild to moderate intellectual disability' *Journal of Intellectual and Developmental Disability*. DOI: 10.3109/13668250.2018.1440773

Robertson, JM, Emerson, EB, Baines, SMJ & Hatton, CR 2018, 'Self-Reported Participation in Sport/Exercise Among Adolescents and Young Adults With and Without Mild to Moderate Intellectual Disability' *Journal of Physical Activity and Health*, vol. 15, no. 4, pp. 247-254. DOI: 10.1123/jpah.2017-0035

Flu vaccinations for people with learning disabilities. September 2018.

<https://www.gov.uk/government/publications/flu-vaccinations-for-people-with-learning-disabilities>

Learning disabilities and CQC inspection reports. July 2018.

<https://www.gov.uk/government/publications/learning-disabilities-and-cqc-inspection-reports>

Blogs

Glover, Donna. (2018). Joint Strategic Needs Assessments (JSNAs): including information about people with learning disabilities. 1st August. <https://khub.net/web/donna.glover/user-blogs/-/blogs/joint-strategic-needs-assessments-jsnas-including-information-about-people-with-learning-disabilities>

Glover, Gyles (2018). Learning Disability Week – improving hospital care. PHE blog, 19th June <https://publichealthmatters.blog.gov.uk/2018/06/19/learning-disability-week-improving-hospital-care/>