

Information for people with learning disabilities and/or mental health problems and other disabled people

Equal Treatment: Closing the Gap



A formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems

Why we conducted this investigation

Everyone should have a fair chance of good health and equal access to good health services. If you have a learning disability and/or mental health problem we want to support you to get your physical health needs met by primary care services – GPs, practice nurses and other staff – and to know your rights, so you can negotiate to get them met. This might mean flexibility about how you can make an appointment, or receive accessible information about your choices on medication. These and other ‘reasonable adjustments’ are your right.

International evidence shows that people with learning disabilities

and/or mental health problems live with poorer health than other citizens. This can stop you participating in your communities or in work or education. The DRC launched this investigation because we wanted to understand more about these inequalities in England and Wales, their causes and what can best be done to address them.

The acid test of a national health service is not whether it works for people who are generally healthy but whether it benefits those with the greatest problems accessing services, and the biggest risk that poor health will stop them taking part in society.

How we undertook the investigation

This investigation is unique internationally in bringing together three powerful sets of data to inform robust recommendations:

- New research – the most comprehensive study of primary care records and mental health issues in the world (eight million primary care records), coupled with Area Studies in four areas, extensive consultation with service users and providers and evidence reviews. This enabled us to undertake detailed exploration of health inequalities, barriers to services and potential solutions.
- Written and oral evidence analysed by a high level Inquiry Panel, including leaders in health policy, general practice, nursing and people with learning disabilities or mental health problems. They generated recommendations designed to work practically in the newly configured national health services.
- Collation of existing evidence through literature review.

The full report, all the primary research and evidence reviews are available at www.drc-gb.org/healthinvestigation

What we found out

We found that people with mental health problems have higher rates of obesity, smoking, heart disease, high blood pressure, respiratory disease, diabetes, stroke and breast cancer than other citizens. People with learning disabilities have higher rates of obesity and respiratory disease, and high levels of unmet needs. One internationally new finding from the investigation is that people with schizophrenia are more likely to have bowel cancer than other citizens. Both groups are likely to die younger than other people. People with mental health problems are more likely than others to get illnesses like strokes and coronary heart disease (CHD) before the age of 55. Once they have them they are less likely to survive for more than five years.

We have also identified variable levels of healthcare interventions:

- People with learning disabilities who have diabetes have fewer measurements of their body mass index (BMI) than others with diabetes. Those with stroke have fewer blood pressure checks than others with a stroke. They have very low cervical and breast cancer screening rates.
- For people with mental health problems, some tests and standard treatments – such as spirometry to identify respiratory illness or cholesterol checks and statins for people with heart disease – are given less often than to people without mental health problems.
- Both people with learning disabilities and people with mental health problems experience ‘diagnostic overshadowing’: that is, reports of physical ill health being viewed as part of the mental health problem or learning disability, and so not investigated or treated. If problems are missed, people experience ill health and its attendant risks unnecessarily.
- There is no evidence that information on the physical health needs of people with learning disabilities and/or mental health problems is either regularly collated or used locally by commissioners to develop improved services.

Access to services is often far from ideal. There are examples of positive practice but many primary care services are not making ‘reasonable adjustments’. These could be simple things like making appointments by email, providing treatment information

in large print, on tape or in Easy Read, or offering text or phone appointment reminders. (These have been required by the Disability Discrimination Act since 1999.) Implementing them would be straightforward and inexpensive, thereby reducing missed appointments, improving early intervention for high risk groups and improving standards of service for everyone.

We are not convinced that the health service is ready for the new Disability Equality Duty (DED), in force from December 2006. There is an expectation embedded in this new duty, not just that disabled people should be treated 'the same' as others but that, in order to achieve equal outcomes, they should, when needed, be treated differently. The DED is a very useful tool raising the quality and access of the patient experience.

What you can do to improve things

1. Assert your rights! Use the findings of this investigation to ensure you receive all necessary support and treatment for your physical health needs.
2. Tell your primary care practice what your access needs are.

Be aware that under the DDA you have a right to expect health providers to be flexible in the way they provide services to you as a disabled person or someone with a long term health condition, to make sure you are treated fairly. This could include, among other things, providing you with written information in alternative formats, offering a first or last appointment, double appointment times, appointments by email, fax or telephone or providing private waiting areas.

3. Ask for a full health check from your GP or practice nurse. In England and Wales, GP surgeries are already expected to provide a regular full health check for people with serious mental health problems. In Wales GPs are also expected to offer people with learning disabilities a health check. The DRC thinks health checks for people with learning disabilities need to be provided in England as well. When you have the health check, ask for information on your health to take away (in a format you can understand) so you can go through it again after the check.
4. You may already be aware that psychiatric medication can cause a number of side effects. If you

feel these are having a bad effect on your health or well-being, speak to your doctor and ask about alternatives.

5. Ask your doctor or practice staff to help you get support with weight problems, smoking or exercise. There may be local groups or individual support which they could tell you about or refer you to. Your doctor could give you a prescription to help cut down smoking.
6. Ask local voluntary organisations or groups of people with mental health problems or learning disabilities about ways to improve your health. They may also be able to help you in your contacts with your doctor or primary care staff.
7. If you are removed from a practice list, or if the practice refuses to register you, make sure you get the reasons in writing. If you feel the reasons are to do with your mental health problem or learning disability, you should complain first to your primary care practitioner. In England if you are unhappy with the response to your complaint, you can ask the Healthcare Commission for an 'Independent Review' of your case. Your local Patient Advisory Liaison Service may be able to offer support. In Wales if you are unhappy with the response to your complaint you can ask the Independent Review Secretariat for an 'Independent Review'. Your local Community Health Council may be able to offer support.
8. If you think you are being treated unfairly because of your learning disability and/or mental health problem, you may have rights under the Disability Discrimination Act which says that service providers have a duty to make changes ('reasonable adjustments') to their services if they are impossible or very difficult for you to use. You can contact the DRC for more information on our Helpline number listed at the back of this publication.
9. Give feedback to the service. There may be patient surveys, or a patient forum (in England there will soon be a local involvement network (LINK)). The health service should be involving disabled people, as part of the Disability Equality Duty (DED), in force from December 2006. The DRC has produced guidance on the DED for disabled people – please contact our Helpline for more details or log on to www.drc-gb.org

What the DRC will be doing next

We are embarking on a programme to ensure that the investigation findings lead to better practice. We shall be working with the Department of Health, the Welsh Assembly Government and others in key positions to effect change.

Find out more

If you feel you have been discriminated against when using health services because of your disability, speak to the person responsible for providing the service. If the matter is not resolved, phone our Helpline on **08457 622 633** or by textphone **08457 622 644**.

If you are still unhappy after local complaints procedures have been exhausted and after independent review, you can also complain to the Health Service Ombudsman at Millbank Tower, Millbank, London SW1P 4QP, telephone **0845 015 4033**.

To read the full report, the conclusions of our Inquiry Panel and investigation evidence reports and to find out more about our work on health please go to www.drc-gb.org/healthinvestigation

For general information on making health services accessible to disabled people, download the joint Department of Health/DRC booklet 'You can make a difference' at www.drc-gb.org/makeadifference

Equal Treatment investigation publications

The publications below are available electronically at www.drc-gb.org/healthinvestigation. Those marked with an asterisk are also available in hard copy and can be ordered from the DRC Helpline **08457 622 633**, textphone **08457 622 644**.

Equal Treatment investigation report – Part 1*

Equal Treatment investigation report – Part 2 (Inquiry Panel) Wales report*

Summary for health commissioners (England only)*

Summary for practitioners*

Summary for disabled people*

Easy Read report*

Evidence from the literature review

Health inequalities monitoring tool

Investigation research reports

An Equal Treatment investigation DVD has also been produced, which will be particularly useful for primary care practitioners and for trainers. Limited copies are available and can be ordered from the DRC Helpline.