



Health charter in practice

2nd edition



#HealthCharter



Why a health charter?

People with learning disabilities experience poorer health and die younger than people in the general population. Many of these health issues are preventable, meaning that people with learning disabilities experience health inequalities. The reasons or determinants of health inequalities include:

- Social determinants of poorer health such as poverty, poor housing, unemployment, discrimination and isolation.
- Increased risk of health problems associated with specific genetic, biological and environmental causes of learning disabilities, and the lack of response, or inappropriate response, to these problems.
- Communication difficulties and reduced understanding of health issues.
- Personal health risks and behaviours such as poor diet and lack of exercise.
- Problems with access to healthcare provision.

The Learning Disabilities Public Health Observatory (LDPHO: www.ihal.org.uk) gathers detailed information on health inequalities and it is clear that health staff need to do much more to make their service accessible. In addition, many of the health issues people with learning disabilities experience are to do with social factors. Social care providers and disability organisations have an important role to play in both promoting health and wellbeing, and enabling access to health services.

To support care providers and disability organisations, the LDPHO worked with the Voluntary Organisations Disability Group (VODG: www.vodg.org.uk) – the leading umbrella group of voluntary sector providers – to develop a health charter. The Health Charter was co-produced with providers, commissioners, self-advocates, carers and health staff. The charter provides a self-assessment framework and guidance for organisations to work through and build their practice upon.

The Health Charter was funded through the voluntary sector strategic partnership grant between the Voluntary Organisations Disability Group and the National Care Forum



Our learning so far

This practical guide is based on the learning of 20 organisations who have been actively using the charter to both improve support provided to people with learning disabilities and to directly address health inequalities. We have also reviewed and refreshed the Health Charter based on feedback based on the feedback received since its initial publication.

The Health Charter
and supporting tools are now
available on the VODG website
www.vodg.org.uk



Why sign up?

Signing up to the charter was seen as a clear commitment to addressing health inequalities by staff and managers, and therefore an important message to commissioners. In many services it is explicitly seen as a central part of the ethics and approach underpinning high quality delivery. The charter has been used as a way of helping with regulatory 'compliance' and providing the work being done within the service with a mechanism for addressing health inequality.

Values

It is the right thing to do and reflected our values.

A means of service improvement agenda

Always eager to improve our company and ensure service user needs are paramount especially in relation to people's health.

To benchmark activity and improve practice.

To commit to improving the health and lives of people with learning disabilities.

To help us evidence our commitment to the health of people we support in a competitive market.

Staff teams need to be clued up and to look out for signs and symptoms we identified in the assessment.

Putting better health on the care agenda



Generating priorities

Many organisations take a team approach to deciding which priorities to focus on, with some organisations also involving people with learning disabilities and carers in these decision-making processes.

We based the priorities on the quality strategy of the company, that came from consultation with service users and the whole company.

A regional manager is the Health Charter lead who works with each of the regions. The priorities identified have now been included in the top performers criteria this year. Staff and parts of the organisation will be measured against how well the priorities of the Health Charter have been delivered. More specific, quantifiable targets and measures have also been introduced to support this.



10 top tips for commissioners

1

Understand the health inequalities experienced by people with learning disabilities locally, and ensure this information, along with plans to address health inequalities, are written into plans including Joint Strategic Needs Assessments (JSNAs).

Information on health inequalities gives commissioners a baseline against which to measure progress, and should inform commissioning plans. Including information in JSNAs can also foster a partnership approach to tackling the root causes of

inequalities. JSNAs through which Health and Wellbeing Board partners jointly analyse the current and future health needs of local populations should include vulnerable or marginalised groups such as people with learning disabilities.

2

Identify which providers are signed up to the Health Charter locally and share this information.

Identifying local champions can be the first step to developing a network of support amongst providers.

“Seeing who else has signed up really helps motivate the organisation to do this too” (provider).

3

Plan an event for senior managers in provider organisations, telling them about The Charter and why they should sign up. Do this in partnership with local health facilitators or others with a similar role, families and people with learning disabilities.

Providers indicated that events were an effective way of raising awareness about the charter. Running the event in partnership gives important messages about shared responsibility for tackling health inequalities,

a theme that underpins all charter documents. Presentations from families and people with learning disabilities are a particularly powerful way of getting the message across.

4

Check what support providers need to implement the charter, and provide it

Research evidence indicates that providers may need support to develop the knowledge, skills and confidence required to support the wider health and wellbeing needs of people with learning disabilities, and enable access to mainstream health services.

“The event hosted a range of guest speakers and market stalls from health, social care agencies and the Care Quality Commission. They provided information and practical resources to support organisations to implement the Charter in practise. Every topic was linked directly to each of the Charter pledges. Every provider was given a resource pack with additional information about the Charter, as well as all presentations and contacts. Providers were given an opportunity to feedback, via a post it session, any issues, concerns or ideas regarding implementation of the Charter. These comments were addressed following the event... (support) has included training, awareness raising within teams, as well as signposting to specialist support via the self- assessment” (commissioner).

5

Suggest providers embed the charter into their local strategies.

Embedding the charter in local strategies helps ensure that health remains on the agenda, and becomes part of the daily routine. It can also help provide evidence of good practice to the Care Quality Commission.

“It has had an impact on the way we do key worker meetings as we have added a bit in for consent around health, and it has made the key worker meetings more structured around health for all service users” (provider).

“The priorities identified have now been included in the Top Performers criteria this year. Staff and parts of the organisation will be measured against how well the priorities of the Health Charter have been delivered. More specific, quantifiable targets and measures have also been introduced to support this” (provider).

Having a key nominated person within the provider organisation to take ownership of the actions from the self-assessment is very important. Some providers also nominate health champions within their organisation to take the charter forward.

6

Write the charter into local contractual agreements with providers.

Writing the charter into local contracts encourages sign-up, raises its profile, and encourages a consistent approach to addressing health inequalities across the local area.

Providers were informed that sign up to The Charter would be included in County Council contractual monitoring arrangements. They were given an action plan, identifying how The Charter would be communicated to staff, service users and families (commissioner).

7

Raise awareness of the charter with mainstream health commissioners.

Having a shared understanding of the health inequalities people with learning disabilities experience, can help develop a shared approach to addressing them, and create an atmosphere of openness to joint working.

(We work) with mainstream health services to put appropriate reasonable adjustments in place so that people with learning disabilities have equal access, as well as working with individuals on how to be more healthy. It is all about empowerment as well as education (provider).

8

Provide opportunities to share good practice and keep The Charter 'alive'.

Sharing good practice and resources such as easy read materials helps prevent duplication and maintains a focus on reducing health inequalities.

(We will) be talking at the health charter follow up event taking place in... September called 'We're all in it together'. The day will be about sharing experiences, benefits,

challenges and practical experiences with an opportunity for group work and networking with other providers and health professionals (provider).

9

Consider other initiatives the Health Charter can contribute to such as the joint Health and Social Care Learning Disability Self-Assessment Framework (SAF)

The Association of Directors of Adult Social Care (ADASS) and NHS England are committed to an annual self-assessment process (SAF) for people with learning disabilities. The SAF provides an important opportunity for people with learning disabilities and family carers to review

and quality assure progress as part of a national programme against nationally agreed measures, as well as being part of agreeing local actions. Implementing the Health Charter has the potential to contribute towards improved indicator ratings.

Information from (the follow up) event will be used to inform the next SAF"(commissioner).

10

Check whether implementing the charter has reduced health inequalities

Providers signed up to the charter should be checking on progress through the self-assessment. Bringing this information together, along with case studies demonstrating the impact on individual's lives and feedback from people with learning disabilities and families has the potential to provide powerful evidence to inform the SAF and Health and Wellbeing Boards,

as well as positive reinforcement to both providers and health partners. The Health Equality Framework (HEF), is an outcomes tool based on the determinants of health inequalities complements the Charter. It designed to help commissioners, providers, people with learning disabilities and their families understand the impact and effectiveness of services.

(We) found the self-assessment process a very positive experience with an opportunity to step back and reflect on current practices and plan for future improvements. It's very much being seen as a dynamic process with actions evolving regularly (provider).

Outcomes from using the charter

Organisations that had embedded the Health Charter into their strategies and operating approaches found it offered a key mechanism for driving service improvement and better outcomes.

Awareness raising and engagement with people using services

It gets people thinking about health needs as well as accessible information, documents and personalisation. It's really useful.

Making accessible information available for everyone. Focusing on prevention as well as medication.

Help to focus on areas that require development and raise greater awareness amongst staff and families of what we are trying to achieve. Staff teams are doing more home cooking. More training sessions available to staff to help in developing their awareness.

Encourages staff to work directly with people to plan is good. Helped to engage with families more...also made us tackle issues about mental capacity.

The charter provides information about the health of people with learning disabilities. We have improved the health related information we hold about the individuals we support.

It has had an impact on the way we do key worker meetings as we have added a bit in for consent around health, and it has made the key worker meetings more structured around health for all service users.

We now hold an annual health survey and health is on all agendas.

A stronger organisational focus on health matters

Outcomes from using the charter

Improving partnership working

Finding out about other services on offer locally.

Shown us that we can link with others for support such as healthcare co-ordinators.

The Durham Health Charter events are good. You can raise issues and get information you need.

Some local councils, including Durham, have hosted Health Charter events which help to build local partnerships.

Ensured we checked off what we are doing and what we need to work on.

Prompted a closer look at HAPs [health action plans] and consideration of a wider training plan. Work on this led us to begin work on an easy read Mental Capacity Act policy.

Identifying areas for service and workforce development

It particularly encouraged me to include more capacity discussions with the team, particularly in areas of duty of care and unwise choices.

The self-assessment has come at a good time for us as we are doing much work in improving quality of support and want to promote and share our best practice with others.

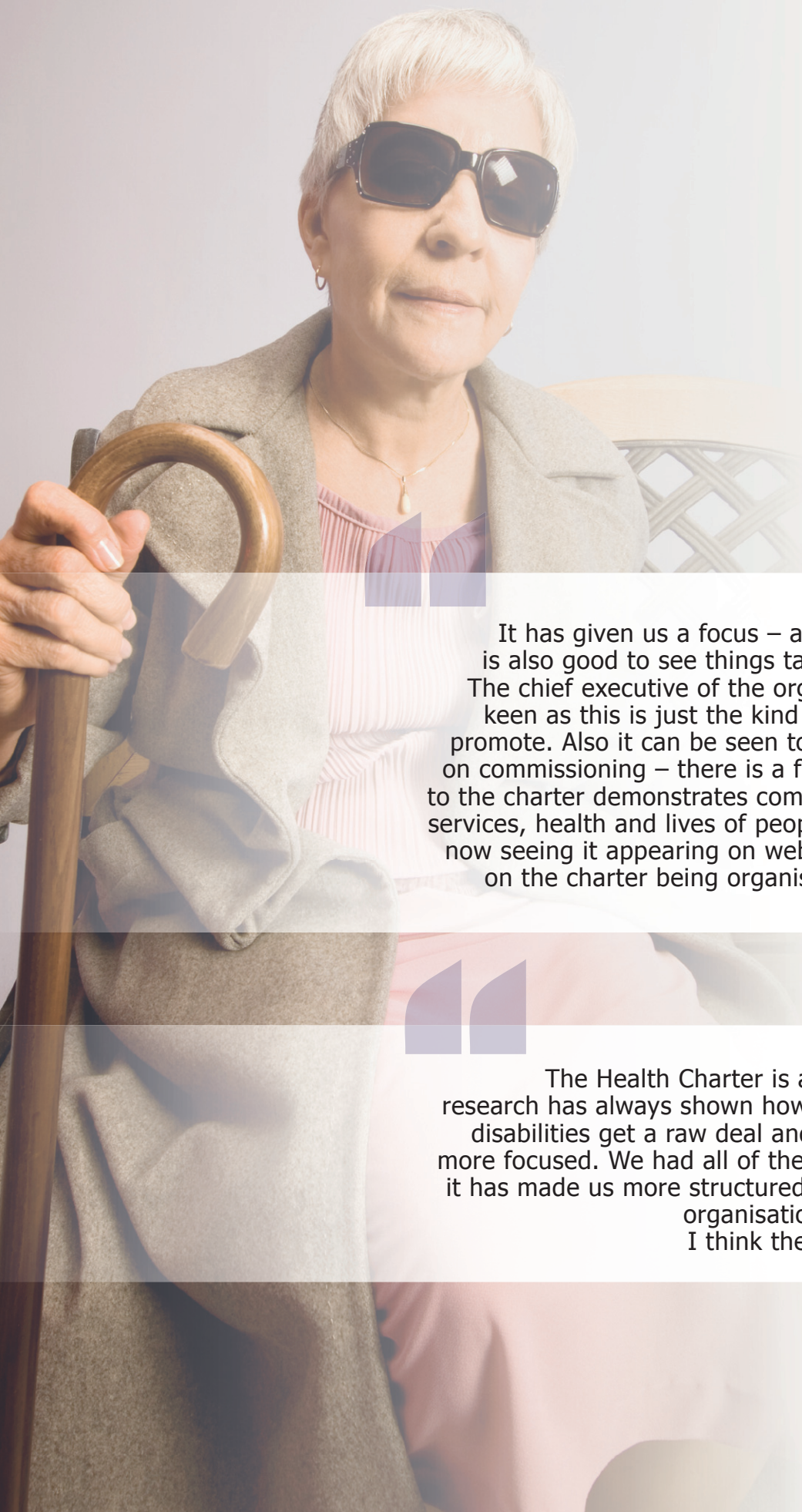
Useful addition to existing governance

Helps you to break down areas. Also good as an audit tool – helps identify where there may be gaps in services.

In general our governance systems are better. We make better use of audit tools and self-assessment tools. We always consult with service users. It has encouraged the use of the Health Equality Framework by the whole company.

This was the most helpful thing. We lifted part of it to use in our internal quality monitoring too, and for logging evidence so we can show CQC or regulators.

Outcomes from using the charter



It has given us a focus – aims and objectives. It is also good to see things talked about nationally. The chief executive of the organisation is also very keen as this is just the kind of thing she wants to promote. Also it can be seen to be having an impact on commissioning – there is a feeling that signing up to the charter demonstrates commitment to improving services, health and lives of people supported. We are now seeing it appearing on websites and also events on the charter being organised in different areas.

The Health Charter is an excellent idea. The research has always shown how people with learning disabilities get a raw deal and I think this makes it more focused. We had all of these things in place but it has made us more structured, and I know of other organisations who fall short and I think the charter would help...

A close look: Health Charter case studies

A commissioner's perspective from Durham

"Durham County Council's commissioning in partnership with Tees Esk and Wear Valley NHS Trust learning disability health facilitation team hosted an event to promote the Health Charter. The key purpose of the event was to raise awareness of the Health Charter and encourage providers to sign up and implement the charter. The focus was on 'we're all in it together', underlining the responsibility that both commissioners and providers have a vital role in improving health outcomes for people with learning disabilities locally. The event reinforced the importance of an integrated approach and co-productive partnerships.

The event hosted a range of guest speakers and market stalls from health and social care agencies as well as the Care Quality Commission. These partners provided information and practical resources to support organisations to implement the

charter. Providers were given a resource pack with additional information about the charter, as well as all presentations and contacts.

The council has delivered a clear message calling for action; asking providers to familiarise themselves with the charter, to sign-up and identify three key priorities. This call to action has been followed up with training and awareness raising, as well as signposting to specialist support. Most providers of supported living and residential care in County Durham, alongside some day care providers, are now signed up to the Health Charter.

Implementation of the charter has also enabled commissioners to identify gaps in health services and prioritise resources. It has helped target those providers who most require support, particularly organisations supporting people with complex health needs."



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Provider perspectives

Thera North

Thera North completed an overall self-assessment based on discussions between local managers, operational managers and the managing director. They used this information to agree a set of actions for continual improvements going forward. The exercise made them think particularly about their relationships with local health services and staff, reflecting on how they could develop more positive, on-going and open dialogue with health staff, and how – through this approach – they could help influence practice in the NHS to ensure people with learning disabilities get a better deal.

The Health Charter also made them think more about capacity assessments, and embedding assessments of capacity in day-to-day work. Choice regarding food is often an issue for people with learning disabilities. Potential new staff are asked by people supported

and their families at interview stage if they can cook, for example, and staff have been successful in introducing menus with healthier choices that people have enjoyed and continue to like. Managers at all levels have found that discussing these issues and solutions with their peers has been really helpful in sharing best practice and learning new ways of working.

The findings of the Health Charter self-assessment process are regularly discussed with managers, and there are also meetings with organisational 'health champions' who work to share good practice across the organisation.

Thera North have found the self-assessment process a very positive experience that has provided an opportunity to step back and reflect on current practices and plan for future improvements. It is seen as a dynamic process with actions evolving to improve care and support.



For further information, please contact **Kevin Griffin**, Thera North.

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Fred's story

Fred's care plan set out a strict timetable for his cigarettes and coffee. The Thera North home that Fred was moving to was told that failure to adhere to the timetable would result in significant challenging behaviour. Fred's health was poor due to his nicotine and caffeine intake. What remained of his teeth were also in a very poor state.

During the first meal in Fred's new home, it became apparent that Fred couldn't see his plate. All people in the home have annual health checks and regular eye tests, dental appointments and any other health checks that need carrying out. It was known that Fred had cataracts but nothing had been done. Fred has now had two successful cataract operations and can see. He has also had what was left of his teeth removed as they were causing infections. Most remarkable of all was that in four weeks Fred has stopped smoking. This was not planned, but he was given things to do, and this directed his attention away from the cigarettes. His caffeine intake has also reduced significantly.

Fred is now a lot healthier and walks for miles every day. There are a few incidents of challenging behaviour but a lot less than previously, and his support has also been reduced. This is really positive for the staff team, who are very proud of what they are doing. The team has a great relationship with the local multi-disciplinary team and the GPs. With health services, the team just keeps pushing until they get the right answer, as they know health is important.

The Health Charter has given a real focus to providers locally. It is great that it is talked about regularly in meetings, and working in this way has now become the norm in Durham, which is very positive.



Provider perspectives

Vibrance

Vibrance were a member of the focus group that first supported the development of the Health Charter. Vibrance staff are trained to challenge barriers to accessing health care with health providers, and the case examples from Vibrance helped inform the charter development. The introduction of the charter was an opportunity to revisit the importance of supporting people to access mainstream healthcare with staff.

“Vibrance believes the introduction of the health charter offers the opportunity to underpin practice that is already expected from own staff, providing a tool and reference point for staff to use when speaking to health care partners. We have been able to offer to present our experiences to local authority partnership boards, therefore giving the opportunity to raise the profile of the Health Charter for wider impact”.

Vibrance:

- Held a series of presentations for managers and staff, using the work of the Learning Disabilities Public Health Observatory to share research and data about the inequalities people with learning disabilities experience.
- Highlighted the importance of the annual health check, and monitor the take up of annual health checks across our services.
- Used case studies (including Margaret’s story – see box) to highlight how to use existing safeguarding processes to challenge inequalities.
- Circulated accessible information on health issues and contact details for different liaison nurses at acute hospitals and in community teams.
- Added into the annual audit for each service a check on how mental capacity is assessed and whether best interest decision-making processes are used.



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Margaret's story

Margaret is a 45 year old lady who has tenancy in supported accommodation with two other ladies. She has severe epilepsy and has had a series of chest infections. Although Margaret has very complex physical and learning disabilities, and very little verbal communication, she clearly expresses her mood, her likes and dislikes and her wishes. Margaret has had many hospital admissions, and these have been of varying quality.

On one occasion, a Vibrance team leader went to visit and noticed that some of Margaret's treatments for her chest infection had been stopped. She found that there was a "do not resuscitate" (DNR) order on the file. She was informed by the doctor in charge of Margaret's care that the team did not feel that Margaret's quality of life was good enough and therefore they did not think it was in her best interests to be treated. However, there had been no assessment or record of Margaret's mental capacity, no multi-disciplinary Best Interests meeting, and- of greater concern-, no discussion with the family.

Vibrance arranged with the ward staff for a meeting with the family the next day, but unfortunately none of the clinical team arrived. Vibrance spoke with the community learning disability team, who put them in touch with the local safeguarding adult team.

The team then took control of the situation, involving Margaret and her family at every stage to challenge the hospital's processes. The DNR order was taken off the file, and Margaret's treatment was recommenced. Margaret's health improved and she was able to return home. Her family made a formal complaint to the hospital, who have assured us that their processes have been reviewed.



Provider perspectives

Certitude

Certitude were involved in the development of the health charter. The organisation have an intensive support service that works across the whole organisation. The service liaises closely with family members and carers to understand and respond to people's needs. They help to develop plans to work with people who challenge. This may include intensive interaction. They have seen real progress with individuals because of this work.

With regard to general health, Certitude have taken a two-pronged approach. They work with mainstream health services to put appropriate reasonable adjustments in place so that people with learning disabilities have equal access, as well as working with individuals on how to be more healthy. It is all about empowerment and education.

They are working with a local hospital on the 'getting it right' charter, and are developing their awareness of the health issues for people with learning disabilities along with accessible care pathways. They are also working with the local clinical commission group and social services and are developing accessible workshops and events for people with learning disabilities and

their carers to raise awareness of common health issues. For example, they have worked with SeeAbility and have developed an eye and vision strategy. SeeAbility already have a wealth of resources, and the challenge is to raise awareness of these resources across frontline services.


Another example is dentistry. They have arranged visits to the dentist where people with learning disabilities can get used to the chair and equipment, so become less frightened of visiting. These visits also help the dental staff get to know individuals. They run healthy lives events offering support and advice to people, and help people fill in their health passports. One person who uses Certitude's services has set up a group to enable others to learn more about going to the dentist and to find ways of keeping themselves healthy. Certitude are helping with this.

The challenge is keeping health on the agenda and Certitude are planning a 'focus on health month'. This is as much about helping managers understand what they can do so that they can constructively challenge on behalf of the people they support, as much as it is putting health on the agenda for people using their services.

For further information, please contact **Elsa Morris**. Treat me Right! Certitude.

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certitude
everyone has the right to a good life



“People with learning disabilities have poorer health than the general population”.

“Health and social care services can do something about this”.

“People with learning disabilities deserve better. Sign up to the Health charter”.



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