

Healthcare for all in the UK

David Congdon
Head of Campaigns & Policy

Bridge 2010

Background

- Treat me right
- Closing the gap
- Death by indifference
- Independent Inquiry
- Ombudsman's report

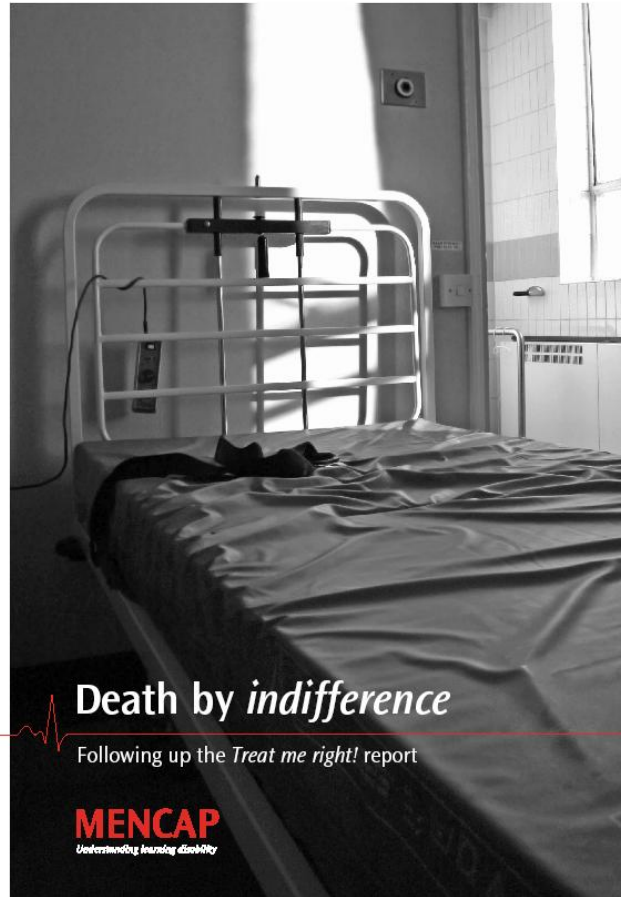
Poorer health, poorer healthcare?

People with a learning disability are:

- More likely to die before the age of 50
- More likely to die of respiratory disease
- More likely to have epilepsy
- More likely to have weight problems
- More likely to have mental health problems

Where have we come from?

Death by indifference





Why people with a learning disability face health inequalities

- Institutional discrimination
- People with a learning disability are not a priority in the health service
- Many healthcare professionals do not understand much about learning disability

Why people with a learning disability face health inequalities

- Major problems when people are unable to communicate
- Not recognising pain
- Diagnostic overshadowing
- Lack of care and neglect
- Failure to listen to carers

Institutional discrimination

Institutional discrimination happens when the people working in a place or organisation do not:

- value all people equally
- understand that different people have different needs
- change the way they deliver a service so that it meets different needs

This happens for a long time and staff become used to it and do not notice it is wrong.

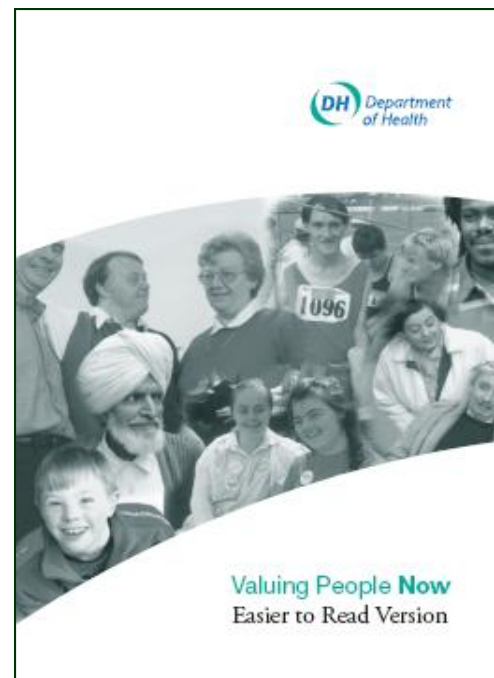
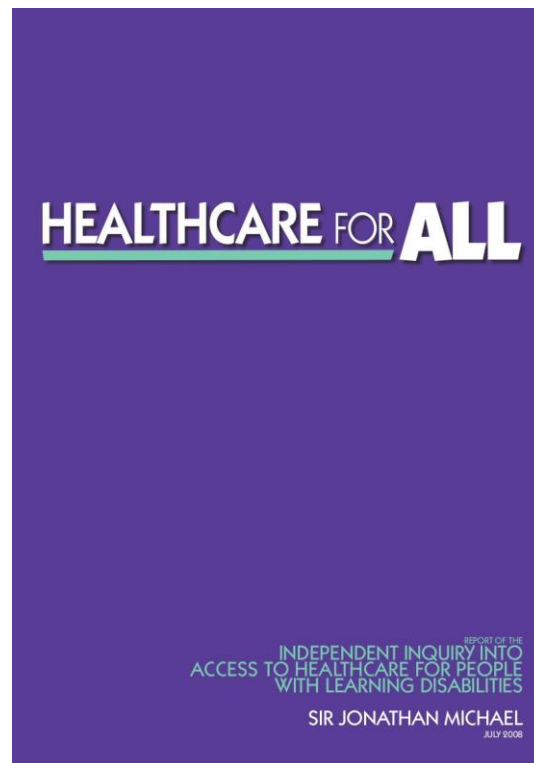
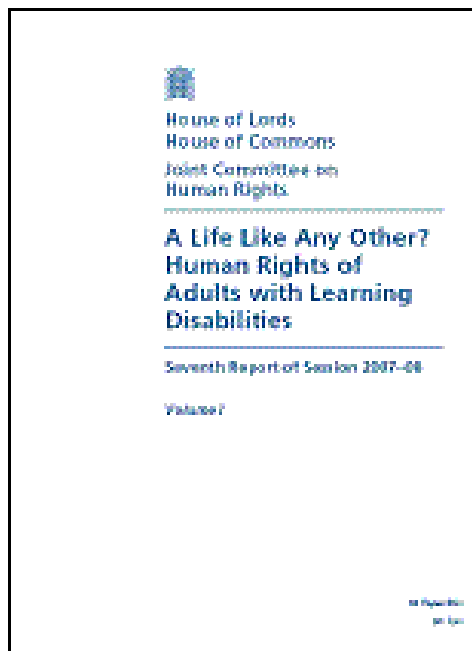
Institutional discrimination



Martin Ryan

Death by
indifference

What have we achieved?



Inquiry recommendations

- Reasonable adjustments for people with a learning disability by health services, including regular health checks and liaison staff across services
- compulsory learning disability training for healthcare professionals
- the involvement of family carers in care and treatment
- better inspection of how the NHS treats people with a learning disability

Healthcare for all



The report of
the independent inquiry into
access to healthcare for
people with learning disabilities
Sir Jonathan Michael

Local Government
OMBUDSMAN

 Parliamentary
and Health Service
Ombudsman



Ann Abraham

Six lives: the provision of public services to people with learning disabilities

We believe these outcomes are a shocking indictment of services which profess to value individuals and to personalise services according to individuals needs.

Getting it right

when treating people with a learning disability



getting it right 
when treating people with a learning disability

See the person – not the disability



- ✓ Find time to:
 - listen to the person
 - listen to the family.

- ✓ Find the best way to communicate:
 - pay attention to facial expressions
 - notice gestures and body language
 - try pointing to pictures
 - try signing

- ✓ Keep information simple and brief

- ✓ Avoid using jargon



Mark

“Mark was in severe uncontrollable pain, in distress, shouting, screaming, biting his hand, hitting his head against the wall and slapping his own face. His mother struggled to comfort him, but no one other than his family seems to have considered that Mr Cannon’s behaviour might be the result of untreated pain.”

Don't make assumptions about the person's quality of life



- ✓ People with a learning disability feel pain too.
- ✓ People with a learning disability get ill too.
- ✓ Don't confuse a learning disability with illness.
- ✓ Be suspicious about serious illness – act quickly!
- ✓ Get to know some of the health conditions that are more common for people with a learning disability.



Tom

“There is no evidence of any intention to humiliate or debase Tom. Nevertheless, the standard of service does raise the question whether the actions of the Council, The Partnership Trust and the Acute Trust constitute degrading treatment and a failure to respect Tom’s dignity.”

The law and you



- ✓ You must make reasonable adjustments to ensure that each person has the same opportunity for health, whether they have a learning disability or not.
(Disability Discrimination Act 2005)
- ✓ Capacity is specific to a particular decision and time. You must assume the person has capacity. If assessment shows they don't, a decision must be made in their best interest.
(Mental Capacity Act 2005)
- ✓ Everyone has a right to expect and receive appropriate healthcare.
(Human Rights Act 1998)



Emma

“The Third Oncologist explained that the 10% figure was not a scientific statement, it’s an overall figure given to the carer, to the grandparents, to Emma’s mother, to try and make them understand what we were putting Emma through and for what purpose, were we to have given treatment.”

Getting it right charter



See the person, not the disability

All people with a learning disability have an equal right to healthcare.

All healthcare professionals have a duty to make reasonable adjustments to the treatment they provide to people with a learning disability.

All healthcare professionals should provide a high standard of care and treatment and value the lives of people with a learning disability.

By signing this charter, we pledge to:

- ✓ make sure that hospital passports are available and used
- ✓ make sure that all our staff understand and apply the principles of mental capacity laws
- ✓ appoint a learning disability liaison nurse in our hospital(s)
- ✓ make sure every eligible person with a learning disability can have an annual health check
- ✓ provide ongoing learning disability awareness training for all staff
- ✓ listen to, respect and involve families and carers
- ✓ provide practical support and information to families and carers
- ✓ provide information that is accessible for people with a learning disability
- ✓ display the *Getting it right* principles for everyone to see.

For guidance on implementing this pledge, please visit www.mencap.org.uk/gettingitright

What needs to happen

- Full implementation of Sir Jonathan Michael's recommendations
- Learning disability to be a priority across the NHS
- All staff to obey the DDA and HRA
- Values based training

But....we're still getting more cases

