

Summary of the White Paper

Health equality for everyone:



Listen to our aims

To be debated on Friday 2nd October 2015

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Thank you

The members of the **Worcestershire People's Parliament** would like to thank all the following people who helped them when they were preparing this White Paper.

The opinions in this document are those of the **Worcestershire People's Parliament for adults with learning disabilities.**



Hard words used in this White Paper:

- Social Care and Health

The County Council's adult services for learning disability

- Clinical Commissioning Group (CCG)

Run by GPs and health professionals they plan, buy and monitor all health services in their area except GPs, dentists and opticians.

- Reasonable adjustments

Reasonable changes that a service makes to the way it does things or the equipment it gives people so that they can get the most out of what is on offer.

- Health Equalities Framework (HEF)

A computer programme that professionals can use to decide what sort of support a person needs.

- Pathway

A Pathway describes the different steps that professionals should take in caring for somebody. Each step or action **depends on how the person's situation changes.**

- Social Prescribing

Instead of giving you medicine a doctor can send you to take part in an activity that will be good for your health.

- NHS England

This organisation buys and monitors the services of GPs, dentists and opticians.

Some of the documents we have looked at preparing this White Paper:

My Hospital Book

Health Action Plans

My Worcestershire Health Plan

Mencap Getting it Right Charter

Improving the Health and well-being of people with learning disabilities: an evidence-based commissioning guide for Clinical Commissioning Groups Oct 2012

Health Checks and people with learning disabilities. Learning Disabilities Observatory

Services for people with learning disabilities and challenging behaviour or mental health needs. Dept. of Health

How well are we doing on Health? NDTi easier read guide to the Health Equalities Framework (HEF)

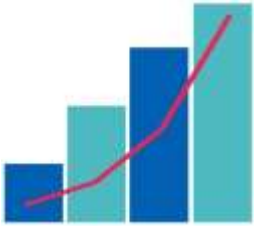
Meeting the needs of people with learning disabilities.
Royal College of Nursing 2013

Equal Treatment: closing the gap. Disability Rights
Commission

Death by Indifference. Mencap 2007

Confidential Inquiry into premature deaths of people with
learning disabilities (CIPOLD) Executive Summary 2013

Introduction



Research shows that people with learning disabilities die younger than other citizens.



We don't want to depress you but we had to hear about it
- so now it's your turn.

People with learning disabilities:



- have higher levels of throat and stomach cancers



- have respiratory disease as the main cause of death. This means problems with their breathing.



- have Coronary heart disease as the 2nd highest cause of death



- are more likely to have tooth decay, loose teeth and gum disease



- are more likely to get diabetes.



- have higher rates of epilepsy



- are more likely to be obese – that means overweight.



- are vulnerable to all kinds of mental health problems.



Because these things are more likely to happen to people with learning disabilities they are called Health Inequalities.



Anything that can be done to remove health inequality is a good thing.



Our aim is that every person with a learning disability in Worcestershire should have an equal chance of a long and healthy life.

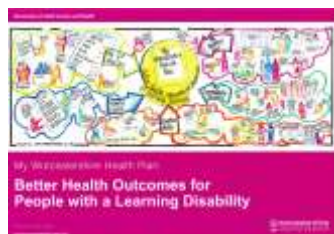
What we have done so far.



We talked about our own health and the things that have happened.



The Health Checkers project has already done a lot of really good work on health and learning disabilities. We talked to them and looked at their reports.



The Staying Healthy Sub-group of the Learning Disability Partnership Board has written an Action Plan. They call it My Worcestershire Health Plan. We have used this as our guide to the important issues.



- We have interviewed Elaine Carolan and Rachel Barrett, co-chairs of Staying Healthy Sub-group



- We have interviewed Rani Virk about what happens in hospitals



- We have interviewed the Family Carer sub group about Big Health Aim 5



- We have talked to people who provide healthy lifestyle support



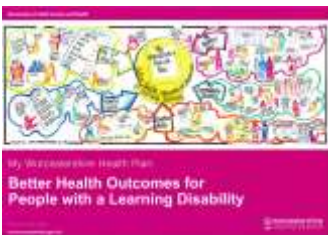
- We have talked to Kay Dalloway about the work of Learning Disability Liaison Nurses for primary and acute care.



- We have spoken to Matt and Paul, people with learning disabilities who have high support needs, to find out their stories.



- We have done a survey of Housing and Support providers in Worcestershire to find out what they do to support healthy lifestyles.



In this White Paper Members of the Worcestershire **People's Parliament (MWP)** ask questions about My Worcestershire Health Plan and the different partners that are responsible for it.



We hope that the White Paper helps you think about this important subject.



Issues that affect lots of things -Umbrella issues

An umbrella covers everything. We think these issues apply to all the different services we talk about later on.

Getting good information



Having Easy Read material is a simple Reasonable Adjustment which can really help people to understand the care or treatment they are getting. They can help all sorts of people, not just people with learning disabilities.



But lots of health organisations tell us they are ‘piloting’ leaflets. They are trying out an idea which we already know works.



In 2013 Health Checkers created a simple template that all GP practices can use to make an Easy Read information leaflet about themselves.



We ask,

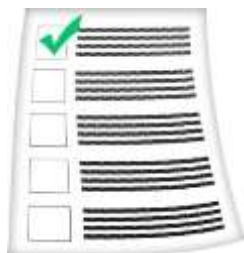
- ?** When will Easy Read become the standard for all the health organisations in Worcestershire?
We mean in GPs, Dentists, Hospitals and clinics, Opticians, Sexual Health and Physiotherapy.



The Getting it Right Charter

Mencap launched their Getting it Right Charter in 2010. It followed the 2007 report Death By Indifference.

Mencap want to be sure that every person with learning disabilities gets equal healthcare.



The Charter is a list of 9 things that an organisation pledges to do. All of them are ways to improve health care for people with learning disabilities. Most of them are included in My Worcestershire Health Plan.



We ask,

- ?** When will all the NHS organisations in the county sign up to **Mencap's Getting** it Right Charter?



What is a Champion?

Every time we hold a **People's** Parliament someone tells us about a new champion. We've had digital champions, Job Centre champions and now Learning Disability Champions in hospital.



We worry that calling people Champions is just a fashion. We also worry that it is a way of papering over cracks in the system.

We need every person working in health to know how to support us and make reasonable adjustments for us.

We ask,



? How much are we spending on Learning Disability Champions in Worcestershire?



Healthy Lifestyles

Many of the health problems that people with learning disabilities have are made worse because they don't do simple things to help themselves.



- Getting regular exercise



- Eating sensibly



- Not smoking



- Not drinking too much



- Keeping active and involved in things



Researching our white paper we found out about some projects that can help people with these things.



Living Well Scheme

This used to be the Health Trainer programme and could be used by anyone. Now you have to be referred onto the scheme. To be referred you must live in a disadvantaged postcode area or be overweight.



People on the scheme get help from:

- Living Well Advisors
- Bridge Builders
- Community Connectors

Health Chats

Health Chats

This project aims to get everyone working in the public sector trained to have short motivating chats with anyone they know who raises a health question.



Social prescribing

This scheme was set up by the Health Improvement Coordinator in Redditch and Bromsgrove. It means that instead of giving drugs GPs can refer them to do an activity instead.

They do it from their computer while they are seeing someone.



Some of the issues the GP can write a Social Prescription for are:

- Support if you have Low Mental Wellbeing
- Getting active
- Getting creative
- Support if a loved one has died
- Support for Carers



At the moment there isn't a way of recording if people getting social prescriptions have a learning disability.



Annual Health Checks

We say more about these in the section on GP Practices.

Health Action Plans

The Health Action Plan is a folder where all the important health information about a person with learning disabilities can be kept. A new version has just been designed which makes it more of an action plan.



Personal support

We know that a lot of people need support to make good choices and change bad habits. We asked Housing and Support providers to tell us what they do to help the people they work with make good lifestyle choices.



A survey was sent out to all the housing and support providers on the County Council's approved list.



When we looked at the replies we had got, we noticed the following things:



- Support Providers **don't always signpost or know** about services that they could signpost people to. Nobody mentioned Health Trainers, Health Chats etc.



- One provider didn't know about Annual Health Checks and Health Action Plans.



- Providers think that because people have a Health Action Plan folder they must have an actual plan. MOWPs Jess and Richard both have the folder but the action plan section is blank.



- Support workers don't have the contact time or the training to give healthy cooking support.



- One provider gets referrals from local GPs to help people with healthy lifestyles.

We asked, 'What do you find are the biggest problems and barriers to people leading healthy lifestyles?'

They told us:



- not enough money to buy quality services



- Poor diet



- Not taking medicines at the right time or in the right way



- No information about making good choices



- Not being motivated to do something



- Not getting enough exercise



- Supermarkets promote bad food choices through offers like Buy One Get One Free



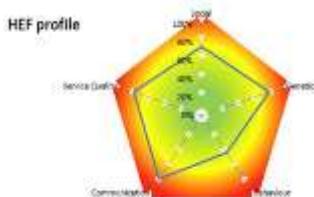
- No access to services – **don't meet the criteria** or no choice in the local area

All of these are issues that projects like Living Well are meant to tackle – but you need to be referred.



The Health Equalities Framework (HEF)

This new assessment method 'measures the impact of care and support in reducing the impact of the 5 main causes of health inequality'.



1. Social factors like housing, and community links
2. Genes and family background
3. How well someone can communicate & understanding their health issues

4. Personal health behaviour & lifestyle risks

5. The quality of healthcare & other services



In Worcestershire the Health Equalities Framework will start to be used later this year.



Using the HEF should help professionals make sense of a **person's health issues** and decide what should go in a **person's health action plan**.



If reducing health inequalities is a priority, we ask,

? How are all these different projects going to be linked up across the county? How will they know if they have made a difference for people with learning disabilities?

? Why not make having a learning disability a reason for referral to all these schemes?



GP Practices

Health Checkers are doing a report on GP practices in the county. We expect their recommendations to be sensible and important. We will be asking for pledges at the **People's Parliament** on 2nd October to support them.





Matt and Paul say: they are very pleased with the service they get from their GP. Their surgeries are accessible and it is easy to get an appointment when they need one.



Everyone we have spoken to for this white paper has said how important the Health Checks are.



We know that Health Checkers have been asking GP Practices about Annual Health Checks.



In our Transitions **people's** Parliament in December 2014 we asked for a pledge from NHS England:



“to work closely with Worcestershire County Council to make sure GP practices are aware of the importance of health checks and actively encourage GP practices to promote Health Checks to young people.”



We have not had a reply to any of our requests for NHS England to come and sign the pledge, or to tell us what they are doing.



We ask,

- ?** Will GP Practices and NHS England pledge to do all the things that the Health Checker GP Practice report says need doing?



Hospitals



We talked to Rani Virk, Lead Nurse for Quality and patient experience at the Acute Trust.



She told us that most people with a learning disability in Worcestershire go into hospital through Accident and Emergency, not through the planned admission route.



Rani told us that when a person with a learning disability goes into hospital they are given a copy of My Hospital Book. All the information about the care they get and the reasonable adjustments they need is put in here.



Rani told us that the Acute Trust is working on a Transitions Pathway so that the change from **children's** services to adult services in hospital is as easy as possible.



The Acute Trust has not agreed this pathway so the system being used by the Learning Disability Liaison Nurses is not a rule of the hospital yet.



Rani told us about Learning Disability Champions. These are people who already work in the hospital who get extra training so that they can promote best practice in the care and treatment of patients with learning disabilities.

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There are about 40 Champions from different departments – doctors, nurses and porters. The scheme has been going for over 2 years.



Learning Disability Liaison Nurses

We talked to Kay Dalloway about her job. Kay told us that both she and Jane Bullock work part time. They cover the whole county and support up to 50 people a month.



They work Monday to Friday. At weekends Learning Disability Champions support new patients.



If a person is already listed as having a learning disability then **the hospital's computer system** sends a text message to the Learning Disability Liaison Nurses. This lets them know that the person is in hospital.

They then get in touch with the ward staff to see how everything is going. They can check that staff know the **person's needs and are using reasonable adjustments.**



The target is that they will support 95% of people with learning disabilities admitted to hospital. At the moment they see 85%.



Matt and Paul say: Going to hospital is very stressful and frightening. Ambulance staff do not always know how to deal with people with high support needs. Driving in the ambulance with the siren going is very frightening.



Jess's Story

Just as the MWP's were starting to research this White Paper one of them found out she needed to go into hospital.



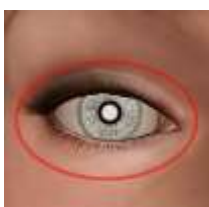
Her story makes very important points about the experience of people with a learning disability in the health system.



Jess lives independently in Redditch. She has a learning disability and has some support to help her with this.



Her mum and dad are also involved with giving her regular support especially with any health care appointments.



Jess has had cataracts on both eyes since she was a young child. She had these removed when she was 21 years old and they needed to remove dust from her eyes with laser treatment.



After this she had an assessment at Kidderminster Hospital to check her eyes.



Jess was told she would need an operation to fix it and that would mean having an anaesthetic.



Jess said that the doctor spoke to her mum not her. She felt upset and angry about this.



Jess said that the nurses were really nice at Kidderminster hospital and explained to her what needed to happen.



The nurses made her feel at ease and she felt able to ask her own questions. They listened to her.



Jess wanted to have the operation to improve her eyesight even though it would mean her not sleeping on her back or being able to look up for a month.

She was given a date to go for the operation on the 8th January 2015.



The hospital rang her mum on the 5th January to say that the operation had been cancelled. They had not received a report from the Queen Elisabeth Hospital about Jess's heart condition.



Staff at Kidderminster hospital should have contacted them but this **hadn't happened**.



Jess wasn't happy about this. She had geared herself up to have it done. Jess was angry that the operation had to be cancelled because they **hadn't got all the information**.



Plans had been made so that she could be looked after when she came out of hospital. About 100 hours of care had been changed and needed to be rearranged again.



When Jess did have the eye operation she was supported by a Learning Disability Liaison Nurse.



She wasn't given a My Hospital Book. When she asked for a leaflet about her operation that she could understand there wasn't anything in Easy Read.



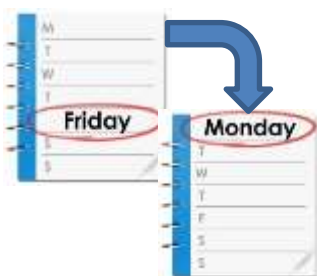
The Learning Disability Liaison Nurse said that she would make contact with Jess afterwards. This didn't happen.



At her follow-up session the consultant told her she had a detached retina and needed surgery right away. Because **they couldn't do it in** Worcestershire she would have to go to Birmingham.



She was told to go home and wait for a phone call. She was told not to look up or she could go blind.



This happened on a Friday. She got a call to say that she **was going to a hospital in Birmingham on Monday.** Don't look up for the whole weekend!



Jess thinks the staff and doctors in Birmingham were great. But Jess didn't meet a Learning Disability Nurse while she was there. And she didn't meet a Learning Disability Nurse when she was sent back to Worcester.



Jess feels that if her family hadn't been there for her she wouldn't have coped with it all.

We ask,



? Who is trying to find out why more people with learning disabilities end up in hospital through Emergency than through planned admission? What is going to be done to change this?

? Learning Disability Nurses do a great job but they are part time. How can the Acute Trust make sure that people get support 24/7?



? The Acute Trust employs 1000s of people. It has taken 2 years to train 40 Learning Disability Champions. Is this really making any difference?

? How quickly is the Acute Trust planning to agree the Transitions Pathway so that it is followed by everyone?

? **Information is really important. Why doesn't the Acute Trust have Easy Read information in all of its hospitals?**



Community Services

The Health **Checker's** Dental Review was published in April 2014. They came up with a list of Reasonable Adjustments that Dentists need to make for people with a learning disability.



We ask,

- ?** Will NHS England make the Health Checker Dental Review Reasonable Adjustments part of their contracts for dentists in future?



Our Next Steps

- We will take our White Paper to self-advocacy groups all over the county.
- We will send copies to lots of organisations involved in this topic.
- We will send copies to the papers, radio and TV



We will invite people to our People**e's** Parliament

- On Friday 2nd October 2015

- 10.30 – 1.30 at County Hall



At the end of the Parliament we will ask commissioners and providers to make Pledges about how they will improve their plans.



Get involved!

To tell us what you think of the things in this White Paper please contact our Coordinator, Ian Craigan.



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