Integrating Physical Health

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Aims

- Reflect on research findings and DH initiatives over the last 19 years around the physical health needs of people with learning disabilities
- Look at Current Initiatives
- Think about how we can get it right across our patch
- Making Every Contact Count (MECC) – a useful tool
St George's research was led by Prof Sheila Hollins, discovered that adults with LD were 58 times more likely to die before the age of 50 than an average citizen. Identified leading cause of death pertained to aspiration, dysphagia and choking.

WHO paper identified that the average age of death of pwld in the uk was 56 years old and that this compared badly to similar socio-economies within northern europe. Identified that pwld had 2.5 times the health needs or risks of an average person but that in the UK pwld used primary care services less than half of the occasions than their non-disabled equivalents. Inferred that the NHS is failing.
Acknowledged that Primary care had been ‘slow to respond’ to meeting the health needs of pwld who had arrived in local communities as a result of the disestablishment of the large institutions. Criticised community teams for their efforts to cover what primary care ought to be doing.

Health was one of 4 key strategic areas. Demanded that everyone with LD be registered with a GP by June 2004 and that everyone with LD be offered a Health Action Plan by June 2005.

Said that Community LD nurses were ‘ideally placed’ to roll out a programme of Health action plans but the guidance was extremely sketchy.

No financial incentives; in the context of Tony Blair’s first labour government. The NHS Act creating PCT’s in 2008 and National Service Frameworks for other Long-term conditions that did have financial incentives. Valuing People health section remained largely ineffective in preventing avoidable deaths. (In my opinion).
Mencap described Treat me right! as a wake up call to the NHS. Through real stories, Treat me right! confirmed sobering national and international research findings about the health of people with a learning disability and demanded that urgent action was needed to improve the health of people with a learning disability.

No systemic change as a result of this paper.
2004-2006 Disability Rights Commission

Enquiry and recommendations including:

- Access to primary care
- Annual health-checks
- Accessible and appropriate support to encourage healthy living including information advice and support in an accessible relevant and targeted form

This document proved to be a useful contribution in the struggle to get the health needs of pwld met as it gives a definition of a reasonable adjustment which amounts to – whatever is needed to be in place for a person with a disability to have the same health outcome as their non-disabled neighbour.
Mencap Death by Indifference 2007

• Told in distressing detail the stories of Emma, Mark, Martin, Tom, Warren and Ted who had all died of preventable causes within the NHS.

• Led to Independent Enquiry and Ombudsman Enquiry

Mencap invested a lot in a communications strategy to accompany this launch and it also was published on an otherwise quiet news day resulting in the Chief Exec of Mencap being interviewed on the Today Programme and on breakfast TV.

The minister of state for health at the time (Patricia Hewitt) required significant further lobbying before she called for the 2008 Independent enquiry which finally led to the establishment of annual health checks in primary care and the 2009 Ombudsman enquiry ‘Six Lives’
2008 Healthcare for All

- Recommended Introduction of Annual Health Checks in Primary Care.
- Tightened PCT accountability – led to the introduction of the Self-Assessment Framework
- Creation of LD Health Observatory

Annual Health Checks in primary care launched as a Directed Enhanced Service (DES) Autumn of 2008.

GP practices can choose which DES they take on – and it is still the case that practices can opt not to offer annual health checks if they choose to.

Originally the programme was for 3 years, but it was extended following Winterbourne View.

NHS England Self-Assessment Framework has raised LD to NHS board level across CCG's and the hospitals, has created change by stealth. For example in one year asking – Is there an LD Liaison Nurse within your Local Hospital, to Who is the LD nurse within your local hospital.

Results of the Self-Assessment Framework are published across regions using a RAG rating so organisations are being forced to change in order to improve their regional ratings.
2013 CIPOLD REPORT

Examined the deaths of 247 PWLD over 2 years.
Average age of death 65 for men
63 for women
43% were Unexpected deaths
42% Premature
Has led to National Mortality Review programme

Average age of death for all men in the UK is 78
Average age of death for all women in the UK is 83
Almost all of the pwld in the study had 1 or more long term or treatable health condition
Delays in diagnosis, further investigation or specialist referral contributing factors
30% experienced problem with treatment

The CIPOLD website is regularly updated and shows that cause of death is changing. The original study concurred with the 1998 SW London Study in that respiratory issues as a result of aspiration/dysphagia and choking were the number 1 cause of death with cardiovascular issues being the second highest cause of death. They are now roughly equal suggesting that significant work has been done to safely manage saliva, eating and drinking. Cardiovascular health whilst there are some congenital factors involved for some genetic causes of LD there are also significant lifestyle implications that services need to be aware of.
CQIN Physical Health MOT’s in Mental Health Services

Recognition that PW enduring MH problems die 14 – 20 years younger than average
Overlap creates potential for full systems review and partnership working

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Locally PWLD might know that they do have an OK health check (which is their health action plan) rather than being familiar with the words Health Action Plan.

Mencap are strongly advocating for PWLD to know their rights in terms of expectations of the whole healthcare system.

PWLD are often worried/frightened to hear that average age of death is 63-65 and believe that that will happen to them. We need to be careful about how we broach health issues with the population.
Annual Health Checks in Primary Care

GP Practices paid to maintain a register of PWLD on their list
Payments available for completion of annual health check
Training requirement
Welsh Check recommended but not mandatory
Production of Health Action Plan added requirement in 2014

The original tariff for completion of a register and Health action plan was £100 per patient with LD. Was deemed not enough in comparison to other Directed Enhanced Services at the time. Current tariff is £160 but primary care colleagues still complain that the full health check is too long and laborious.

Practices locally have not got a planned response to production of a health action plan. Have heard of pwld being given a copy of the EMIS template to take away.
The Welsh Health Check

Designed for the convenience of primary care clinicians
Issues about the order of the consultation
Inaccessible
No healthy lifestyle inquiry
No Mental Health inquiry
No Health Action Plan template
? Inappropriate physical examinations

Inappropriate physical examinations – breasts and testicles?????  No evidence base to support this.

The communication section is at the bottom of page 6!

One of the first conversations is about vaccinations and injections – creating fear and distress in some people with LD.
Local Developments – Lambeth CCG

Have recently begun joint work with Lambeth CCG to produce an accessible template for the annual health check AND health action plan. Still in it's infancy, these next few slides are prototypes and have yet to be approved.

I wonder if there is room for joint work with MH colleagues here so that your physical health checks could be recorded within the one document, thereby reinforcing to pdwld the importance of this document and the need to take it to all health/medical appointments for updates and information.
My Annual Health Check and Health Action Plan

Communicating with me

Communicate
All people with learning disability will require extra time to process information. It is important that information is given in small chunks and in the most appropriate way for the person

Many people with learning disability will have a communication passport that was created following a speech and language therapy assessment. Talk to see that is order to plan this appointment properly

I can communicate by using Makaton signs and pictures
I can speak for myself and understand everything that you do
I can communicate using specialist aids and/or objects of reference, and sometimes struggle to express myself. Please be patient
I need full support to communicate about anything in any circumstances

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### My Annual Health Check and Health Action Plan

**Information Sharing**

<table>
<thead>
<tr>
<th>My personal assistant</th>
<th>I am happy for you to share my health check with my personal assistant</th>
<th>I am not happy for you to share my health check with my personal assistant</th>
</tr>
</thead>
<tbody>
<tr>
<td>My family</td>
<td>I am happy for you to share my health check with my family</td>
<td>I am not happy for you to share my health check with my family</td>
</tr>
<tr>
<td>Other Healthcare Professionals</td>
<td>I am happy for you to share my health check with other healthcare professionals</td>
<td>I am not happy for you to share my health check with other healthcare professionals</td>
</tr>
</tbody>
</table>

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# My Annual Health Check and Health Action Plan

It's a good idea to check with the person with CJD and then carry whether they have any specific concerns or issues they wish to be covered during this appointment.

<table>
<thead>
<tr>
<th>My blood pressure is:</th>
<th>Urine Test Result:</th>
<th>Random blood glucose test result:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

My weight is: | My height is: |
<table>
<thead>
<tr>
<th></th>
<th></th>
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</thead>
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<td></td>
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</tbody>
</table>

I want to know more about:

I do not smoke | I smoke about 5 cigarettes a day | I smoke about 10 cigarettes a day | I smoke 20 or more cigarettes a day

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My Annual Health Check and Health Action Plan

**My hearing**

- **I do not have any problems with my hearing**
- **I have a minor hearing problem; please remember to speak up**
- **I have a major hearing problem**
- **I have a hearing aid and I don’t wear it**

Around 40% of adults with Learning disability have hearing impairment significant enough to interfere with conversation. Make referral to audiology services if you judge that a person has undiagnosed hearing loss. People with Down Syndrome should have audiology every 3 years. People over 45 should have audiology screen every 3 years. Please check ears for wax.

My personal assistant is concerned/not concerned about my hearing

I have been to the audiology on;

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# My Annual Health Check and Health Action Plan

## My eyes and vision

<table>
<thead>
<tr>
<th>Condition</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have normal vision (with/without glasses or contact lenses)</td>
<td></td>
</tr>
<tr>
<td>I have minor visual problems</td>
<td></td>
</tr>
<tr>
<td>I have major visual problems (not registered blind)</td>
<td></td>
</tr>
<tr>
<td>I last had an eye test on:</td>
<td>I need to go for an eye test soon;</td>
</tr>
<tr>
<td>I often rub my eyes, or get discharge from my eyes.</td>
<td></td>
</tr>
</tbody>
</table>

There is huge discrepancy in the evidence base around numbers of people with Learning Disability suffering visual impairment, however, Cataracts and Keratoconus are more common. Please examine the person's eyes carefully. Make a judgement around whether to recommend that the person sees an ophthalmologist.
Further opportunities to integrate our physical health check work. There is soon to be a subgroup of the Southwark LD partnership board that could lead/influence the roll out of both workstreams.
Would have the effect of reinforcing a single unified document for all pwid to carry to all appointments.
MECC is an approach to behaviour change that utilises the millions of day to
day interactions that organisations and people have with other people to
encourage changes in behaviour that have a positive effect on the health and
wellbeing of individuals, communities and populations.

Within GSTT there is a CQIN for all clinical staff to be trained in the use of
MECC.

Offers a model for light touch motivational interviewing and 1 off coaching. It
emphasises the positive effects of one small change.
MECC is not about;

Adding another job to an already busy working day
Staff becoming specialists in certain lifestyle areas
Staff becoming counsellors or providing ongoing support to particular individuals
Staff telling somebody what to do or how to live their life

It offers opportunity to provide a single message about healthy living in an easily accessed format.

We also need to think through how our services model and encourage lifestyle change and gain broader sign up to work with other agencies and the population on health promotion targets and campaigns.