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An Evaluation of the Clinical Directed Enhanced Service for People with Learning Disabilities in the Yorkshire and the Humber Region.

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Introduction

The Yorkshire and Humber Healthy Ambitions Programme Board commissioned Speakup Self Advocacy (a national self advocacy organisation run by people with learning disabilities) and Sheffield Hallam University to undertake an evaluation of the Clinical Directed Enhanced Service (hereafter referred to as the DES) for People with Learning Disabilities across the Yorkshire and Humber region between July and October, 2010. This report presents a summary of the design, implementation and findings of this evaluation.

The aims of the evaluation were to:

- *Explore the impact of the DES on people with a learning disability, assessing the role and impact of training in learning disability to deliver annual health checks.*
- *Explore examples of where GPs, Nurses, Practice Managers and Receptionists have used reasonable adjustments to improve access to annual health checks for people with a learning disability.*
- *Identify the percentage of health checks undertaken in each area within the region compared to the actual numbers of people with a learning disability in the local population.*

The above aims were to be achieved by undertaking a predominantly quantitative study. It was agreed that the study would benefit from having a large-scale response so that possible correlations in the data could be examined. The evaluation team did discuss that there was a risk that the target audience for this study may have 'evaluation fatigue' and be disinterested in participating. We were also aware that we had no incentive to offer to encourage participation and that we were asking people to participate in a questionnaire on one aspect of their professional responsibility.

While it was recognised by the evaluation team that the experience of having a health check is important to evaluate, it was not the focus of this particular study. The experience of health checks from the perspective of people with a learning disability has been explored in other studies (Martin et al, 1997; Perry et al, 2010). To complement this evaluation Speakup has commissioned a piece of work from its self advocates, to produce a series of narratives and expressions from people with a learning disability to communicate their experience of annual health checks in the Yorkshire and the Humber region. This work is due to be available in December 2010 and is available from sally@speakup.org.uk

The evaluation was designed and implemented over a four-month period between July and October 2010. There was an initial planning meeting that was held in June and various discussions around the focus and remit of the

evaluation. The evaluation study was originally to have been a larger scale study, which was eventually scaled back in line with the reduced budget for this piece of work. The outcomes of the evaluation were agreed to form a report to the Healthy Ambitions Programme Board so that the Yorkshire and the Humber region had a clear picture of the services being offered to people with learning disabilities under the Directed Enhanced Services (DES).

Directed Enhanced Services (DES)

Annual Health Checks for people with a learning disability have been repeatedly recommended over the last five years (Robertson et al, 2010) by the Disability Rights Commission in 2006, as a 'reasonable adjustment' under Disability Discrimination legislation, and in 2008 by the Inquiry into Access to Health Care (The Sir Michael Inquiry). In 2009 the Department of Health published directions to give GP practices the opportunity to provide health checks as part of a Directed Enhanced Service (DES). The DES was originally agreed for two years and now has been extended to 2010-11. Several pieces of legislation, which directly address healthcare inequalities of people with a learning disability, have been published. Some of these, such as Valuing People and Valuing People Now, are specific to learning disability (DH, 2001; DH, 2009). Others such as Our Health, Our Care, Our Say (DH, 2006) make specific mention of learning disability within more generic reforms. High Quality Care for All (2008) a.k.a. 'The Darzi Report' outlined the need for the NHS to be more universal and accessible in its customer relations; in this detail it was the suggestion that perhaps this had not always been the case. 'Six Lives' (2009) then fully vindicated these findings. One positive outcome emerged. First mooted in 'Valuing People' (DH, 2001) the idea of an annual health check for people with learning disability is now in place. Nationally however, it has been reported that less than 50% of eligible adults received a health check in 2009/10 (Emerson and Glover, 2010).

Directed Enhanced Services (DES) are extra services or activities provided by GP practices that have been negotiated nationally. The rationale behind the service is to offer people with learning disabilities and complex needs an annual health check as they are at a higher risk of undetected health conditions. The intention is that such enhanced services will lessen demand on secondary care. However, practices are not legally obliged to provide these services but, for those, which agree to deliver, there are financial incentives. These incentives are usually paid on a 'per capita' basis. In the learning disability DES the annual health check attracts £100 per patient for the practice. Every PCT must offer the DES to its practices, GP practices can then choose to take up the DES with the PCT paying the incentive if it judges the practice has adopted the requirements of the des.

An outline of the training required for the DES contract is presented in Appendix A.

Health Checks and People with a Learning Disability

It has been well documented elsewhere (Baxter *et al* 2006; Elliot, Hatton, Emerson, 2003; Emerson *et al*, 2001; Robertson *et al*, 2010) that people with a learning disability are likely to experience increased health problems but are less likely to have access to health care services to deal with these issues. People with a learning disability live with poorer health at a rate of two and a half times that of the general population (Hardy *et al*, 2007; Kerr, 2004; Melville, 2005). The report 'Equal Treatment: Closing the Gap' (DRC, 2006) continued the debate by highlighting the disparities that exist in health care settings particularly for people with a learning disability and or a mental health problem.

Health checks for people with learning disability are not new and were suggested by Howells (1986) and subsequently Matthews (1997) who developed the 'OK' Health Check. Cassidy *et al* (2002) reported an attempt to promote good practice by involving GPs and community learning disability teams. More recently Marsh and Drummond (2008) have issued a reminder for the 'OK' Health Check to be used with people with a learning disability. Felce *et al* (2008) demonstrate their worth in terms of detecting and treating unmet health needs while Romeo *et al* (2009) are the first to have attempted a cost-benefit analysis which suggests that health checks are also economically justified. In addition to this the DES guidance (2010/11) stipulates that all practices offering the DES should base their health checks on the model adopted in Wales known as the Cardiff Health Check protocol as this method had been proven as an effective model throughout Wales. Perry *et al* (2010) outline an education pack, which has been devised by Kerr *et al* (2006) and is a useful guide for GPs in outlining the knowledge and information to consider about learning disability when considering carrying out a 'Health Check' with a person with a learning disability. In addition to this the Royal College of General Practitioners have launched "A Step by Step Guide for GP Practices" (2010) to help ensure quality annual health checks are performed.

In 'Health Care for All' (2008) Sir Jonathon Michael suggested that the NHS needed urgently to provide 'reasonable adjustments' across all service provision. By adopting this legal language he hinted strongly that failure to do so could result in prosecution. The Disability Discrimination Act (1995), Disability Equality Duty (2006) and the Equality Act (2010) require that all public bodies, such as PCTs, NHS trusts and local authorities produce a Disability Equality Scheme. This should be compiled in collaboration with people from 'disabled' groups and should demonstrate how the organisation will accommodate such individuals on its premises and in its care. In addition article 14 of the European Convention on Human Rights (made law in the UK by the Human Rights Act 1998) outlines the right to be offered treatment free from any discrimination. Providing an annual health check to all people with a learning disability should be provided under the Disability Discrimination Act (1995; 2006). Providing a health check should be seen as a 'reasonable adjustment' under this legislation to enable better access to health care for people with a learning disability. There is now a requirement to provide annual health checks in England where PCTs commission GPs within the GMS

contracts to do so via a DES. Even in the absence of GPs signing up to the DES, Robertson et al (2010) argue that “failures of health systems to appropriately respond to identified treatable morbidity cannot ethically or legally be used to justify failing to make ‘reasonable adjustments’ to the detection of potentially treatable ill health”. Health Checks should inform the development of a 'Health Action Plan' and reasonable adjustments should be used to enable effective access to health care services to enable the implementation of the 'Health Action Plan'.

Evaluation Design

The design of the evaluation has been a collaborative process between Speakup (SF) and Sheffield Hallam University (JA and KK). The qualitative researcher (JA) has an academic and research interest in learning disability and was able to provide guidance from her area of expertise, while the quantitative researcher in public health (KK) advised as to how best to structure the quantitative questions for quantitative data analysis. Speakup have taken a lead role in administering the questionnaire, with guidance from Sheffield Hallam University to address methodological and ethical issues in data collection. The evaluation was designed in two stages:

Stage 1 Mapping the current provision (Appendix B) - with Primary Care Team leads to undertake a mapping exercise across the region to identify the following:

- The number of practices within each locality signed up to delivering the DES.
- The number of GPs, Nurses, Receptionists/Admin/IT and Practice Managers who had attended the DES training conducted within their locality.
- The mode of training received within each locality and the method of delivery.
- The total numbers of people eligible for a health check within each locality compared to the actual number of health checks received.

Stage 2 Online Questionnaire (Appendix C) – The Clinical Directed Enhanced Service (DES) for GMS contracts (2008/09) required that all practices delivering this service would attend a multi-professional education session. The online electronic questionnaire targeted all General Practitioners, Nurses, Practice Managers and Receptionists/Admin/IT staff who had participated in the DES training and who were identified in the Stage 1 mapping exercise. The questionnaire aimed to explore the method of delivery, the outcomes and knowledge gained from such training:

- The type of training received e.g. seminar or on-line learning.
- Who facilitated the training e.g. a professional, or a person with a learning disability.
- Knowledge of learning disability (based on the core content of the DES guidance Appendix A).

- The number of health checks undertaken and the average completion time.
- Any health care needs identified through the health check.
- Any problems or issues in carrying out the health check.
- Examples of any reasonable adjustments taken since the training to enable better access by people with a learning disability.

The questionnaire was designed in two parts, the first with questions specific to all professionals who attended the training and the second with questions only to be completed by GPs and Nurses completing the check.

As the evaluation was a significant regional study it was important to secure the support of key PCT leads from each of the areas within the region to support the mapping exercise at Stage 1. The key PCT leads would also be able to support the distribution of the questionnaire at Stage 2. Speakup planned to invest time to build relationships with key individuals at Stage 1 of the evaluation through telephone calls and emails to maximise the support for completion of the questionnaire at Stage 2 of the process. Building relationships with key PCT leads led to a meeting with one of the areas (Wakefield) who were in the process of undertaking their own evaluation. It was agreed that Wakefield would support the regional study and each PCT area would have an opportunity to comment on the design of the questionnaire at Stage 2. In addition to this, Speakup contacted lead clinicians across the region to discuss the process for Stage 1 and received feedback from Barnsley, Rotherham and Calderdale. All lead clinicians were contacted for Stage 2 with regards to feedback on the online questionnaire with comments and feedback being given by, Barnsley, Doncaster, Leeds, Rotherham and Wakefield.

The regions that agreed to participate in the study and influenced the design of Stages 1 and 2 are detailed in Table 1:

Locality	PCT lead identified and supported their regions involvement in the evaluation	PCT lead influenced the design at stage 1	PCT lead influenced the design at stage 2
Barnsley	√	√	√
Bradford	√		
Calderdale	√	√	
Doncaster	√		√
East Riding	√		
Hull	√		
Kirklees	√		
Leeds	√		√
NE Lincs	√		
Rotherham	√	√	√
Wakefield	√	√	√

Table 1: Levels of participation across the region with the DES for people with a learning disability

Implementing the Evaluation

The mapping exercise (Stage 1) required the PCT leads to send returns electronically with relevant and significant data. This data went through a first stage checking system and any discrepancies in the numbers were highlighted and the PCT that had submitted the data was contacted to confirm or amend the data. A copy of the mapping questionnaire sent to the regions is presented at Appendix B.

Speakup created a rigorous system of checking the data that was returned and would follow up with a telephone call, in addition to corresponding via email, should there continue to be gaps in the data or any obvious inaccuracies. Leading self advocates from Speakup, David McCormick and James Wyatt, were responsible for checking the information received under supervision at stage 1. David and James worked closely with Sally Ferguson (offering support) to input and check the information gathered within Excel.

The spreadsheet was shared with Sheffield Hallam University through an online document share facility and as the returns were entered the data could be viewed and checked for any omissions or irregularities by Sheffield Hallam University who were able to advise accordingly.

Once the Stage 2 questionnaire had been commented on by the areas within the region (please see Table 1), some changes were made to the questions and some questions were removed as they were not thought relevant to the delivery of the DES/LES. The link to the online questionnaire was sent out with a two-week return date in October 2010. This was extended by a week and respondents had a total of 3 weeks to return the questionnaire. There were some difficulties in receiving the online questionnaire from some areas as PCT leads sent the questionnaire late; this was one of the reasons for the low return rates.

Limitations and reliability

Stage 1

- There were disparities with the data received from the mapping exercise at Stage 1. Some PCTs had kept accurate and up to date information on the number of people trained in each practice, whilst other areas had not.
- Only 11 areas out of 14 submitted information; therefore a true regional comparison cannot be achieved.

Stage 2

- The online questionnaire was anonymous so we cannot identify respondents to determine if more than one person responded from each practice.
- The sample is small and self selected; hence it is not necessarily representative and likely to be biased towards those with a positive response to the DES. For this reason it must be regarded as indicative only. **We do not claim that any result is statistically significant.**

- The sending out of questionnaires via key PCT leads is liable to have led to varying levels of response between PCTs dependent upon the enthusiasm of the lead.
- Some respondents were unable to complete the questionnaire by the required deadline because PCT leads did not send out the questionnaire in time.

Results

This section will present the findings of both Stage 1 and Stage 2 data. The full mapping exercise is presented as Appendix C and a summary of the respondents for Stages 1 and 2 is presented in Table 2;

Stage 1		Stage 2	
Areas who returned data		Areas who returned data	
Barnsley	√	Barnsley	√
Bradford	√	Bradford	√
Calderdale	√	Calderdale	√
Doncaster	√	Doncaster	√
East Riding	√	East Riding	√
Kirklees	√	Kirklees	√
Leeds	√	Leeds	√
NE Lincs	√	NE Lincs	√
Rotherham	√	Rotherham	√
Wakefield	√	Wakefield	√

Table 2: Respondents by area

Stage 1 Mapping

Eleven PCT areas supplied information. North Lincolnshire, Sheffield and North Yorkshire and York were unable to supply any information in the time available and so do not appear in any totals.

Across the 11 areas overall, 77% of practices have signed up to provide an Enhanced Service (Table 3). In most areas upwards of about 60% of practices have signed up. The exceptions are Hull* and NE Lincs†. Although staff at a high proportion of practices in Hull received training, the proportion implementing the DES has been low due to difficulties in verifying patient records with Social Services. This should hopefully be resolved with the appointment of a Wellbeing Nurse for Learning Disability who will work with GP practices to increase the uptake. In NE Lincs† the data refers to implementation of a Local Enhanced Service as opposed to a Directed Enhanced Service.

PCT Area	Total No. of GP Practices	No. of Practices signed up to DES	% of Practices signed up to DES
Barnsley	46	32	70%
Bradford	88	88	100%
Calderdale	26	23	88%
Doncaster	44	35	80%
East Riding	39	23	59%
Hull*	60	13	22%
Kirklees	75	71	95%
Leeds	114	97	85%
NE Lincs†	33	14	42%
Rotherham	40	40	100%
Wakefield	41	32	78%
Total (for 11 areas)	606	468	77%

Table 3: GP Practices signed up to provide Directed Enhanced Service

*Although staff at many practices in Hull received training, the proportion implementing the DES has been low due to difficulties in corroboration with Social Services.

† A Local Enhanced Service has been implemented in NE Lincs.

PCT Area	No. eligible for a health check	No. received a health check	% received a health check
Barnsley	266	106	40%
Bradford	2033	1545	76%
Calderdale	651	326	50%
Doncaster	914	452	49%
East Riding	1128	441	39%
Kirklees	1073	678	63%
Leeds	2251	377	17%
NE Lincs	487	168	34%
Rotherham	778	338	43%
Wakefield	1093	625	57%
Total (for 10 areas)	10674	5056	47%

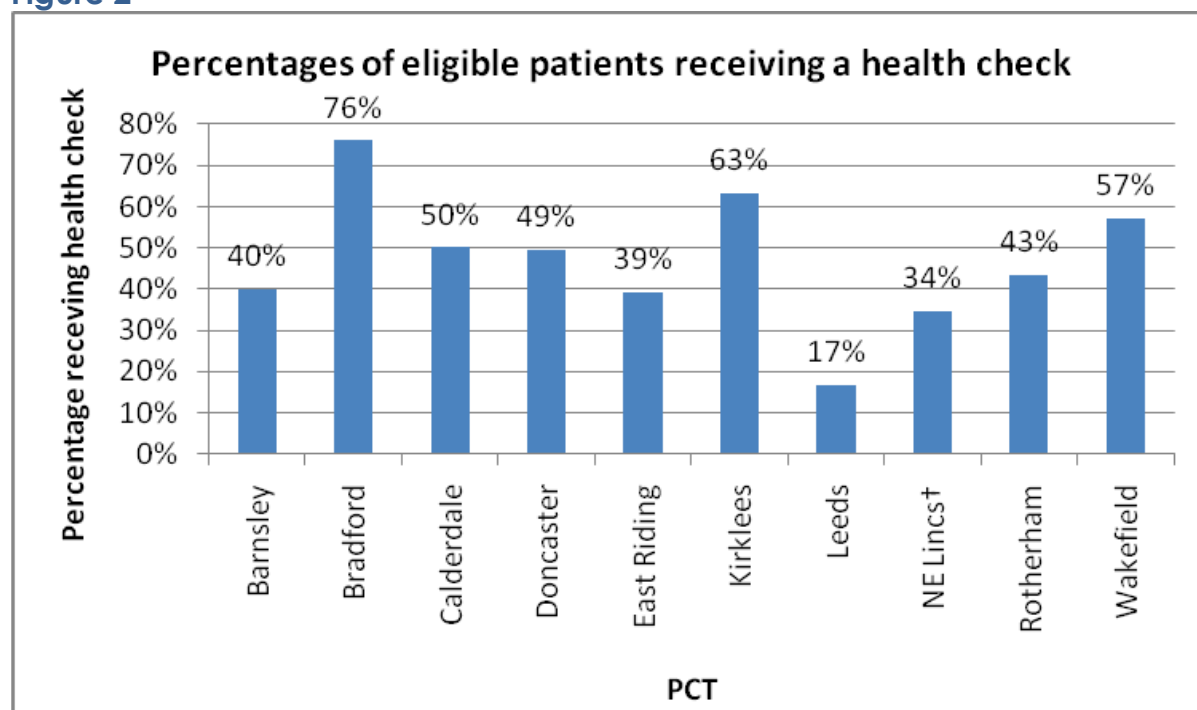
Table 4: Number of people eligible for a health check

Table 4 and Figure 2 show numbers and percentages of eligible patients receiving a health check in 10 of the different areas. Hull was unable to provide the relevant information.

Across the 11 areas an estimated 46% (about 5000) of those eligible for a health check under the service have received one. In some areas the process is ongoing and others have a partly completed check. There are considerable differences in the levels of completed health checks across areas. Most areas claim to have completed checks for 40%-65% of those

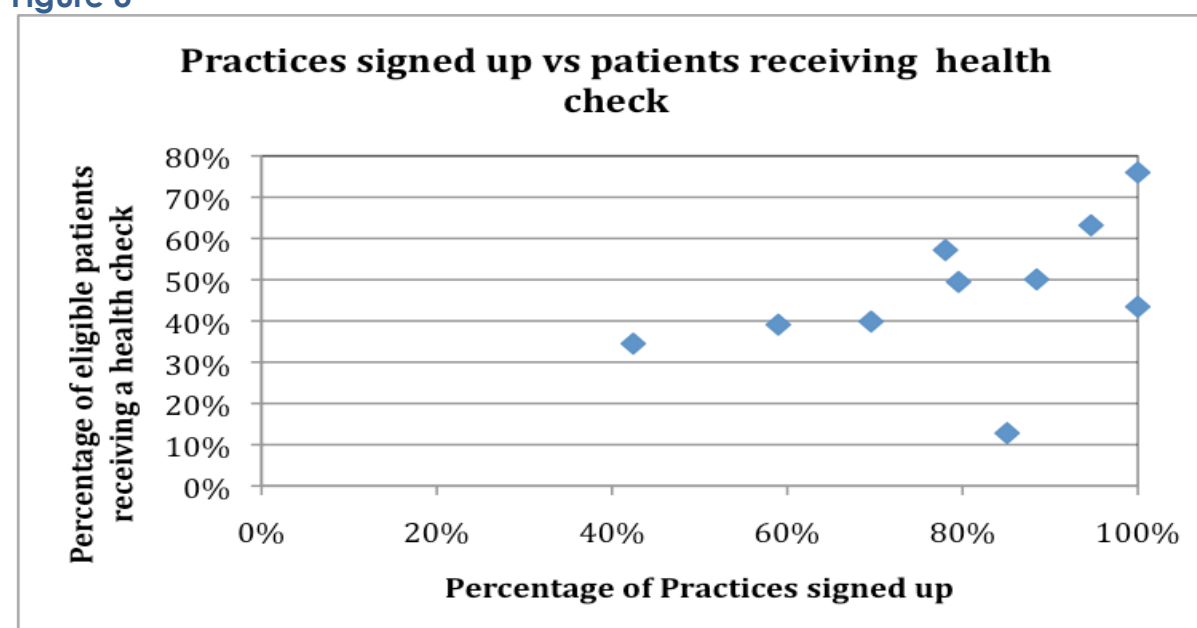
eligible. The most notable contrast is between the two largest areas; a very high proportion of completed health checks have been recorded in Bradford (76%), but a very low proportion in Leeds (17%).

Figure 2



As would be anticipated, there is a generally increasing relationship between the percentage of GP practices signed up and the percentage of eligible patients in a PCT who have received a health check, as demonstrated in Figure 3. The exception to this would appear to be Leeds where, despite an 85% sign up, only 17% of eligible patients are recorded as having received health checks.

Figure 3



PCT Area	Practices signed up to DES/LES	Total no. of individuals receiving formal training	Median no. of individuals per signed up practice	Minimum no. of individuals per signed up practice	Maximum no. of individuals per signed up practice
Barnsley	32	113	3	0	9
Calderdale	23	72	3	1	5
Doncaster	35	143	3	2	15
East Riding*	23	72	3	3	3
Kirklees**	71	142	2	2	2
Leeds	97	352	3	0	34
NE Lincs†	14	187	16	4	39
Rotherham	40	261	4‡	1	37
Wakefield	32	122	3	0	15
Total (over 9 areas)	367	1432	3	13	39

Table 5: Individuals receiving formal training

* According to data received, exactly 3 individuals per practice received formal training in the East Riding

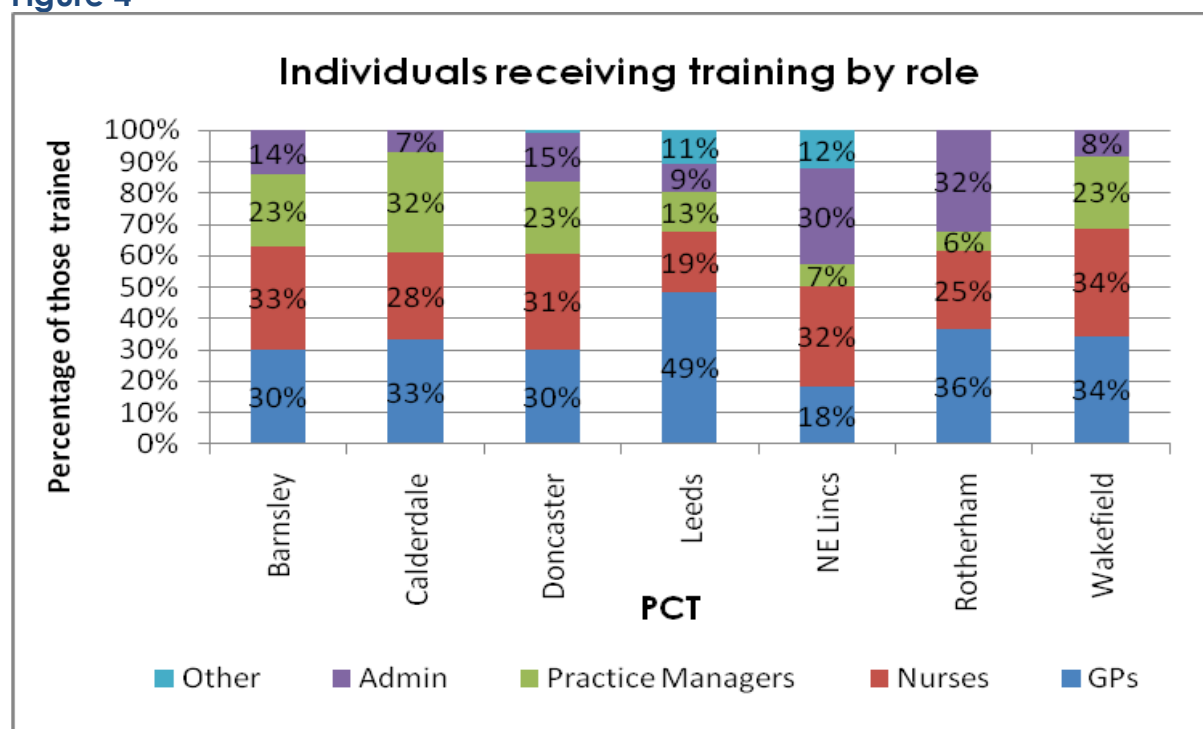
** According to data received, exactly 2 individuals per practice received formal training in Kirklees

† 3 practices in NE Lincolnshire were unable to supply data

‡ Does not include 27 individuals who were trained at a non-practice based event

Bradford and Hull were unable to provide information on the numbers of practice staff receiving training. Across the other 9 areas, 1432 individuals were recorded as having received formal training, including GPs, Nurses, Practice Managers and Admin/Reception staff. This is a median of 3 individuals per practice across all 9 areas but ranges from 2 per practice in Wakefield to 16 per practice in North East Lincolnshire; naturally, this will to some extent reflect the average size of practices signed up in each area, but it indicates exceptional disparity. A few practices in Leeds, NE Lincolnshire and Rotherham each had more than 30 staff receiving training. Some practices in Barnsley, Leeds and Wakefield had only recently signed up so had not had formal training yet.

Figure 4



Seven PCTs were able to supply information regarding the roles of those who received formal training: Barnsley, Calderdale, Doncaster, Leeds, NE Lincolnshire, Rotherham and Wakefield (Figure 4 and Table 6). In most areas, around 60% of those trained were in clinical roles and the rest non-clinical. Nearly half of those trained in Leeds were GPs, compared with less than a fifth in NE Lincolnshire and about a third elsewhere.

PCT Area	GPs		Nurses		Practice Managers		Admin		Other		Total Trained
	No.	%	No.	%	No.	%	No.	%	No.	%	
Barnsley	34	30%	37	33%	26	23%	16	14%	0	0%	113
Calderdale	24	33%	20	28%	23	32%	5	7%	0	0%	72
Doncaster	43	30%	44	31%	33	23%	22	15%	1	1%	143
Leeds	171	49%	67	19%	45	13%	32	9%	37	11%	352
NE Lincs	28	18%	50	32%	11	7%	47	30%	19	12%	155
Rotherham	95	36%	66	25%	16	6%	84	32%	0	0%	261
Wakefield	42	34%	42	34%	28	23%	10	8%	0	0%	122
Total (7 practices)	437	36%	326	27%	182	15%	216	18%	57	5%	1218

Table 6: Individuals receiving formal training by role

Results – Stage 2 Online Questionnaire all professionals

Role	No.	% of responses
GP	37	27.6%
Nurse	37	28.4%
Practice Manager	45	34.6%
Receptionist/IT/Admin	7	5.3%
Other	5	3.8%
Total	130	100.0%

Table 7: Responses by Job Role

Completed online questionnaires were received from 130 individuals across the 11 included PCTs. They were mostly completed by GPs, nurses and practice managers, with a much smaller number of other staff participating (Table 7).

PCT Area	No. responding	% of all responses	No. trained by 'People with a Learning Disability'
Barnsley	16	12.2%	1
Bradford	5	3.8%	3
Calderdale	18	13.7%	11
Doncaster	1	0.8%	1
East Riding	17	13.0%	0
Hull	2	1.5%	1
Kirklees	22	16.8%	9
Leeds	4	3.1%	0
NE Lincs	3	2.3%	0
Rotherham	19	14.5%	16
Wakefield	24	18.3%	14
Total	131	100.0%	56

Table 8: Number of respondents by PCT

Responses were not evenly divided amongst areas (Table 8) with a majority of responses coming from Wakefield and Kirklees (over 20 each), followed by Rotherham, Calderdale, the East Riding and Barnsley. When asked who had delivered their training, 55 respondents mentioned 'People with a Learning Disability'. These respondents were distributed across the PCTs as shown in Table 8.

99 respondents (76%) had received their training wholly or partly via a Conference/Seminar. The majority of the rest (17%) had had in-house dedicated practice learning time for at least some of their training, with the remainder mentioning on-line or distance learning. There were no particular differences across areas, although respondents from Kirklees mentioned the widest range of different combinations of training methods.

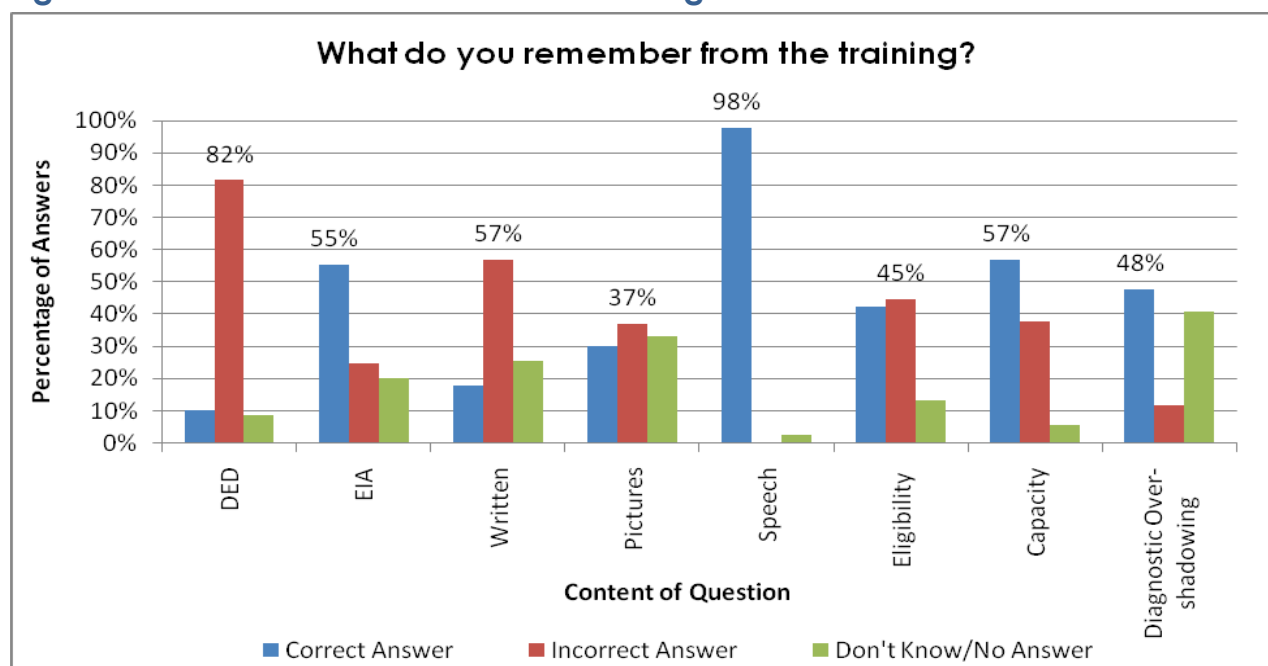
Length of Training	No. of Respondents	% of Respondents
1-2 hours	29	22.1%
2-3 hours	43	32.8%
half a day	48	36.6%
full day	7	5.3%
not stated	4	3.1%
Total	131	100.0%

Table 9: Length of training.

Table 9 shows the length of training received by different respondents. The percentages did not differ greatly over PCT areas or job roles, except that nurses tended to have longer training and only nurses and GPs (about 10%) received a full day's training.

Figure 5 shows responses received from a number of multiple-choice questions relating to facts that may have been remembered from the training.

Figure 5: Facts remembered from the training



These included questions about:

(a) Legal obligations [the Disability Equality Duty (DED) and Equality Impact Assessments (EIA),

(b) Best practice for communicating with a person with a learning disability, [in terms of written text, placement of pictures and alternatives to speech],

(c) Definitions [eligibility, mental capacity and diagnostic overshadowing].

Two or three incorrect choices were available for each question, along with the correct answer and a 'Don't Know' option. There is some suggestion from the data that knowledge of the information may differ from one PCT area to another. This is most likely to represent differences in the coverage of information during the training. There is no indication that answers differed if people with a learning disability were involved in delivering the training.

73% of respondents said that they offered a Health Action Plan to people with learning disabilities who attended their practice. However, the level of provision of a Health Action Plan appeared to vary considerably from one PCT to another. Also, practice managers and administrative staff were more likely to report that a Health Action Plan was provided (80-85%) than GPs or Nurses (66-68%).

Examples of Reasonable Adjustments

Figure 5 identifies that over 82% of respondents did not know to whom the Disability Equality Duty applied, or understand the use of Equalities Impact Assessment. Presently, it is not a requirement for GP practices to work to equalities legislation as they are not classed as a public body; however, it is a core requirement of local PCTs and NHS under the Disability Discrimination Acts of 1995 and 2006 and the Equalities Act 2010 to ensure the organisations with whom they commission services from have a positive impact on disabled people.

Question 15 asked participants to give an example of a reasonable adjustment they had made to improve the experiences of patients with learning disabilities when visiting their practice.

104 respondents answered this question and gave examples of reasonable adjustments made. Encouragingly, many of these adjustments related to making changes in delivery systems as opposed to changes with staff or the environment. Only two respondents provided an integrated response to this question, illustrating reasonable adjustments covering delivery and operational systems, staff and the environment:

"The practice has made adjustments in the following areas to improve the experiences of our patients with Learning Disabilities. We now allocate sufficient time for all assessments and are able to extend slot times within our clinics. We also work closely with carers who attend with our patients and afford more communication time to discuss needs etc".

"All our patients with LD are offered checks with a named lead nurse/Dr. Time allocated is 1hr plus depending on the patients needs, the patients can be seen in surgery or their home which ever is most comfortable to them."

Most respondents replied to the question of 'reasonable adjustments' with a single response answer. The most highly cited reasonable adjustment was in the offering of more flexible and longer duration appointment times (22

responses) while others looked to integrate a more interprofessional approach to the service being offered by setting up clinics or meetings with more than one professional:

"We have a joint learning disabilities clinic with the GP, nurse and those with epilepsy, we have a visiting Epilepsy Specialist Pharmacist, and we work together as a team, those without epilepsy as part of a diagnosis are invited in for screening with either parents, or their carers. We try to do at least one specialist clinic a yr and the others are when they can attend at their convenience" (5 responses).

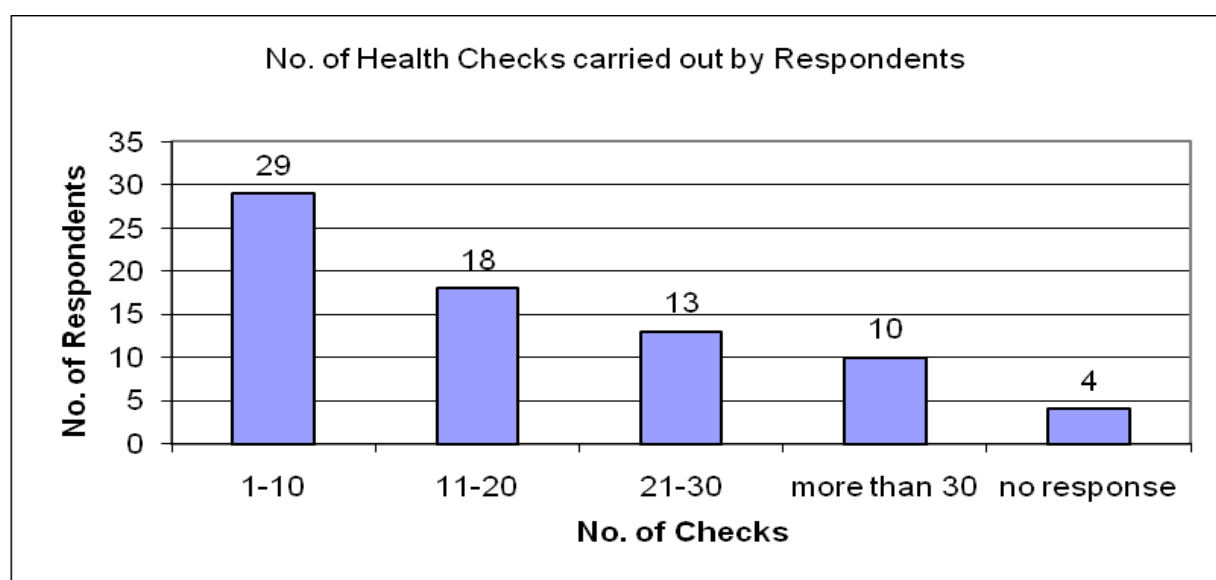
Some respondents (4) felt that offering an annual health check was a reasonable adjustment on its own, which it was in 2006, but all respondents were supplying the DES as a contracted service and not a reasonable adjustment. This suggests an example of where there is still a lack of clarity in understanding what is meant by making a 'reasonable adjustment'. Others (4 responses) recognised that offering the health check in the person's own home may be a more appropriate use of 'reasonable adjustments'.

Information from GP's and Nurses:

Thirty seven (37) GPs and thirty seven (37) nurses completed questions 17 to 25 of the online questionnaire focusing on the delivery of the annual health check.

Figure 6 and table 11 show the number of health checks each GP and Nurse completed in 2009/2010 and the average time each check took to complete.

Figure 6



Average Length of time taken to complete a health check	No. of GP/Nurse Respondents	Percentage of Respondents
Less than 10 minutes	0	0%
10-20 minutes	13	18%
21-30 minutes	27	36%
31-40 minutes	15	20%
41-50 minutes	6	8%
More than 50 minutes	9	12%
No response	4	5%
Total	74	100%

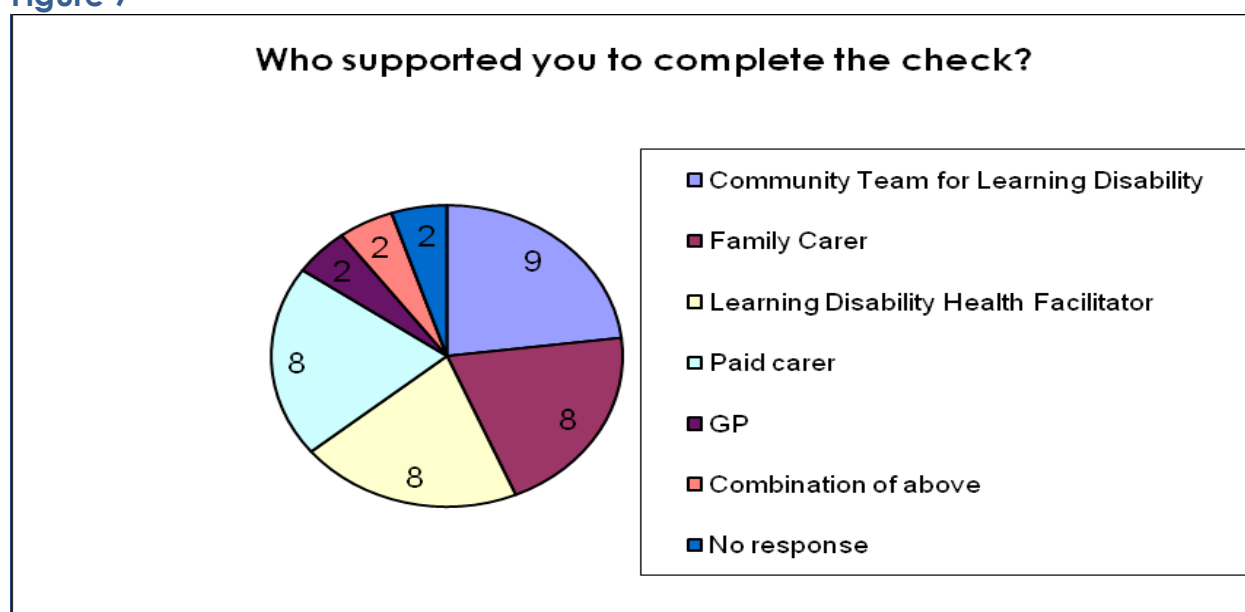
Table 10: Time taken to complete Health Checks

Thirty nine (39) respondents (53%) stated that they received additional support to complete the health check with figure 7 and table 11 highlighting where this additional support came from.

Who supported you to complete the check?	No. of GP and Nurse respondents	Percentage of Respondents
Community Team for Learning Disability	9	23%
Family Carer	8	21%
Learning Disability Health Facilitator	8	21%
Paid carer	8	21%
GP	2	5%
Combination of above	2	5%
No response	2	5%
Total	39	100%

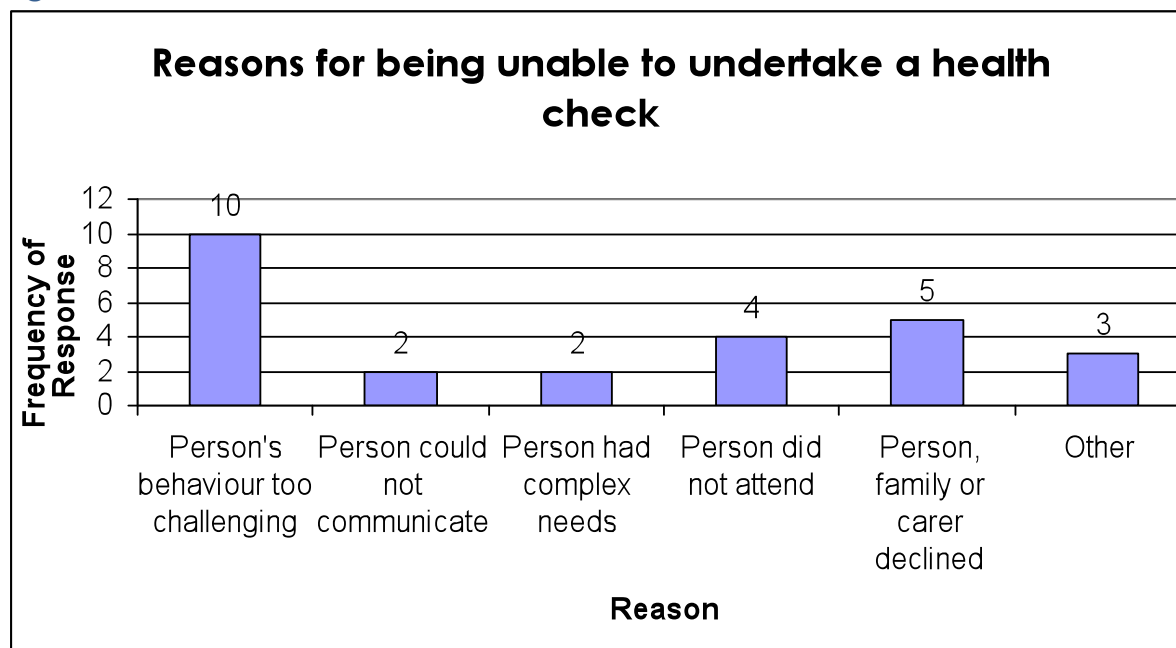
Table 11: Support received to complete the check

Figure 7



38% of GPs and Nurses stated they had been unable to undertake a health check with some individuals with figure 8 showing some of the reasons for this. Some respondents gave multiple reasons.

Figure 8



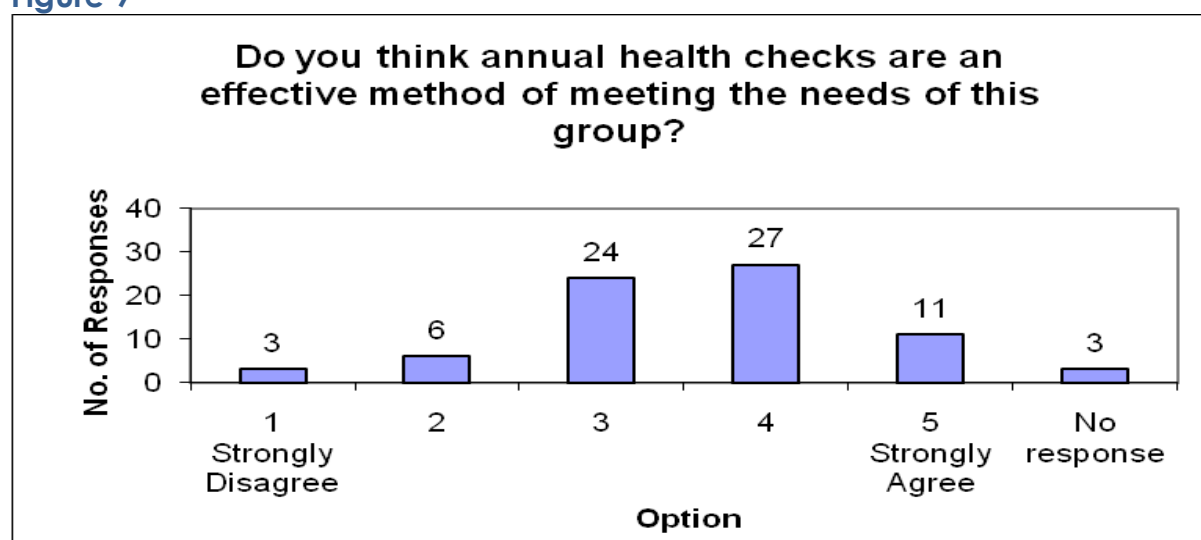
Question 22 asked practitioners if they had agreed to set personal goals with each patient. 28% answered, "Yes, all of them", 54% answered "Some of them" and 11% answered "No, none of them" (table 12).

Did you agree to set personal goals with each patient	No. of GP and Nurse respondents	Percentage of Respondents
Yes, all of them	21	28%
Some of them	40	54%
No, none of them	8	11%
No response	5	7%
Total	74	100%

Table 12: As a result of delivering the annual health check did you agree to set personal goals with the patient?

When asked if the health checks were an effective method of meeting the health needs of people with learning disabilities. 51% of GPs and Nurses agreed they were (figure 9), with 78% of practitioners stating they believed the benefits of the annual health check led to **"better management of existing illnesses and conditions"** (table 13).

Figure 9



Benefits of the annual health check	No. of GP and Nurse respondents	Percentage of Respondents
Better management of existing illness and conditions	57	78%
Improving access to health services	54	74%
Diagnosing and treating new conditions	52	71%
Promoting healthy choices	54	74%

Table 13: What do you think are the benefits of the annual health check?

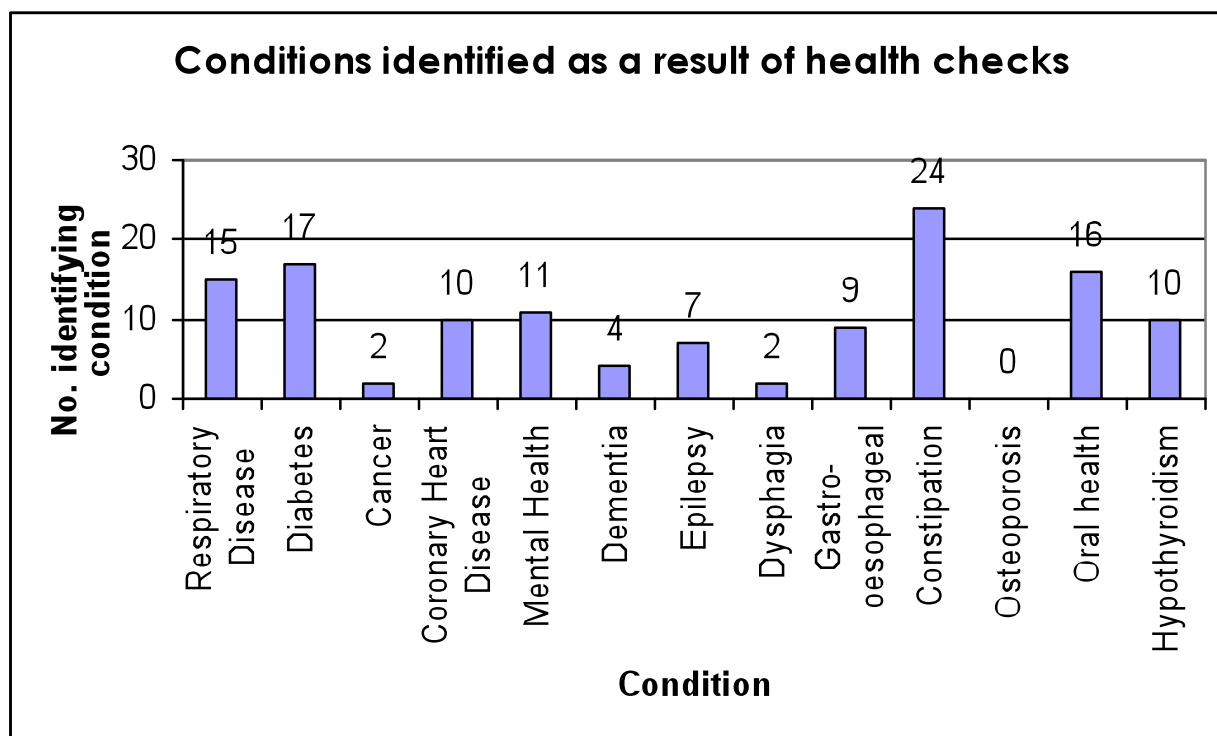
Respondents could select more than one response

Conditions identified as a result of the check	No. of GP and Nurse Respondents	Percentage of Respondents
Respiratory Disease	15	21%
Diabetes	17	23%
Cancer	2	3%
Coronary Heart Disease	10	14%
Mental Health	11	15%
Dementia	4	5%
Epilepsy	7	10%
Dysphagia	2	3%
Gastro-oesophageal Reflux Disease	9	12%
Constipation	24	33%
Osteoporosis	0	0%
Oral health	16	22%
Hypothyroidism	10	14%

Table 14: Have you identified any of the following as a result of the health checks, either new or existing conditions? Respondents could select more than one response.

In line with reducing health inequalities caused through preventable illness, question 25 asked GPs and Nurses if they had identified any of the following conditions as the result of the health check as either new or existing conditions. Table 14 and figure 10 highlight the responses.

Figure 10



Question 25B asked GPs and Nurses that in light of the above how this had changed their practice. 39 responses were received, some practices said that this had very little or no change to their practice (7 responses). Others stated it had raised awareness (9 responses). 6 GPs and nurses highlighted changes in access. Only one nurse answered the question in more detail stating:

"I would be concerned that this becomes a tick box exercise, we work hard to develop one to one relationships and to improve communication with both paid and family carers"

Discussion

This is the first study to research the impact in terms of knowledge and outcomes of the DES training and annual health checks completed by GP practices across the Yorkshire and the Humber Region. However, no definite conclusions can be drawn from Stage 2. The respondents cannot be assumed to be representative of the PCTs from which they come, nor of those holding particular roles. The sample size is insufficient for statistical testing to be appropriate. However, the data gives an interesting picture of current practice and highlights wide variability both within and across PCTs.

Across Yorkshire and the Humber region there was great disparity in the levels of completing annual Health Checks for people with a learning disability (40 –

65%). Nationally in 2009/10 it has been reported that less than 50% of people with a learning disability had an annual health check (Emerson and Glover, 2010), so the findings in the region support the national data. However it is unclear why there is such disparity between the best achiever Bradford, (76% of people with a learning disability received a Health Check) and the worst Leeds, (just 17% of people with a learning disability had a Health Check). While Leeds had a high level of its practice staff trained it achieved the poorest results. Yet Figure 4 suggests that 50% of those trained in Leeds were GPs, compared to other areas, which had more of a balance of practice staff attending the training for the DES. Further research is required to explore the impact of individual training versus practice based training to enable the service to more effectively deliver annual Health Checks to people with a learning disability.

In terms of the knowledge remembered about the training, reasonable adjustments and the Disability Equality Duty were poorly recalled concepts, or it could be that this aspect of the training was given minimal coverage in training that tended to last on average about half a day. Robertson *et al* (2010) argue that targeted health checks should be considered to constitute an effective and important adjustment to the operation of primary health services in the UK as required by Disability Discrimination Acts 1995, 2005 and the Equality Act, 2010. 'Reasonable adjustments' should be a key component of the training as there are a significant number of people with a learning disability still not accessing annual health checks.

The sample was small but a high number of Nurses and GPs identified that they had support to undertake the health check with a high number of responses indicating that they received support from community learning disability teams. Even when support was recognised to be available (table 11), there were still some people with a learning disability who were unable to have a health check. One of the highest reasons reported was that the person's behaviour was too challenging. Further research into the presentation of challenging behaviour in relation to health checks is required. The second highest response to being unable to undertake a health check was that the person or family declined the intervention. This has been reported elsewhere (Robertson *et al*, 2010) where it has been discussed in relation to the barriers to health checks. Robertson identified examples in the literature where, out of an exit poll of 53 people with a learning disability, 18 people indicated a dislike of needles or had refused a blood test or inoculation. Both challenging behaviour and resistance to health care interventions require more tailored training for GPs and nurses. It is likely that people with a learning disability yet to have an annual health check will present with complexities in behaviour and health care needs. With GPs and nurses will requiring support, practical advice and guidance in working through difficult situations.

An encouraging finding from this evaluation was that 75% of nurses and GPs identified the benefits of the annual health check. It is hopeful that a core group of GPs and nurses will become advocates and champions of the health care check within the region. It might be possible to work with some

22

GPs to work with others to develop capacity within the practice to undertake further training. There is no doubt that significant health issues emerged or were identified as a result or outcome of the health check (Figure 10). It is worrying to consider that there is still an urgent need to address a significant amount of unmet health care needs with other people with a learning disability in the region who are yet to have an annual health check.

“The evidence is clear in indicating that health checks are effective in identifying previously undetected health conditions in people with learning disabilities” (Robertson et al, 2010)

Recommendations

1. Further research is needed to build on this study with a larger sample size to determine if the areas for further development are a true reflection of that across the region.
2. PCTs (and future Practice Based Commissioning) need to get better at ensuring that their duties under the DDA and the Equalities Act 2010 are met through their contracts with services. Our report has highlighted that practices need more training on the requirements of this legislation, with all professionals working within practices aware of their obligation.
3. This research has highlighted several areas where knowledge needs to be developed further (figure 5); these include reasonable adjustments and communication. In order to support people with learning disabilities to understand their health issues, GPs and practice staff doing health checks should have good access to accessible information and any relevant research. The Easy Health website is an excellent source of accessible information on health, most of which can be downloaded for free (Emmerson, 2010).
4. Data from PCTs needs to be collected in a consistent way to enable a proper understanding on any differences in approach between PCTs
5. In the same way rigorous training has been conducted on the Mental Capacity Act, all practitioners need a core set of training ensuring that all services receive the same consistent information on Equalities, Accessible Information, Reasonable Adjustments, Communication.
6. Further work needs undertaking focussing on the barriers to conducting the health check, particularly in the area of challenging behaviour and refusal of interventions required in the annual health check.

Conclusion

In order to ensure that people with learning disabilities across Yorkshire and the Humber receive an equitable service through the annual health check it is imperative that systems are introduced to ensure that all professionals responsible for delivering this service have an adequate baseline knowledge of learning disability. It is only by ensuring that all health professionals understand how to make meaningful reasonable adjustments which include the barriers to accessing a health check will the health inequalities of people with learning disabilities truly be tackled. This document has highlighted the need for commissioners to ensure that data is collected in a clear consistent way and that any future training commissioned can clearly identify gains in knowledge and areas for further development.

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Appendices

Appendix A

Clinical Directed Enhanced Services (DES) Guidance for General Medical Services Contract 2008/09 - Delivering investment in General Practice (April 2008)

Appendix 3

Specification for a directed enhanced service in England:
learning disabilities

Introduction

1. There is good evidence that patients with learning disabilities (LD) have more health problems and die at a younger age than the rest of the population.

2. The existing QOF registers do not differentiate LD by severity. There are estimated to be 240,000 people with moderate to severe LDs in England known to social services. The DES is designed to encourage practices to identify those patients with moderate to severe LD as defined by the same criteria used by the local authority (LA).

3. The pre-requisites for taking part in the DES are as follows:

- practices will have liaised with the LA to share and collate information, in order to identify the people on their practice LD register with moderate to severe learning disabilities
- a practice providing this service will be expected to have attended a multi-professional education session (refer to paragraphs 13 to 15 for further information). The minimum expectation of staff attending will include the lead general practitioner (GP), lead practice nurse and practice manager/senior receptionist. Practices may also wish to involve specialist LD staff from the community learning disability team to provide support and advice.

4. The total investment available for this two-year DES in England is £22m per year for 2008/09 and 2009/10.

Details of the DES

5. Practices will be expected to provide an annual health check to patients on the local authority LD register. Practices are recommended to use the Cardiff health check protocol or a protocol as agreed locally with the PCT.

6. Further information on the Cardiff Protocol is available at:

http://www.rcgp.org.uk/PDF/clinical_Welsh_Health_Check_newA.pdf

7. As a minimum, the health check should include:

- a review of physical and mental health with referral through the usual practice routes if health problems are identified:
 - health promotion
 - chronic illness and systems enquiry
 - physical examination
 - epilepsy
 - behaviour and mental health
 - specific syndrome check
- a check on the accuracy of prescribed medications
- a review of coordination arrangements with secondary care
- a review of transition arrangements where appropriate.

8. Health checks should integrate with the patients' personal health record or health action plan. Where possible, and with the consent of the patient, this should involve carers and support workers. Practices should liaise with relevant local support services such as social services and educational support services in addition to learning disability health professionals.

Payment and validation

9. Payment will be based on a report to the PCT at the end of each year (31 March) on the number of patients on the health check LD register who have received the health check.

10. Once a practice has agreed the health check LD register with their PCT, it will receive a £50 aspiration payment for each patient on the register.

11. The reward for each health check will be £100.

12. The cost of aspiration payments will be deducted from payments made for the health checks. If practices do not complete enough health checks to fund the full cost of their aspiration payment, the PCT will recover any overpayment made as result, in line with normal practice.

Multi-professional education session – training for primary healthcare staff

13. Further information regarding training for primary healthcare staff, together with good practice examples, is available on the Valuing People website at:

<http://valuingpeople.gov.uk/dynamic/valuingpeople144.jsp>

14. A framework for the content that the training should include is:

- understanding of learning disabilities
- identification of people with learning disabilities and clinical coding
- understanding of the range and increased health needs associated with learning disabilities
- understanding of what an annual health check should cover
- information that should be requested prior to an annual health check
- Understanding of health action plans
- understanding and awareness of 1:1 health facilitation and strategic health facilitation
- ways to increase the effectiveness of health checks
- overcoming barriers including:
 - ❖ communication needs
 - ❖ using accessible information and aids
 - ❖ physical access
 - ❖ social and cognitive attitudes
 - ❖ values and attitudes
- collaborative working including:
 - ❖ working in partnership with family carers
 - ❖ the role of the community learning disability team
 - ❖ the role of social care supporters
 - ❖ the role of other health care professional and services
- experiences and expectations
- consent
- Disability Discrimination Act and the Disability Equality Duty
- resources – local contacts, networks, practitioners with special interest and information.

15. The training should be provided by the strategic primary health care facilitator for people with learning disabilities (where PCTs have invested in this support) and / or members of the local community learning disability team (this may need to be commissioned via the local specialist NHS trust) in partnership with self advocates (as paid co-trainers). Each PCT should use their internal procedures to approve the content of the training for their locality using the framework provided as guidance.

Appendix B Stage 1 Mapping Questionnaire

Yorkshire and Humber Audit on behalf of the Healthy Ambitions Programme Board

Stage 1 Mapping: The aim of this mapping exercise is to build a comprehensive profile of the training GP practices across Yorkshire and Humber have received as part of the Clinical Directed Enhanced Service for people with learning disabilities. **Please can you return this form by September 10th.**

1. Your Name and Job Role:

2. Area (e.g. Sheffield):

East Riding of Yorkshire

3. How many G.P practices are there within your area?

4. How many of these have signed up to delivering the Directed Enhanced Service for people with learning disabilities within your area?

5. How many GP's, Nurses, Receptionists and Practice Managers have completed awareness training as part of the Clinical Directed Enhanced Service?

Name of GP Practice	Email	Address	Tel Number	Total Number of people who work in the practice	Total Number of people who have been trained in the practice	Number of Nurses trained in the practice	Number of Receptionists trained in the practice	Number of GPs trained in the practice	Number of practice managers trained in the practice
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6. The Clinical Directed Enhanced Service Guidance for GMS contracts stated that all practice staff undertaking the DES needed to undertake awareness raising training. Please can you provide a brief outline of your training, including who delivered the training, the topics covered, approximately how long the session(s) lasted and where the training took place?

7. Please provide the name of a lead person who would be willing to have a follow up phone call to discuss the content of your training in more depth?

8. Please tell us how many people with learning disabilities are eligible for the Annual Health Check within your area?

9. Please tell us how many people have had an Annual Health Check within your area?

On behalf of the Healthy Ambitions Programme Board for People with Learning Disabilities we would like to thank you for completing this form.

Please send your completed form back electronically to Sally@speakup.org.uk If you would like any further information please contact Sally Ferguson by email (address above) or on 01709 720462.

Appendix C – Stage 2 Online Questionnaire

Evaluation of Clinical Directed Enhanced Service for people with a learning disability Questionnaire

08/11/2010 14:26



Evaluation of Clinical Directed Enhanced Service for people with a learning disability Questionnaire

This questionnaire is to be completed only by people who received training to offer the DES/LES to people with learning disabilities as part of the Annual Health Check.

1. What is your role within the GP practice?

- ☐ GP
- ☐ Nurse
- ☐ Receptionist/IT/Admin
- ☐ Practice Manager
- ☐ Other:

2. Which locality do you work in? e.g. Sheffield

Learning Disability Training:

3. Who delivered the training for the DES/LES Service for people with learning disabilities?

Please tick all boxes that apply

- ☐ Health and Social Care Consultant
- ☐ People with learning disabilities
- ☐ Nurse
- ☐ On-line learning materials
- ☐ Strategic Health Facilitator/Acute Liaison Nurse
- ☐ Don't Know
- ☐ Other:

4. Method of Delivery

Please tick all boxes that apply

- ☐ Conference/seminar
- ☐ Distance learning
- ☐ On-line learning

- ☐ In-house dedicated practice learning time
- ☐ One to One

5. How long did the training session last for?

Please tick all the boxes that apply

- ☐ less than 1 hour
- ☐ 1 - 2 hours
- ☐ 2 - 3 hours
- ☐ Half a day
- ☐ Full day
- ☐ More than one day
- ☐ The training is ongoing

What you remember from the training:

6. The Disability Equality Duty applies to?

please tick one box only

- ☐ All services in industry, construction and care
- ☐ All public sector services
- ☐ All services
- ☐ Don't Know

7. An Equalities Impact Assessment is needed to ?

please tick one box only

- ☐ Exclude people with a disability from the service
- ☐ Assess the condition of the person with a disability
- ☐ Assess the impact on the basis of disability
- ☐ Don't Know

8. Written or typed Information for people with learning disabilities is best presented.....

please tick one box only

- ☐ Black ink on blue paper
- ☐ Black ink on white paper
- ☐ Black ink on yellow paper
- ☐ Blue ink on yellow paper
- ☐ Don't Know

9. When using pictures and photographs with written information ?

please tick one box only

- ☐ Place the pictures on the right hand side of the page
- ☐ Place the pictures on the left hand side of the page
- ☐ Place the pictures after each word
- ☐ Place the pictures at the bottom of the page
- ☐ Don't know

10. People eligible for a health check are.....

please tick one box only

- ☐ People with a mild learning disability
- ☐ People with a moderate learning disability
- ☐ People with a severe Learning Disability
- ☐ Don't Know

11. Having mental capacity is.....

please tick one box only

- ☐ The ability to make decisions in all aspects of ones life
- ☐ The ability to make decisions consistently
- ☐ The ability to make a decision at the time the decision needs to be taken
- ☐ Don't Know

12. If a person with a learning disability does not have speech.....

please tick one box only

- ☐ Do not attempt to talk to the person
- ☐ Use slow and exaggerated speech
- ☐ Try to communicate with the person using a range of communication methods
- ☐ Refer the person to the doctor
- ☐ Don't Know

13. Diagnostic Overshadowing is

please tick one box only

- ☐ Overlooking the severity of learning disability
- ☐ Overlooking health problems and attributing them to learning disability
- ☐ Overlooking the diagnostic frameworks for learning disability
- ☐ Don't Know

14. Do you offer people with learning disabilities who attend your practice a health action plan?

please tick one box only

- ☐ Yes
- ☐ No
- ☐ Don't Know

15. Please give an example of a reasonable adjustment you have made to improve the experiences of patients with learning disabilities when visiting your practice?

Please write your answer in the box below

16. Are you a

If you are a GP or Nurse there is one more page of questions, if you are a receptionist/admin, practice manager or other this will take you to the submit page.

- ☐ GP/ Nurse
- ☐ Receptionist/IT/Admin
- ☐ Practice Manager
- ☐ Other

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Evaluation of Clinical Directed Enhanced Service for people with a learning disability Questionnaire

For Nurses and Gps Only

This section is for nurses and Gps who undertake the health check

17. Are you a Gp or Nurse?

please tick one box only

- ☐ Gp
☐ Nurse

18. In 2009/2010 how many annual health checks have you as a GP/Nurse completed?

please tick one box only

- ☐ 1-10
☐ 11 – 20
☐ 21 – 30
☐ More than 30

19. On average how long does an annual health check take you to complete?

please tick one box only

- ☐ Less than 10 mins
☐ 10 – 20 mins
☐ 21 – 30 mins
☐ 31 – 40 mins
☐ 41- 50 mins
☐ more than 50 mins

20a. Did you receive any additional support to deliver the annual health check?

please tick one box only

- ☐ Yes (Go to Q20b)
☐ No - (Go to Q21)

20b If Yes who supported you?

please tick one box only

- ☐ Community Team for Learning Disability

- ☐ Learning Disability Health Facilitator
- ☐ Family Carer
- ☐ Paid carer
- ☐ Other:

21a. Have you been unable to undertake a health check on any individuals?

please tick one box only

- ☐ Yes (Go to Q21b)
- ☐ No (Go to Q22)

21b. If yes please can you give a reason.....

please tick all that apply

- ☐ The person's behaviour was too challenging
- ☐ The person could not communicate
- ☐ The person had complex needs
- ☐ I needed more support
- ☐ Other:

22. As a result of delivering annual health checks did you agree and set personal goals with each patient?

please tick one box only

- ☐ Yes all of them
- ☐ Some of them
- ☐ No none of them

23. Do you think annual health checks are an effective method of meeting the health needs of this group?

please tick one box

	1	2	3	4	5	
Strongly Disagree	☐	☐	☐	☐	☐	Strongly Agree

24. What do you think are the benefits of the annual health check?

please tick all that apply

- ☐ Better management of existing illnesses and conditions
- ☐ Improving access to health services
- ☐ Diagnosing and treating new conditions
- ☐ Promoting healthy choices

25a. Have you identified any of the following as a result of the health checks, either new or existing conditions?

please tick as all that apply

- ☐ Respiratory Disease
- ☐ Diabetes
- ☐ Cancer
- ☐ Coronary Heart Disease
- ☐ Mental Health
- ☐ Dementia
- ☐ Epilepsy
- ☐ Dysphagia
- ☐ Gastro -oesophageal Reflux Disease
- ☐ Constipation
- ☐ Osteoporosis
- ☐ Oral health
- ☐ Hypothyroidism

25b. How has this changed the way that you provide your services?

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An evaluation of the Clinical Directed Enhanced Service for People with Learning Disabilities in the Yorkshire and the Humber Region.

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