

Reasonable adjustments for people with learning disabilities in England 2010: A national survey of NHS Trusts



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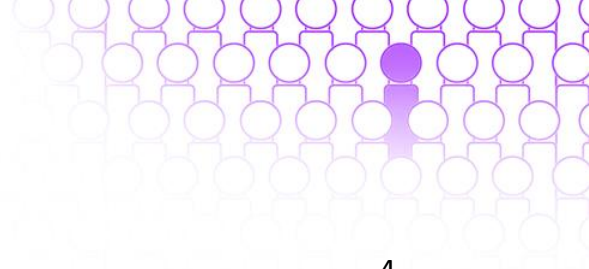
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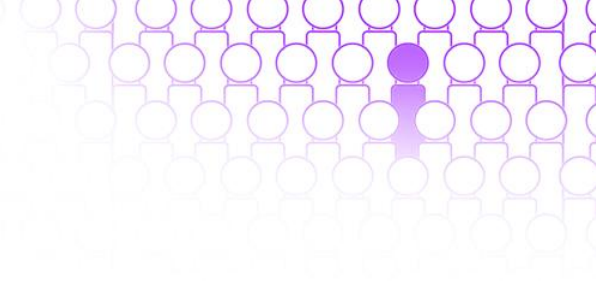
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List of abbreviations

BME- Black and Minority Ethnic

EIA- Equality Impact Assessment

IHaL- Improving Health and Lives Learning Disabilities Observatory

ICAS -Independent Complaints Advocacy Service

IMCA- Independent Mental Capacity Advocate

FPLD- Foundation for People with Learning Disabilities

LDPB- Learning Disability Partnership Board

MCA- Mental Capacity Act (2005)

NHS- National Health Service

NRES- National Research Ethics Service

PALS- Patient Advice and Liaison Service

PCT- Primary Care Trust

Summary

Background

In law, all public sector services have a legal duty to provide 'reasonable adjustments' for people with learning disabilities. Reasonable adjustments include removing physical barriers to accessing services, but importantly also include changing the ways in which services are delivered and ensuring that policies, procedures and staff training all enable services to work equally well for people with learning disabilities.

A series of investigations and inquiries has repeatedly demonstrated that, despite this legal duty and Department of Health policy and guidance, NHS services are not routinely making the range of reasonable adjustments required to reduce the stark health inequalities experienced by people with learning disabilities.

The Project


As part of our agreed programme of work with the Department of Health for the first year of the Improving Health and Lives: Learning Disabilities Observatory, we conducted a national survey of NHS Trusts in Autumn 2010 (along with a preliminary survey of Learning Disability Partnership Boards and an assessment of NHS Trust websites) to map the extent and nature of reasonable adjustments they were making for people with learning disabilities in England.

In total, 119 Trusts (30% of all NHS Trusts in England) responded to the survey, including 61 Acute Trusts (36% of Acute Trusts in England), 25 Mental Health Trusts (including specialist Learning Disability Trusts; 42% of these Trusts in England) and 32 Primary Care Trusts (PCTs) (21% of PCTs in England).

Survey Findings and Conclusions

This project has helped to identify many examples of reasonable adjustments that NHS Trusts state they provide for people with learning disabilities, and show some encouraging signs of innovation in the provision of reasonable adjustments within health services in England. There were examples of good practice in reasonable adjustments provided by some Trusts in all the areas we asked about in the survey; these examples will be made publicly available through the IHaL online searchable database in spring 2011.

Trusts most commonly reported making reasonable adjustments in terms of accessible information, with a substantial majority of responding Trusts providing Easy Read information for people with learning disabilities and reporting the use of Health Passports and/or Health Action Plans. It seems clear that this is often a first step for NHS Trusts in thinking about making reasonable adjustments for people with learning disabilities. However, we were not clear that this 'accessible' information was always specifically designed for people with learning disabilities, comprehensible to the people for whom it was intended, and proactively delivered to people with learning disabilities who become patients within the Trust. Many Trusts reported that information was available 'on request' or on



Trust intranet sites, which do not seem optimal strategies for routinely ensuring access to such information.

Similar issues were apparent in Trusts' responses concerning support for carers, with accessible information for carers being commonly mentioned but robust evidence being more sparsely reported.


There were several other areas of reasonable adjustment where a vast majority of Trusts reported that they had reasonable adjustments in place, including: policies concerning mental capacity, staff training concerning communicating effectively with people with learning disabilities (including supporting non-verbal patients), having Trust patients with learning disabilities who have made use of an IMCA, using Health Passports and Health Action Plans, having staff training that addresses attitudes towards staff with learning disabilities, using information from people with learning disabilities in Trust planning and development, considering the views of people with learning disabilities and carers at Trust Board level, and having Equality Impact Assessments that considered multiple forms of discrimination for people with learning disabilities.

However, far fewer Trusts provided robust evidence to support their statements in these areas, and the extent to which these policies and procedures specifically addressed the needs of people with learning disabilities and family carers was sometimes unclear.

Areas of reasonable adjustments relating to the actual face-to-face treatment of people with learning disabilities and carers were only reported by a minority of Trusts, including support for carers (beyond providing accessible information), and all stages of the patient journey, from first contact through diagnosis to clinical intervention and discharge/follow-up.

The most common solution for Trusts concerning face-to-face contact with patients with learning disabilities and carers was to rely on staff with specialist learning disability training, skills or roles to act as liaison between the person with learning disabilities, the carer, the various parts of the Trust and other learning disabilities services involved in the support of the individual. Many Trusts relied heavily on staff in Community Learning Disability Teams to perform these liaison and partnership working activities. It was often unclear whether such specialist support included a strategic role to enable Trusts to change their routine systems and procedures to become accessible for patients with learning disabilities, or whether such specialist support was solely concerned with working with individual patients with learning disabilities, leaving the Trust with 'unadjusted' routine systems and procedures. It was also sometimes unclear whether these specialist roles were seen as core to the effective functioning of the Trust, or as potentially vulnerable in times of resource constraint. There is also a question about how to make reasonable adjustments routine to Trust practice while at the same time ensuring they are personalised to the specific needs of individuals – this routine person-centredness may be a particular challenge to the standard operating procedures of many Trusts.

Finally, it was clear that only a minority of responding Trusts could provide us with specific information about people with learning disabilities using the Trust, for example in terms of the number of patients with learning disabilities who had used the Trust's services or the number of patients with learning disabilities using IMCAs or accessing ICAS.



The results of this survey may seem to confirm the view of the Michael Inquiry that “There is a clear legal framework for the provision of equal treatment for people with disabilities and yet it seems clear that ... services are not yet being provided to an adequate standard” (Michael, 2008, p. 55). However, the findings of this survey also make clear that some forms of reasonable adjustment are being widely adopted in some Trusts, that work is underway to develop further provision, and that in all of the identified areas of reasonable adjustments there are some Trusts that have developed innovative, effective and low cost reasonable adjustments that have the potential to radically improve the experience of patients with learning disabilities and their carers.

These examples of good practice will be included in the forthcoming IHAL reasonable adjustments database, and some have been outlined in this report. A forthcoming IHAL report will also highlight the key guidance for commissioners that emerge from the results of this report. These should be a valuable addition to mechanisms of sharing good practice for NHS Trusts.

Introduction

What are reasonable adjustments?

Since the Disability Discrimination Act¹, people with learning disabilities (along with other groups of disabled people) have had a legal entitlement to have equal access to public services, including those provided by the NHS. Over time, principally through the Disability Discrimination Act² and reinforced in the recent Equality Act³, this fundamental entitlement has been increasingly well-defined as the Disability Equality Duty.

In law, all public sector services have a legal duty to make 'reasonable adjustments' to the way they make their services available to people with learning disabilities, to make them as accessible and effective as they would be for people without disabilities.

Reasonable adjustments include removing physical barriers to accessing health services, but importantly also include making whatever alterations are necessary to policies, procedures, staff training and service delivery to ensure that they work equally well for people with learning disabilities⁴⁻⁶.


This legal duty for health services is 'anticipatory'. This means that health service organisations are required to consider in advance what adjustments people with learning disabilities will require, rather than waiting until people with learning disabilities attempt to use health services to put reasonable adjustments into place.

Why are reasonable adjustments important for people with learning disabilities?

Over the past 20 years, the substantial and wide-ranging health inequalities experienced by people with learning disabilities have become increasingly well-documented⁷. A major contributory factor has been stark inequalities in the accessibility of health services for people with learning disabilities, and the treatments they receive (or are denied). These inequalities in access and treatment to health services have been thoroughly documented in a series of investigations and inquiries.

In 2006, the Disability Rights Commission reported on the findings of its formal investigation into the physical health inequalities experienced by people with learning disabilities and/or mental health problems⁸, focusing particularly on primary care health services. Although there were isolated examples of effective reasonable adjustments, the general picture was that primary care services, whilst they had removed physical access barriers (for example through installation of wheelchair ramps), had not altered the policies, procedures and requirements that made them inaccessible and unresponsive for people with learning disabilities. There was also evidence of substantial unmet health needs amongst people with learning disabilities that were not being addressed through primary care health screening and subsequent treatment.

In 2007, a national audit of specialist inpatient healthcare services for people with learning disabilities carried out by the Healthcare Commission⁹, reported concerns about aspects of the quality of most services, with common problems in safeguarding procedures, access to advocates,



care planning, staff training, institutional regimes and rigorous scrutiny of service quality. Also in 2007, Mencap highlighted the cases of six people with learning disabilities who their families believed had died avoidably while in NHS or social services care¹⁰ (see also the ‘Six Lives’ report of the investigation into these six cases by the Parliamentary and Health Service Ombudsman and Local Government Ombudsman in 2009¹¹).

These and evidence from other inquiries resulted in the Department of Health setting up an independent inquiry into the healthcare experienced by people with learning disabilities, which reported in 2008¹². This report reinforced the findings of previous inquiries, stating that “There is a clear legal framework for the provision of equal treatment for people with disabilities and yet it seems clear that ... services are not yet being provided to an adequate standard” (p. 55)¹². Four of the 10 recommendations from the inquiry were directed at health service providers (p. 54-55)¹² and a further recommendation was related to health service commissioning, all of which concern health services making various types of reasonable adjustments to improve the healthcare experiences of people with learning disabilities:

- Recommendation 2: All health care organisations...should ensure that they collect the data and information necessary to allow people with learning disability to be identified by the health service and their pathways of care tracked.
- Recommendation 3: Family and other carers should be involved as a matter of course as partners in the provision of treatment and care, unless good reason is given, and Trust Boards should ensure that reasonable adjustments are made to enable and support carers to do this effectively. This will include the provision of information, but may also involve practical support and service co-ordination.
- Recommendation 8: The Department of Health should direct Primary Care Trusts (PCTs) to secure general health services that make reasonable adjustments for people with learning disabilities through a Directed Enhanced Service. In particular, the Department should direct PCTs to commission enhanced primary care services which include regular health checks provided by GP practices and improve data, communication and cross-boundary partnership working. This should include liaison staff who work with primary care services to improve the overall quality of health care for people with learning disabilities across the spectrum of care.
- Recommendation 9: Section 242 of the National Health Service Act 2006 requires NHS bodies to involve and consult patients and the public in the planning and development of services, and in decisions affecting the operation of services. All Trust Boards should ensure that the views and interests of people with learning disabilities and their carers are included.
- Recommendation 10: All Trust Boards should demonstrate in routine public reports that they have effective systems in place to deliver effective, ‘reasonably adjusted’ health services. This should include arrangements to provide advocacy for all those who need it, and arrangements to secure effective representation on PALs from all client groups including people with learning disabilities.

The Department of Health have been and are continuing to make concerted efforts to address the recommendations of the Independent Inquiry¹² and the ‘Six Lives’ report¹¹ in several ways, including

general policy for people with learning disabilities¹³ and reporting progress in response to the specific recommendations of the 'Six Lives' report¹⁴.

For example, the Government has instructed PCTs to offer financial incentives to GP practices (through a Directed Enhanced Service) to conduct annual health checks with people with learning disabilities. There is robust evidence that health checks uncover substantial unmet health need and led to further health interventions¹⁵. There is also evidence that increasing numbers of people with learning disabilities in England are receiving health checks¹⁶ – from 23% of eligible people with learning disabilities in 2008/2009 to 41% of eligible people in 2009/2010 – although access to health checks is patchy and a majority of eligible people with learning disabilities are still not receiving health checks.

Across other NHS agencies (principally NHS Trusts), Strategic Health Authorities have been working with PCTs and their provider NHS Trusts, using a voluntary self-assessment framework to assess progress in health services for people with learning disabilities¹⁴. This is now being used by all Strategic Health Authorities in England, to monitor their progress against a commonly-agreed set of targets.

However, as the investigations and inquiries have noted, a robust legal framework and strong policy leadership have not resulted in health services routinely providing comprehensive reasonable adjustments for people with learning disabilities. As the current Mencap campaign 'Getting It Right' emphasises¹⁷, institutional discrimination within health services towards people with learning disabilities still exists, with many barriers relating to the attitudes, knowledge and skills of health service staff, and the routine operation of the health systems within which staff work.

The Department of Health recognises the importance of identifying, sharing and encouraging good practice in reasonable adjustments for people with learning disabilities across health services in England. To assist with this process, the Department of Health commissioned practical guidance for NHS services making reasonable adjustments for people with learning disabilities¹⁸. This comprehensive guidance gives a very good sense of the wide range of systemic changes that are required for an NHS service to run a truly effective service for people with learning disabilities, including:

- Information for people with learning disabilities
- Working in partnership with families
- Capacity, consent and advocacy
- Service delivery (including making an appointment, initial attendance, receiving a service, referral, discharge and follow-up)
- Gathering, monitoring and reporting information about access and effectiveness of the health service by people with learning disabilities
- Patient and public involvement
- Employment of people with learning disabilities.

This project: aims and rationale

The project described here is part of the programme of work agreed with the Department of Health for the Improving Health and Lives: Learning Disabilities Observatory. The aims of this project are:

- To map the extent to which NHS Trusts in England are making progress in reasonable adjustments for people with learning disabilities
- To collate and share examples of good practice in reasonable adjustments made by NHS Trusts in England.

The major vehicle for us to achieve these aims was a national survey of all NHS Trusts in England using the same major headings as the Department of Health guidance outlined above. This was intended to help us map good practice across all relevant types of organisation, including Primary Care Trusts (in both commissioner and provider capacities), acute care (through Acute Trusts and Ambulance Trusts) and more specialist health services (through Care Trusts, Mental Health Trusts, and specialist Learning Disability Trusts).

Although the survey methodology was intended to give us an overall snapshot of good practice in reasonable adjustments for people with learning disabilities across diverse types of NHS Trust, we are aware that this method gives only a partial picture of reasonable adjustments for people with learning disabilities. Potential developments of this work are explored at the end of this report.

This report addresses the first aim of our project, to map the extent to which NHS Trusts in England are making progress in reasonable adjustments for people with learning disabilities.

We are addressing our second aim, to collate and share examples of good practice in this area, firstly by developing an online, searchable database which will become live on the IHaL website in spring 2011, and secondly by writing a briefing paper that explores the implications of the project's findings for commissioners of health services.

What we did

Our Reasonable Adjustments in the NHS project had three strands: 1) A survey of Learning Disability Partnership Boards; 2) A survey of all NHS Trusts in England; and 3) An audit of publicly available information on reasonable adjustments that Trusts made available on their websites.

Survey of Learning Disability Partnership Boards

Using a survey distributed via email, members of Learning Disability Partnership Boards (LDPBs) were asked for evidence of reasonable adjustments being made by individual NHS Trusts in 2010, including examples of good practice. The LDPB survey also sought to identify examples of good practice in making reasonable adjustments and appropriate contacts in local NHS Trusts (see Appendix 9 in the separate downloadable appendices accompanying this report).

Survey of NHS Trusts in England


The LDPB survey formed part of a consultation process for the design of questions for the Trust-wide NHS survey. We also consulted with members of Mencap, the Foundation for People with Learning Disabilities (FPLD), IHaL advisory group members and the IHaL Confidential Inquiry. A discussion area was set up on the Learning Disabilities Observatory website and a message posted on the UK Health and Learning Disability Network (hosted by the FPLD) encouraging contributions to the consultation.

Following this preliminary consultation we structured the NHS Trust survey in sections reflecting the areas identified in the *Equal Access?* report commissioned by the Department of Health¹⁸:

- Information for people with learning disabilities
- Working in partnership with carers
- Capacity, consent and advocacy
- Service delivery
- Gathering and monitoring information
- Patient and public involvement;
- Employment
- Mapping impact through Equality Impact Assessments.

Trusts were also asked to provide examples of relevant policies and protocols and other evidence to support their answers to the survey. Further details can be found in the survey covering letter in Appendix 10 and the survey itself in Appendix 11. All the Appendices for this project report are available in a separate downloadable document on the IHaL website.

The survey was distributed via post and email to the Chief Executives of all NHS Trusts in England, including Acute Trusts, Ambulance Trusts, Care Trusts, Mental Health Trusts; and PCTs. Where we had details of additional specific contact people within Trusts, we also sent surveys to them. Finally, the survey was also made available for download from the IHaL website (at the time of writing, the survey had been downloaded from the IHaL website 371 times). The survey was sent on 26th October 2010 and the initial deadline for responses was 12th November 2010, although by



arrangement survey responses were received and analysed up to a month after this deadline. We received feedback through IHaL regional events that surveys may not have always reached the most appropriate person within a Trust to provide information on reasonable adjustments. The implications of this will be discussed in more detail later in the report.

The survey data were recorded and analysed using quantitative coding procedures for 'yes/no' questions and qualitative thematic coding procedures for responses to open questions and for evidence to back up Trust responses. These responses were analysed using a coding framework involving at least two researchers, where one researcher identified categories of Trust response for each question, with another researcher carrying out detailed coding of Trust responses in relation to this category.

Audit of publicly available information on reasonable adjustments

The audit of publicly available information aimed to get a sense of the information NHS Trusts provide on their websites in relation to the reasonable adjustments they provide for people with learning disabilities. For each category of NHS Trust, a random 10% sample was selected and a web search carried out to find publicly available information related to reasonable adjustments for people with learning disabilities on Trust websites.

In January 2011, using each Trust's website 'Search' facility, a search was made for each of these sets of keywords in turn:

- Learning disab/learning disability/ learning disabilities/ learning difficulties
- Intellectual disab/ intellectual disability/ intellectual disabilities
- Reasonable adjustment/ reasonable adjustments
- If no results for the three strands above, disab/ disability/ disabilities.

Once the websearch produced a list of webpages or documents, these were searched using the sets of keywords listed above, and significant examples of reasonable adjustments for people with learning disabilities, including the provision of accessible information, policy documents and anecdotal examples were recorded.

Use of data

An important part of the project was to gather and share examples of good practice in making reasonable adjustments for people with learning disabilities. Where information was gathered from Learning Disability Partnership Boards and NHS Trusts, organisations were asked to indicate whether the information could be shared publicly with others or should remain confidential to the research team. Information from the audit of available information on reasonable adjustments was, by definition, already in the public domain.

Summary data on the number of Trusts carrying out specific types of reasonable adjustments are presented anonymously so that individual Trusts cannot be identified. Examples of good practice that Trusts have indicated can be shared have been provided in summary boxes within the report and many more examples will be made available in a searchable database on the IHaL website in spring 2011.

Ethical issues

In addition to respect for the confidentiality, where requested, of information provided by and about NHS Trusts, further steps have been taken to ensure the anonymity and confidentiality of individual patients and their carers who may feature in examples of practice in relation to reasonable adjustments. Where it is possible that individuals may be identified, accounts will either be anonymised or not included in project outputs.

Under National Research Ethics Service (NRES) guidelines (checked by a formal query to NRES) this project is considered to be a service evaluation, and thus not requiring ethical review by a NHS Research Ethics Committee.

Project outputs

This report is one of three planned outputs from the reasonable adjustments project:

- A summary report of the state of reasonable adjustments for people with learning disabilities by NHS Trusts in England (this report)
- A searchable database of good practice in reasonable adjustments by NHS Trusts
- A briefing paper relevant to commissioners (PCTs, forthcoming GP commissioning consortia) containing:
 - 1) A summary of relevant findings
 - 2) Guidance on how to carry out effective reasonable adjustments
 - 3) Examples of good practice.

Results

Summary of results from Learning Disability Partnership Board survey

We received 16 returns from the Learning Disability Partnership Board (LDPB) survey. The main focus of this exercise was to gain feedback on and relevant contacts for the NHS Trust survey. LDPBs were asked for information about reasonable adjustments for people with learning disabilities being made in their area, and provided a range of examples. These included Easy Read leaflets and other materials, resource folders, the use of Hospital Passports and Health Action Plans, the involvement and support of liaison staff, individual case studies of patient care, staff training programmes, the development of specific pathways and flexible practice for appointments. These responses informed the development of the NHS Trust survey (see below).

In addition LDPBs were asked to identify examples of good practice in making reasonable adjustments for people with learning disabilities for potential inclusion in a database of reasonable adjustments. Responses to this question included work experience placements, resource packs, protocols, and anonymised examples of care and treatment received by individual patients with learning disabilities. These examples will be made available in the searchable database of good practice in reasonable adjustments in NHS Trusts, hosted by the IHaL website.

NHS Trust survey: response rates

Table 1 shows the NHS Trust survey responses received, broken down into Trust type. Overall, 119 Trusts (30% of Trusts in England) returned a response to the survey.

Table 1: Survey response rate by type of Trust

	Acute Trusts		Mental Health Trusts		PCTs		Total	
	No. of Trusts	% of all Trusts	No. of Trusts	% of all Trusts	No. of Trusts	% of all Trusts	No. of Trusts	% of all Trusts
Response rate	61	36%	25	42%	32	21%	119	30%

The Mental Health Trust category (which includes Trusts with specialist learning disability services) had the highest response rate, at 42% of all Mental Health Trusts in England. The Acute Trust response rate was 36%, and the response rate for PCTs was 21%. The lower response rate from PCTs may have been affected by issues over the distinction between commissioning and provider Trust functions, which are described in more detail in the next section.

A note on the presentation of data

As a way of understanding how results varied by Trust type, we divided the survey results into three broad Trust types: Acute Trusts, Mental Health Trusts and PCTs. The category Mental Health Trusts includes specialist Learning Disability Trusts. In addition we received one return from a Care Trust, but due to this limited return detailed presentation of the Care Trust information is not given in tables, although it is included in the data for overall Trust returns. Surveys were sent to all Ambulance Trusts but we did not receive any replies.

Some PCTs indicated that certain survey questions, particularly those relating to service delivery, were not relevant to their activities because they were commissioners rather than providers of services. Where this is the case, responses have been excluded from the analysis.

Full tables in the Appendices (included in a separate document downloadable from the IHaL website) present the following information:

- The number of Trusts stating that they carry out a particular reasonable adjustment
- The percentage of Trusts responding to the particular survey question stating that they carry out a particular reasonable adjustment
- The number of responding Trusts stating that they carry out a particular reasonable adjustment expressed as a percentage of all Trusts of the type in England.

In the main text of the report, text, figures and tables present the number of Trusts and/or the percentage of respondent Trusts responding to the specific question being reported - those not answering or indicating that a particular question was not relevant are excluded from the analysis for that question.

Trusts gave many examples of good practice in the ways that they made reasonable adjustments for people with learning disabilities, some of which have been highlighted using summary boxes. A key aim of the survey was to ask for evidence of the reasonable adjustments Trusts say that they are carrying out. Responses to open-ended questions asking for evidence were thematically analysed. For each section of the survey, after the responses of Trusts are presented, an appraisal of the quality of the evidence Trusts provided for their responses to the survey is also provided.

Full details of responses to all survey questions are given in Appendices 1 to 8 available as a separate downloadable document – the main body of the report summarises these responses.

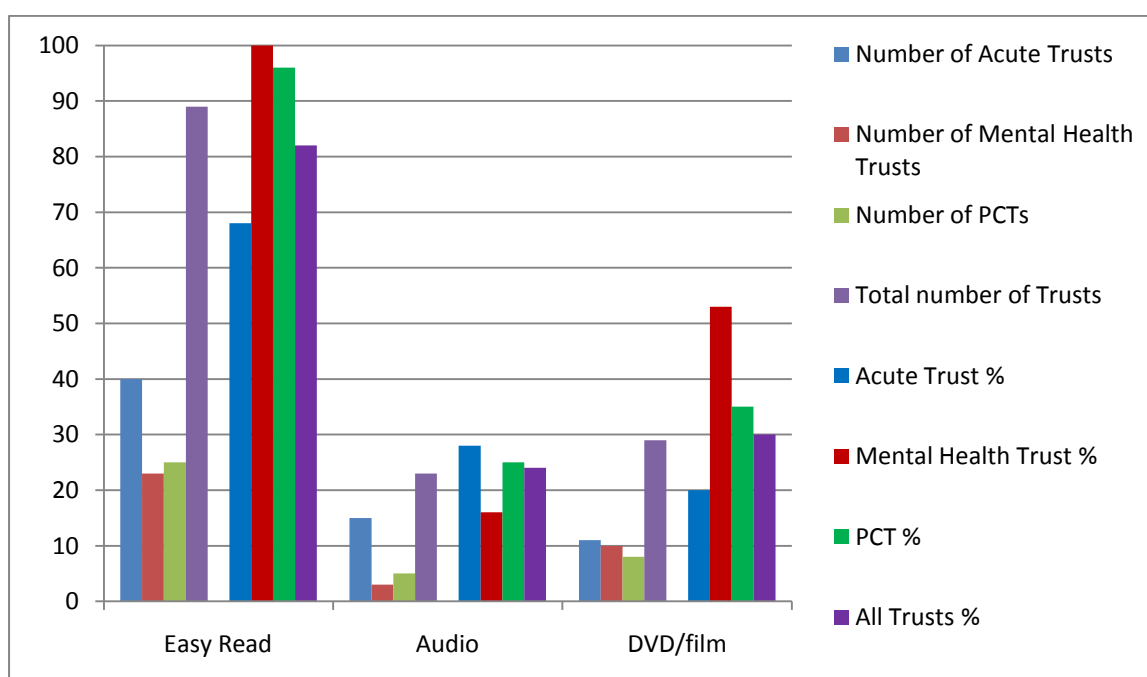
Information

We asked Trusts what information they provided about services, health problems, health promotion, patients' rights, complaints and any other type of information that was designed to be accessible to people with learning disabilities.

Information about services

The vast majority of Trusts (82% of responding Trusts) said that they provided information about their services in Easy Read formats, including all of the 23 Mental Health Trusts who responded to the question about services and almost all of the responding PCTs (96%). 29 Trusts (30%) said that they provided information in a DVD or film format, and 23 (24%) in an audio format (see Figure 1).

Figure 1: Information about services



As evidence for their provision of information about services (see Appendix 1 for a detailed breakdown of Trust responses):

- 24 Trusts (20% of responders) mentioned using their website or intranet as a tool for providing information about services
- 13 Trusts (11%) indicated that information about services was available on request
- 13 Trusts (11%) stated that they provided leaflets, including Easy Read or accessible information (several Trusts stated that they provided 'accessible' information without specifying that it was Easy Read).

In terms of the location of accessible information, seven Trusts (6%) mentioned reception areas, and 11 Trusts (9%) said that service information was routinely available on wards and departments. Eight Trusts (7%) said that information about services was available through local advocacy groups.

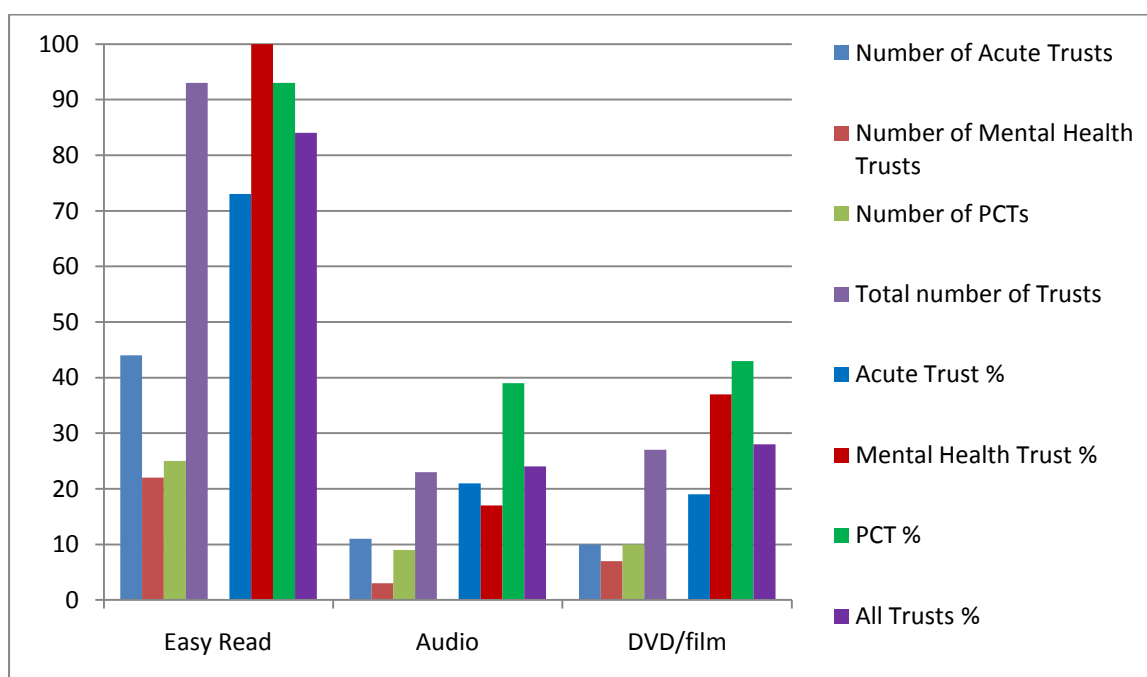
14 Trusts (12%; not counted in Figure 1 above), indicated that their information about services was under development, including improvements to websites, Easy Read leaflets and DVDs.

Within *Your Healthcare*, the social enterprise provider arm of NHS Kingston, an Easy Info group, made up of speech and language therapists and service users, scrutinises all new written material for people with learning disabilities and provides advice on how to improve the quality and readability of material designed.

Information about health problems

Figure 2 shows that the vast majority of Trusts said that they provided information about health problems in Easy Read formats, including all of the 22 Mental Health Trusts who responded to the question about health problems. 27 Trusts (28%) said that they provided information in a DVD or film format, and 23 Trusts (24%) in an audio format (see Figure 2).

Figure 2: Information about health problems



As evidence for their provision of information about health problems (a full breakdown of Trust responses is available in Appendix 1):

- 20 Trusts (17% of responders) mentioned their website or intranet as a way of providing information about health problems
- Nine Trusts (8%) indicated that they used links to outside websites such as *Easy Health*¹ and the South West's *A Picture of Health*² (see good practice box below)

¹ www.easyhealth.org.uk

² <http://www.apictureofhealth.southwest.nhs.uk>

- Nine Trusts (8% of responders) said that the information they provided about health problems was personalised or individualised for patients with learning disabilities.

Leaflets were a popular format for providing information about health problems, with 18 Trusts (15%) stating that they provided leaflets, including Easy Read and accessible leaflets.

13 Trusts (11%, not included in Figure 2) said that their information about health problems was in progress or under development, including DVDs, Easy Read and audio leaflets, websites and a library of accessible information.

A Picture of Health (<http://www.apictureofhealth.southwest.nhs.uk/>) is a website that aims to help clinicians across the South West of England provide Easy Read information to people with learning disabilities. The website provides information in Easy Read about acute hospitals, cancer screening, Healthy Life Styles, Maternity, Mental Health, Primary Care, Sexual Health and Easy Read Tools. There is also a DVD which has been widely distributed to GP surgeries and other health services.

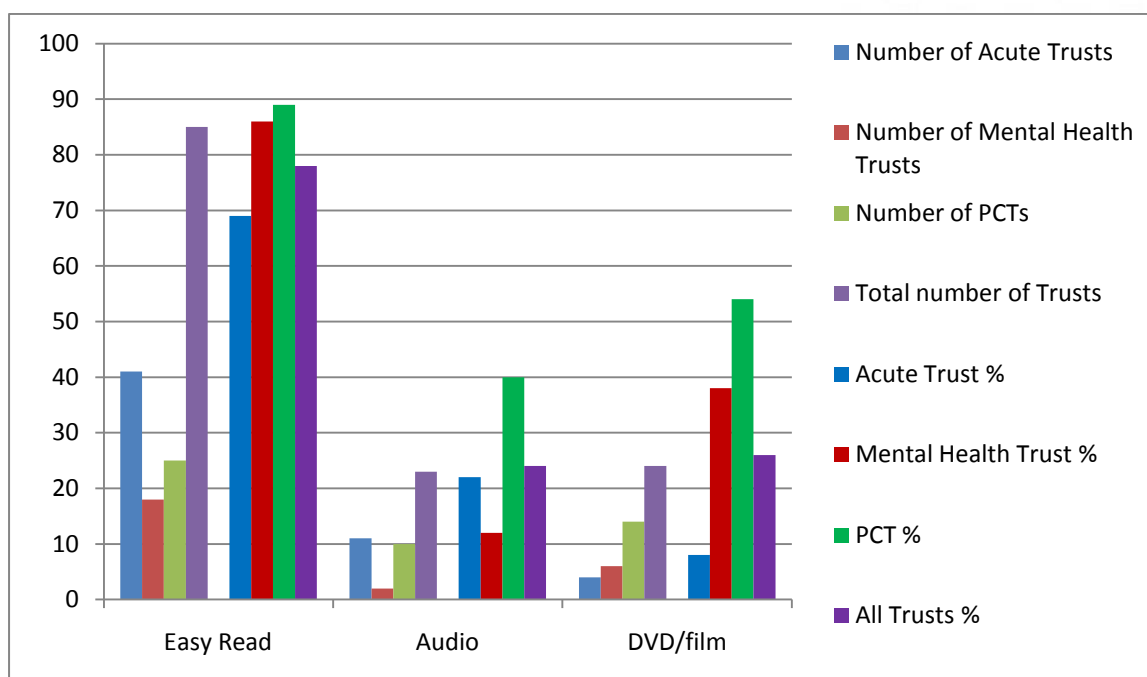
Information about health promotion

Figure 3 shows that overall, 78% of responding Trusts (85 Trusts) stated that they provided information about health promotion in an Easy Read format, 24% (23 Trusts) provided this information in an audio format, and 26% (24 Trusts) as a DVD or film. PCTs who responded to this question provided the highest proportion of health promotion information in Easy Read (89%, 25 Trusts), DVD/film (54%, 14 Trusts) and audio (40%, 10 Trusts).

As evidence for their provision of information about health promotion for people with learning disabilities:

- 23 Trusts (19% of responders) mentioned using their website or intranet as a means of providing information about health promotion
- Nine Trusts (8%) stated that the information they provide about health promotion was personalised or individualised
- A further nine Trusts (8%) said that they provided leaflets, including Easy Read leaflets, that gave information on health promotion.

Figure 3: Information about health promotion



Mid Yorkshire Hospitals NHS Trust promotes and takes part in an annual “It’s My Health Day” joint event with neighbouring authorities. The event is aimed at people with a learning disability, family carers and paid support workers. The focus of the day is for people with learning disabilities to have their say about local health services and find out about health promotion activities.

Information about patients’ rights

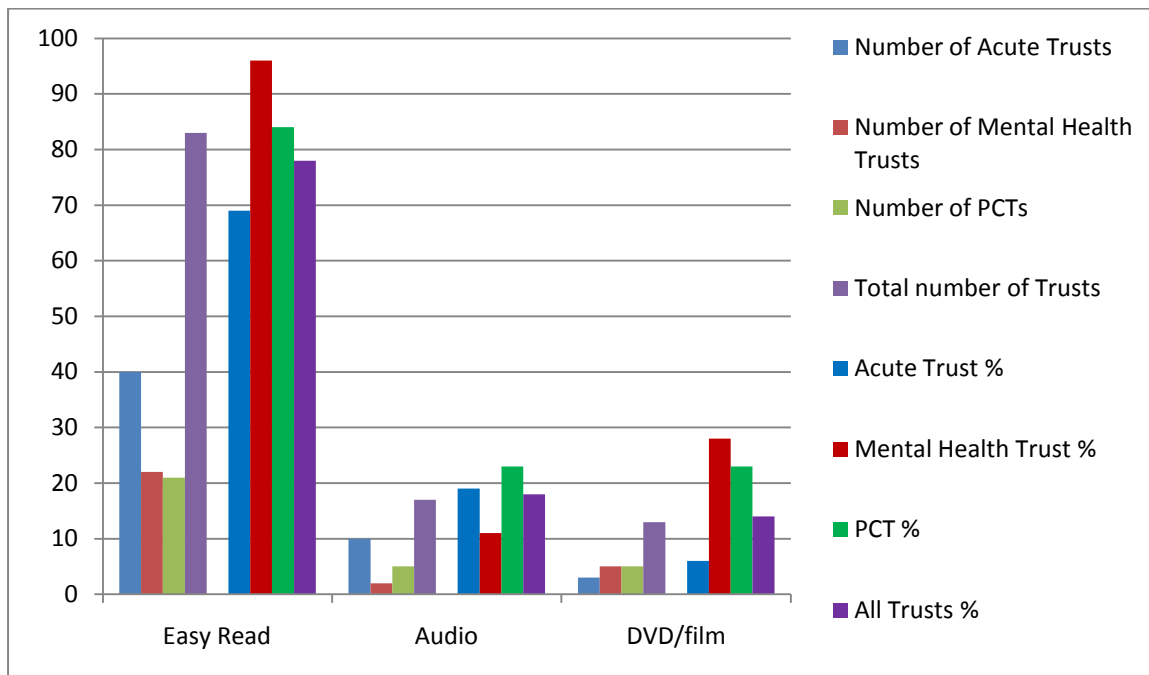
78% of responding Trusts said that they provided information about patients’ rights in Easy Read format (as shown in Figure 4). The percentage of Trusts providing patients’ rights information in an audio format ranged from 23% of PCTs to 11% of Mental Health Trusts. 14% of Trusts gave information about complaints through DVDs or films.

As evidence for the provision of information about patients’ rights (a full breakdown of Trust responses is available in Appendix 1):

- 24 Trusts (20% of responders) described using their website or intranet to provide information
- 13 Trusts (11%) used Easy Read information or leaflets
- Six Trusts (5%) said that information about patients’ rights was provided through the Patient Advice and Liaison Service (PALS)

- Information about patients' rights was most commonly described as being provided in reception areas and on wards and departments (seven Trusts, 6%).

Figure 4: Information about patients' rights



An Easy Read version of the NHS Constitution is available for download at:

<http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Documents/EasyRead2010.pdf>

Information about complaints

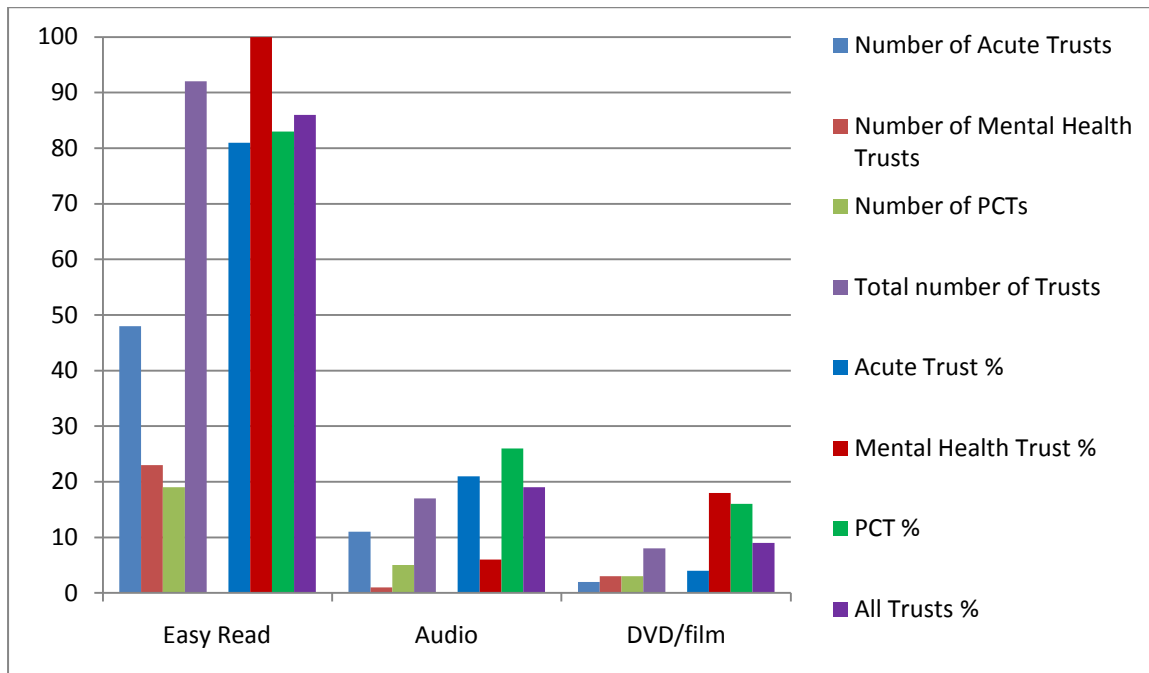
Figure 5 shows that 86% of Trusts (91 in total) responding to the question about complaints information said that this was available in an Easy Read format, compared to 19% providing an audio format and 9% providing a DVD or film. Mental Health Trusts had the highest proportion of Easy Read information about complaints, at 100% (23 Trusts), and DVD/film information (18%, three Trusts) while PCTs provided the highest percentage of audio information (26%, five Trusts). However, positive responses to the questions about the availability of information about complaints in audio and DVD/film were scarce, representing just 4% and 2% of Trusts in England, respectively.

Leaflets, including Easy Read and accessible leaflets, were the most common format for providing information about complaints, with 27 Trusts (23% of responders) mentioning these. A detailed breakdown of Trust responses to this question is provided in Appendix 1, but key points include:

- 22 Trusts (19%) described using their own website or intranet for the provision of information about complaints procedures
- 10 Trusts (8%) said that information about complaints was provided through PALS

- Six Trusts (5%) mentioned work with local or voluntary groups
- Six Trusts (5% of responders) said that information about complaints was available on request or as required
- Five Trusts (4%) highlighted the role of Learning Disability Liaison Nurses (including Acute Liaison Nurses) in providing this information
- 15 Trusts (13%, not included in Table 6 above) said that they were developing their information provision in this area, of which 10 (8%) were developing Easy Read leaflets.

Figure 5: Information about complaints



NHS Bradford and Airedale worked with a group of local disabled people, including people with learning disabilities, to produce accessible information about their PALS service, which was sent to local groups and is available on their website: <http://www.bradford.nhs.uk/get-involved/patient-advice-and-liaison-service-pals/pals-information-for-disabled-people/>

Any other information

Trusts were also asked if they provided any other information for people with learning disabilities not covered by previous questions. Full details of Trust responses are available in Appendix 1. In terms of the evidence that Trusts provided in response to this question:

- 12 Trusts (14% of responders) stated that other information was available on their website or intranet, including accessible or Easy Read web pages
- Nine Trusts (10%) highlighted their use of leaflets, including Easy Read and accessible leaflets
- Eight Trusts (9% of responders) said that information was personalised or individualised

- Six Trusts (7%) mentioned the use of a Hospital Communication Book (which provides pictorial information to support communication with patients with learning disabilities)
- Five Trusts (6%) described the use of patient satisfaction surveys or comment cards
- Four Trusts (5%) used pictures, photo stories or story boards as a way of providing information to patients with learning disabilities
- Six Trusts (5%) said that they were developing other types of information, including Easy Read leaflets (three Trusts, 3%), DVDs (two Trusts, 2%), a patient journey book and a communication strategy.

Accessible on-site information and information to take away

Finally in terms of information, Trusts were asked whether and how accessible on-site information and information to take away was made available for patients with learning disabilities.

Mental Health Trusts were most likely to state that on-site information was available in an accessible format (91% of responders), although rates were also high for Acute Trusts (89%) and PCTs (85%). As evidence for their provision of accessible on-site information (see Appendix 1 for a breakdown of Trust response):

- Nine Trusts (8% of responders) included Easy Read leaflets as evidence for their on-site information and four (4%) included other types of Easy Read information
- Seven Trusts (6%) said that on-site information was personalised or individualised
- Five Trusts (4%) stated that information was available on request or as required
- 13 Trusts (11%, not included in Table 10 above) indicated that their on-site information was under development, including signage (three Trusts), Easy Read information (three Trusts), a photosymbols glossary and emergency admission procedures.

Barking, Havering and Redbridge University Hospitals NHS Trust provides a Communication Corner – an Easy Read Information section for patients, carers, visitors and staff. This collection includes information on the questions to ask while in hospital, what will happen in hospital and the Hospital Communication Book.

88% of responding Trusts stated that information for patients to take away was provided in an accessible format, including all responding Mental Health Trusts. Leaflets, including Easy Read leaflets, were the most popular format for information to take away, with 16 Trusts (15%) mentioning some form of leaflet. Other evidence for the provision of information to take away included (see Appendix 1 for a detailed breakdown):

- 10 Trusts (10%) said that information to take away was prepared by Learning Disability Liaison services, including Learning Disability Liaison Nurses or Acute Liaison Nurses
- Eight Trusts (8%) said that information was available on their intranet for staff to give to patients to take away
- Eight Trusts (8%) said that information was available on request or as required

- Six Trusts (6%) highlighted the individual or personalised nature of information they provided to take away
- A further four Trusts (4%) highlighted information on their website.

Information – Summary and appraisal of evidence

- Overall, a substantial majority of responding Trusts reported providing Easy Read information for people with learning disabilities about: their services (82%); health problems (84%); health promotion (78%); patients' rights (78%); and complaints procedures (86%)
- Information in audio formats (18%-24%) and DVD/film formats (9%-30%) was much less commonly provided
- Mental Health Trusts were most likely to report providing accessible information for people with learning disabilities
- Across all Trust types it was not always clear that this information was routinely provided to people with learning disabilities using the service. In total 30 Trusts (25% of Trust responders) stated that some form of information was available on request, which raises questions about whether the implementation of reasonable adjustments is sufficiently proactive in nature. However the large amount of information stated to be available on request may be linked to the need to tailor information to the communication needs of individuals, and 24 (20%) of Trusts said that information was personalised or individualised for individual patients by Learning Disability Liaison staff
- It was also common for Trusts to say that information was available on their website (48 Trusts, 40%) and intranet (22 Trusts, 18%). As our audit of publicly available information shows (see below), we found the provision of information for and about patients to be variable in quality. The provision of information on Trust intranet sites was clearly a valuable resource tool for staff but does not provide a direct link to information for patients with learning disabilities
- It was clear from Trust responses that a lot of development work was being undertaken in the area of information provision
- The majority of Trusts provided some form of evidence to back up their responses to questions about the information they provided to patients. This evidence commonly took the form of Easy Read leaflets and other Easy Read information, such as booklets, letters, forms, questionnaires, patient passport and web pages. In this project we could not evaluate how many people with learning disabilities using Trust services actually received this information, or how accessible people found the information provided
- Some Trusts were frank about the limitations of the information provided, for example three Trusts (3% of responders) said that accessible information was often limited to their specialised learning disability services.

Working in Partnership with Carers

*Equal Access?*¹⁸ highlighted the importance of carers as partners in the healthcare of people with learning disabilities. We asked Trusts about the reasonable adjustments they carried out to support carers as partners in the provision of treatment and care to patients with learning disabilities. Trusts provided a broad range of responses to this question, in the following general categories: Policies and Protocols, Accommodating Carers in Health Services, Carer Representation, and Supporting Carers (see Appendix 2 for full details). We also asked Trusts about the on-site information and information to take away they provided for the carers of people with learning disabilities

Policies and protocols

12 Trusts (10% of responding Trusts) gave their carers policy as evidence of the reasonable adjustments they carried out, with a further nine Trusts (8%) indicating that their carers policy was under development.

17 Trusts (14%) mentioned some other form of guidance or protocol to support family carers.

Three Trusts (3%) mentioned or described their carers strategy.

Accommodating carers in health services

11 Trusts (9% of responding Trusts) said that they made some provision for open hours or for carers to stay longer than usual, including the use of badges that sign-posted their status as carers.

13 Trusts (11%) stated they made some provision for carers to stay with patients on site, including the provision of shower or bathroom facilities and provision for carers to eat.

Other less common adjustments included amending appointment times and providing home visits (see Appendix 2 for a detailed breakdown of Trust responses).

Carer representation

15 Trusts (13% of responding Trusts) said that carers were routinely involved in care planning or discussions about patient care, and seven Trusts (6%) said that carers were invited to key meetings.

Six Trusts (5%) said that carers were members of or represented on their local Learning Disability Partnership Boards.

Supporting carers

11 Trusts (9% of responding Trusts) said that carers were supported by Learning Disability Liaison staff.

Nine Trusts (8%) mentioned the use of carers' assessments as a tool for supporting carers of people with learning disabilities.

Six Trusts (5%) reported using carers' Learning Disability groups and forums.

Information for carers: On-site and take away information

Trusts were also asked whether on-site information and information to take away for the carers of patients with learning disabilities was provided in an accessible format (see Appendix 2 for full details of Trust responses).

Overall 72 Trusts (69% of responding Trusts) stated that information for carers was available on-site, and 76 Trusts (75%) said that information for carers was available to take away. There was variation between Trust types, so that a higher proportion of Mental Health Trusts stated that information was available on site (83% compared to 67% for PCTs and 65% for Acute Trusts) and to take away (96% compared to 72% for PCTs and 65% for Acute Trusts).

As evidence for their provision of on-site information for carers:

- 19 Trusts (18% of responders) stated that they provide accessible on-site information in the form of information leaflets, including accessible or Easy Read leaflets
- Nine Trusts (9% of responders) said that accessible information was available on request
- Seven Trusts (7%) said that accessible information was available on their website, and five Trusts (5%) mentioned the use of their intranet to provide information for carers
- Six Trusts (6%) said that accessible on-site information for carers was available through Learning Disability Nurses or Learning Disability Teams
- Three Trusts (3%) stated that information was given on an individualised or personalised basis
- Six Trusts (6%) said that their information for carers was under development
- Five Trusts (5%) said that information for the carers of people with learning disabilities was not in place, with a further three Trusts (3%) indicating that information was available in some (e.g. specialised Learning Disability services) but not all services.

As evidence for their provision of information for carers to take away:

- 26 Trusts (25% of responders) stated that they used leaflets to provide information to take away
- Seven Trusts (7%) mentioned their website, and four (3%) their intranet, including staff printing off information for carers
- Seven Trusts (7%) said that information to take away was available for carers on request
- Seven Trusts (7% of responders) said that information for carers to take away was available through Learning Disability Nurses or Learning Disability Teams
- Seven Trusts (7%, not included in Table 9 above) said that their information to take away was under development
- Four Trusts (4%) said that all the Easy Read information they produced was also available to carers, while three Trusts (3%) indicated that no specific information for carers of patients with learning disabilities was available to take away.

Working in Partnership with carers - Summary and appraisal of evidence

- Small minorities of responding Trusts reported a range of reasonable adjustments for carers of people with learning disabilities, such as having a carers policy (10%), involving carers in care planning (13%) or key meetings (6%), altering opening hours (9%), having facilities for carers to stay with the person (11%), changing appointment times (4%) or having support from liaison staff (9%).
- Although a majority of responding Trusts reported that information for carers was available either on-site (69%) or to take away (75%), much smaller numbers of Trusts provided robust evidence that this information was specifically designed for carers of people with learning disabilities and was made routinely available to all carers.
- Trust responses had a similar profile to those from the previous section on information for people with learning disabilities themselves, in terms of the common use of leaflets and responses that stated information was made available on request or was personalised.
- It was not always made clear if Trusts provided information for carers that was different to the information provided for patients with learning disabilities or different to general information for carers.

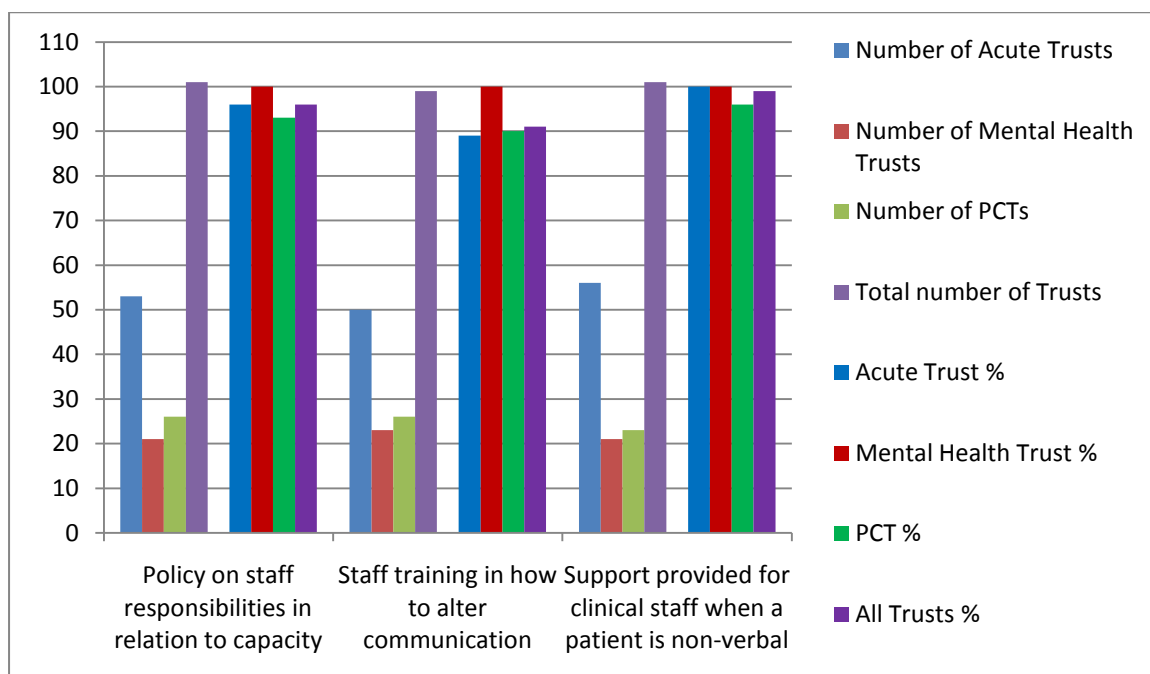
Capacity, Consent and Advocacy

We asked if Trusts had a policy to ensure that staff understood their responsibilities in relation to capacity under the Mental Capacity Act (2005). Trusts were also asked if they provided staff training in how to alter communication to suit individuals with learning disabilities, and if support was provided for clinical staff when a patient did not communicate verbally. Finally, Trusts were asked a general question about how they supported advocacy (see Appendix 3 for full details of responses).

Responsibilities in relation to capacity - policy

Figure 6 shows that overall 96% of responding Trusts (101) stated that they had a policy to ensure that staff understand their responsibilities in relation to capacity under the Mental Capacity Act. All Mental Health Trust responders (21 Trusts), 96% of Acute Trusts (53 Trusts) and 93% of PCTs (26 Trusts) said that they had this policy.

Figure 6: Trust responses on capacity, training and support



Trusts provided the following responses as evidence for this question:

- 28 Trusts (27% of responders) provided their Mental Capacity Policy, with a further two Trusts (2%) providing their draft policy
- 14 Trusts (13%) stated that they provided Mental Capacity training for staff, with a further six Trusts (6%) stating that staff were helped to understand their responsibilities through the use of an e-learning package
- 12 Trusts (11%) stated that the provisions of the Mental Capacity Act were included in their consent policy, and 10 (10%) that this issue was covered in their safeguarding policy
- Three Trusts (3%) stated that a Mental Capacity Policy was under development.

Training in how to alter communication with people with learning disabilities

91% of Trusts (99 responders) stated that they provided staff training in how to alter communication to suit individuals with learning disabilities (see Figure 6 above). All Mental Health Trust responders (23 Trusts), 90% of PCT responders (26 Trusts) and 89% of Acute Trusts (50 Trusts) said that they provided this training.

As evidence for this question (see Appendix 3 for a detailed breakdown of Trust responses):

- 14 Trusts (13% of responders) stated that they provided training in general Learning Disability awareness
- 12 Trusts (11%) stated that Learning Disability training was mandatory
- Eight Trusts (7%) said that training in communication with people with learning disabilities was included in staff inductions
- Seven Trusts(6%) stated this training was provided in training/study days or workshops, with a further six (6%) stating that it was included in mental capacity training
- Seven Trusts (6% of responders) stated that the LD Liaison nurse or co-ordinator provided specific staff training on communication
- Six Trusts (6%) said that they provided training in Total Communication or Makaton
- Four Trusts (4%) mentioned use of an e-learning package and two Trusts (2%) said that they provided a Learning Disability qualification for new starters
- In addition to the responses shown in Figure 6 above, seven Trusts (6% of responders) stated that training in this area was planned or under development, four Trusts (4%) said that this training was only provided in specialist Learning Disability Services, whilst a further three Trusts (3%) said that they did not provide specific training in communication with people with learning disabilities.

Mid Essex Hospital Trust makes Learning Disability Awareness Training available for all Trust staff, which covers different modes of communication. A communication resource file is distributed to each ward and department which identifies pictorial, BSL and Makaton signing. The Hospital Liaison Nurse facilitates training within Equality and Diversity and Learning Disability Link Training sessions, covering communication.

Support for clinical staff when a patient is non-verbal

Figure 6 above shows that overall, 99% of Trust responders said that they provided support for clinical staff when a patient is non-verbal. All Acute Trust (56 Trusts) and Mental Health Trust (21 Trusts) responders said that they provided this, and 96% of PCTs (23 Trusts).

The role of specialist Learning Disability staff was prominent in responses to this question, with 37 Trusts (36% of responders) highlighting the role of liaison staff in providing support to clinical staff. As other evidence for their provision of support when a patient is non-verbal (a detailed breakdown of Trust responses is provided in Appendix 3):

- 18 Trusts (18%) said that they received support from speech and language therapy services in this area
- Trusts described a range of communication aids, including the use of a Hospital Communication Book (13 Trusts, 13% of responders to this question), the use of communication, picture or symbol boards (10 Trusts, 10%), and communication passports, Hospital Passports or Health Action Plans (14 Trusts, 14%)
- 14 Trusts (14% of responders) mentioned the use of interpreters, including Makaton interpreters (four Trusts, 4%) and British Sign Language interpreters (11 Trusts, 11%)
- 10 Trusts (10%) stated that they sought to engage family carers as experts
- Six Trusts (6%) said that information was available on their intranet
- Four Trusts (4%) mentioned the use of a disability resource file or resource pack.

Supporting advocacy

We also asked a general question about how advocacy was supported within the Trust. Trusts identified a range of ways in which they supported advocacy, although responses differed according to whether Trusts were providers or commissioners of services.

For providers, the most common response mentioned the use of Independent Mental Capacity Advocates (35 Trusts, 40% of responses to this question), and a further 12 Trusts (15%) mentioned the use of the Independent Complaints Advocacy Service (for information about the use of these services by Trust patients, see below). 18 Trusts (21%) said that advocacy was supported through a local advocacy group or service, with a further 10 Trusts (11%) specifically mentioning joint or partnership working with advocacy services. 12 Trusts (15%) said that advocacy was supported through their PALS service.

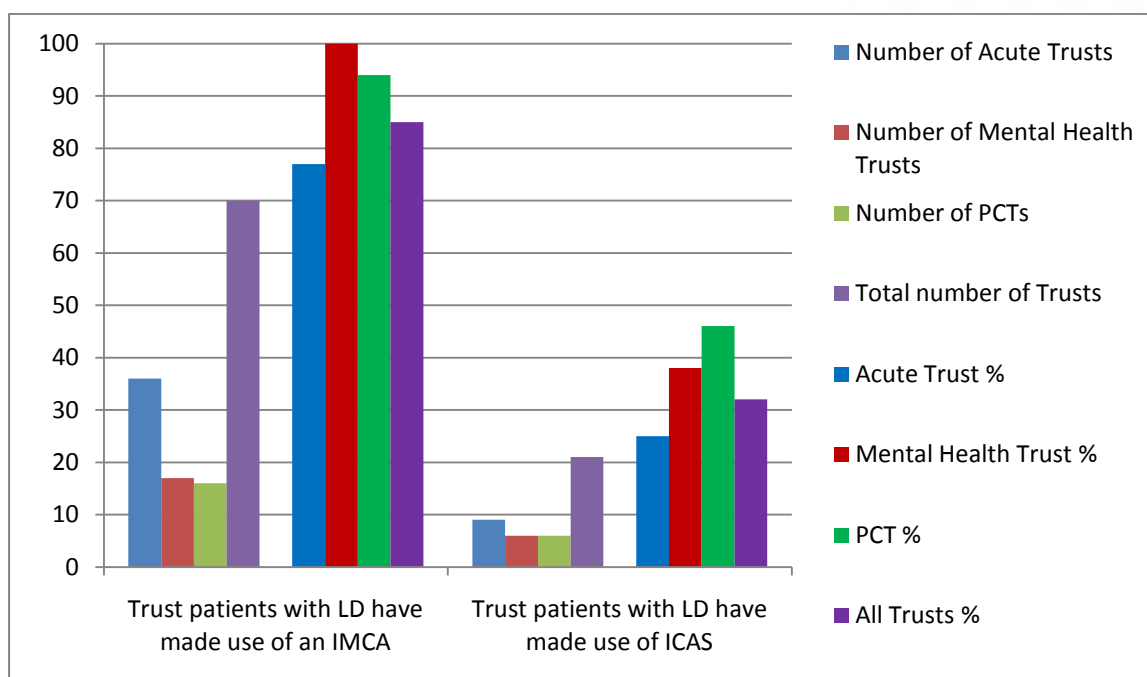
Commissioner Trust responses most commonly focussed on the advocacy services they commissioned jointly with local authorities (nine Trusts, 38% of PCT responses). Three PCTs (13%) stated that they commissioned advocacy services independently. A detailed breakdown of Trust responses is provided in Appendix 3.

Use of Independent Mental Capacity Advocates (IMCAs) and the Independent Complaints and Advocacy Service (ICAS)

Finally, Trusts were asked whether, during 2009/10, any patients had made use of an Independent Mental Capacity Advocate (IMCA) or the Independent Complaints Advocacy Service (ICAS).

Figure 7 shows that overall, 85% of responders (70 Trusts) stated that Trust patients had made use of an IMCA. All Mental Health Trust responders (17 Trusts) stated that Trust patients had made use of an IMCA, compared to 94% of responding PCTs (16 Trusts) and 77% of responding Acute Trusts (36 Trusts).

Figure 7: Use of IMCAs and ICAS by Trust patients, 2009/10



37 Trusts (45% of responders) gave a figure for the exact number of patients who had made use of an IMCA in 2009/2010. This ranged from one patient to 30 patients for provider Trusts, with a mean of 7.25, and from 10 patients to 44 patients for commissioning Trusts, with a mean of 23.8.

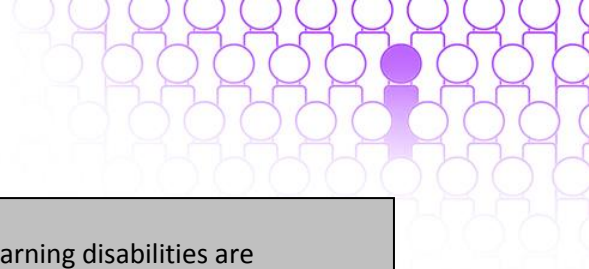
16 Trusts (24 % of responders, not included in Figure 7 above) stated that they did not know or were unsure about whether this information was available, and a further five Trusts (6%) said that they were working on making this information available. Eight Trusts (10%) said that this specific information was not collected, three (4%) said that it was currently unavailable, and three Trusts (4%) said that they had just started to collect this information.

Figure 7 shows that fewer Trust patients had made use of the Independent Complaints Advocacy Service (ICAS), with 32% of responders (21 Trusts) stating that this had taken place.

Nine Trusts gave an exact figure for the number of Trust patients that had made use of ICAS during 2009/10, seven provider Trusts and two PCTs. For both types of Trust, responses ranged from one to five patients, with an average of 1.7 for non-commissioning Trusts and three for PCTs.

38 Trusts (58% of responders, not included in Figure 7 above) said that no Trust patients had made use of ICAS during 2009/10. A further 16 (24% of responders) said that information about Trust use of ICAS was not known, with another 10 (15%) stating that this information was not routinely recorded. Five Trusts (8%) said that specific information about patients with learning disabilities was not recorded, with four Trusts (6%) indicating that the capture of this data was under development.

As part of their evidence for this question, six Trusts (9%) said that ICAS was mentioned in their complaints literature, three Trusts (5%) said they were awaiting information from an ICAS provider, and two Trusts (3%) said they could not answer as this information was confidential to ICAS.



At Harrogate and District NHS Foundation Trust volunteers with learning disabilities are developing a volunteer buddy system for patients admitted to hospital.

Advocacy, consent and capacity – Summary and appraisal of evidence

- Almost all responding Trusts reported having a policy concerning mental capacity (96%), staff training specifically concerning communication with people with learning disabilities (91%), and procedures for providing support to non-verbal patients (99%)
- These reasonable adjustments were met in diverse ways across different Trusts, but were often reliant on specialist learning disability staff
- Most responding NHS Trusts reported some form of advocacy support for people with learning disabilities accessing the service, most commonly through Independent Mental Capacity Advocates (IMCA; 40%), the Independent Complaints Advocacy Service (ICAS; 15%), working with a local learning disability advocacy service (21%) or through specialist learning disability or liaison staff (15%)
- Response rates concerning specific information about the use of IMCAs or ICAS by people with learning disabilities were lower and many Trusts reported not being able to provide this information – in total 70 NHS trusts reported that at least one patient with learning disabilities had used an IMCA in 2009/10, and 21 Trusts reported that at least one patient with learning disabilities had used ICAS in 2009/10.

Service Delivery

We asked Trusts to provide examples of reasonable adjustments they had made in the areas of:

- Initial communications and first appointments
- Processes of diagnosis/ identification of a health issue
- Clinical/professional intervention
- Discharge and follow up.

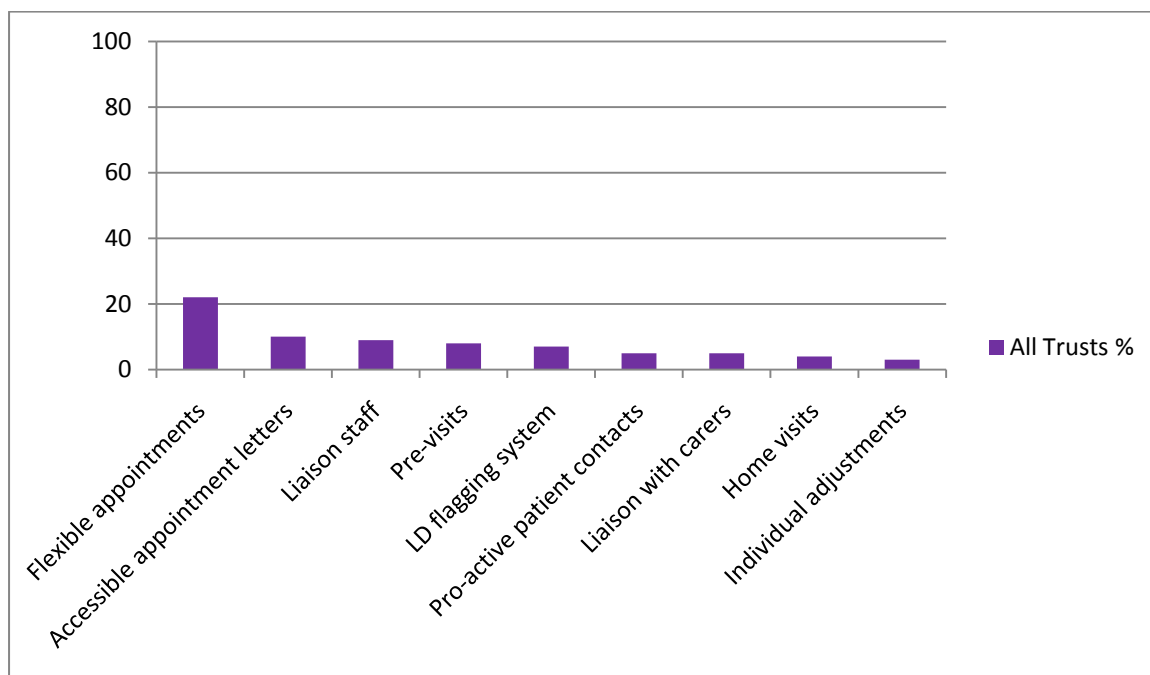
Initial communications and first appointments

In relation to evidence of reasonable adjustments for initial communications and first appointments (see Figure 8; a detailed breakdown of responses is provided in Appendix 4), specific reasonable adjustments with supporting evidence mentioned by 10 or more NHS Trusts included:

- Some form of flexibility for appointments, e.g. first or last appointments, longer appointment times including double appointments, appointments at quiet times and multiple appointments (26 Trusts; 22% of Trust responders)
- Easy Read or accessible appointment invitation letters (12 Trusts; 10%)
- Liaison staff working with other health services to ensure that reasonable adjustments were put in place (11 Trusts; 9%).

Four Trusts (3%) stated that Easy Read appointment letters were under development, with a further three Trusts (3%) mentioning the development of some form of accessible appointment letter.

Figure 8: Reasonable adjustments made by Trusts for initial communication/first appointments

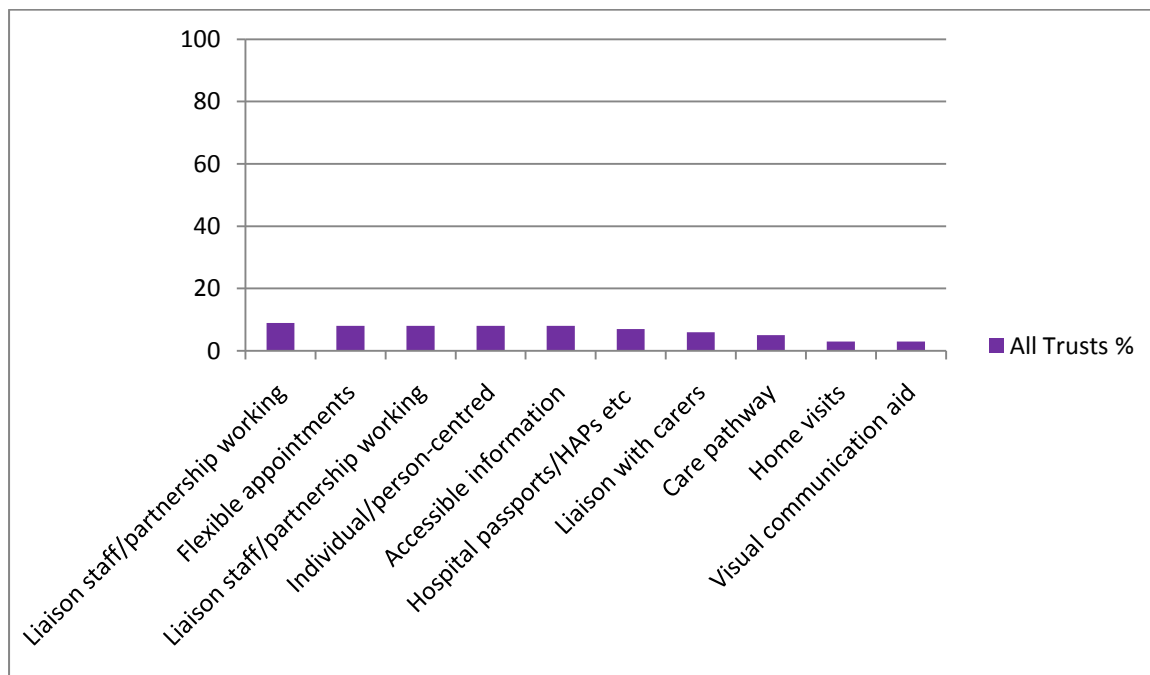


Process of diagnosis/ identification of a health issue

In relation to evidence of reasonable adjustments for diagnosis / identification of health issues (see Figure 9; a detailed breakdown of responses is provided in Appendix 4), specific reasonable adjustments mentioned by 10 or more NHS Trusts included:

- 11 Trusts (9% of Trust responders) described collaboration between liaison staff and other services, including examples of joint and partnership working, as part of an example of how reasonable adjustments were carried out within the process of diagnosis or identification of a health issue
- 10 Trusts (8%) discussed examples of flexible appointment procedures, such as first appointments or longer appointment times
- 10 Trusts (8%) described specific examples where support had been provided by liaison staff to patients with learning disabilities.

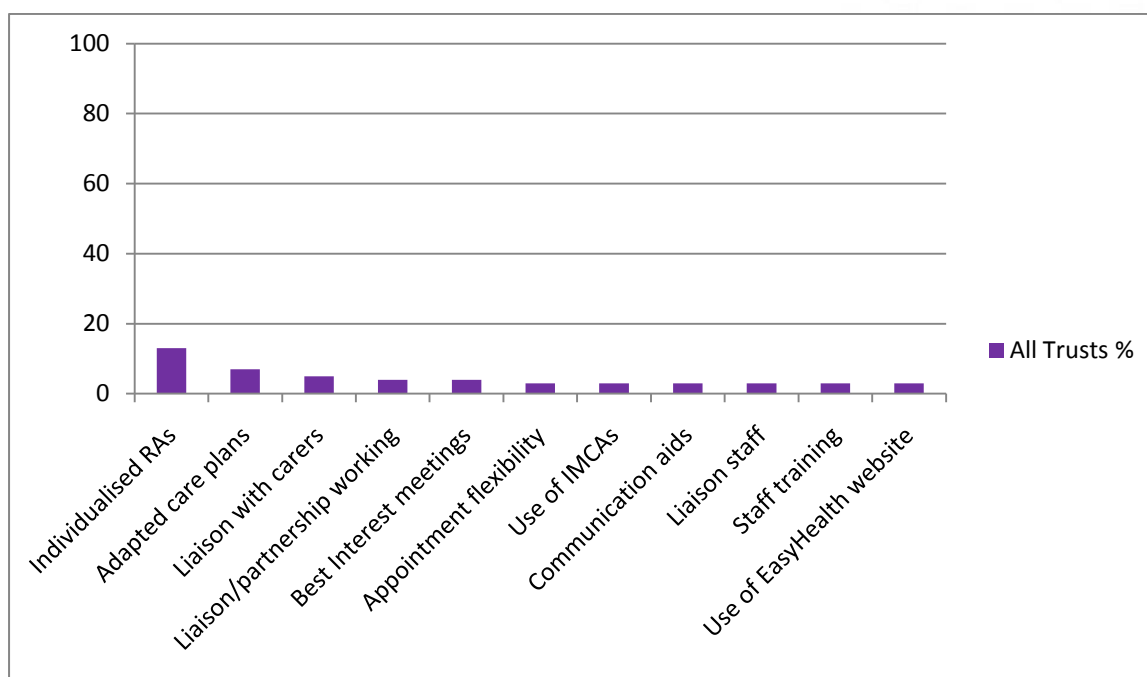
Figure 9: Reasonable adjustments made by Trusts for diagnosis/identification of a health issue



Clinical and professional intervention

In relation to evidence of reasonable adjustments for clinical and professional intervention (see Figure 10; a detailed breakdown of responses is provided in Appendix 4), the only form of reasonable adjustment mentioned by 10 or more NHS Trusts was a statement that they provided individual forms of reasonable adjustments in the area of clinical and professional intervention (15 Trusts; 13%).

Figure 10: Reasonable adjustments made by Trusts for clinical and professional intervention

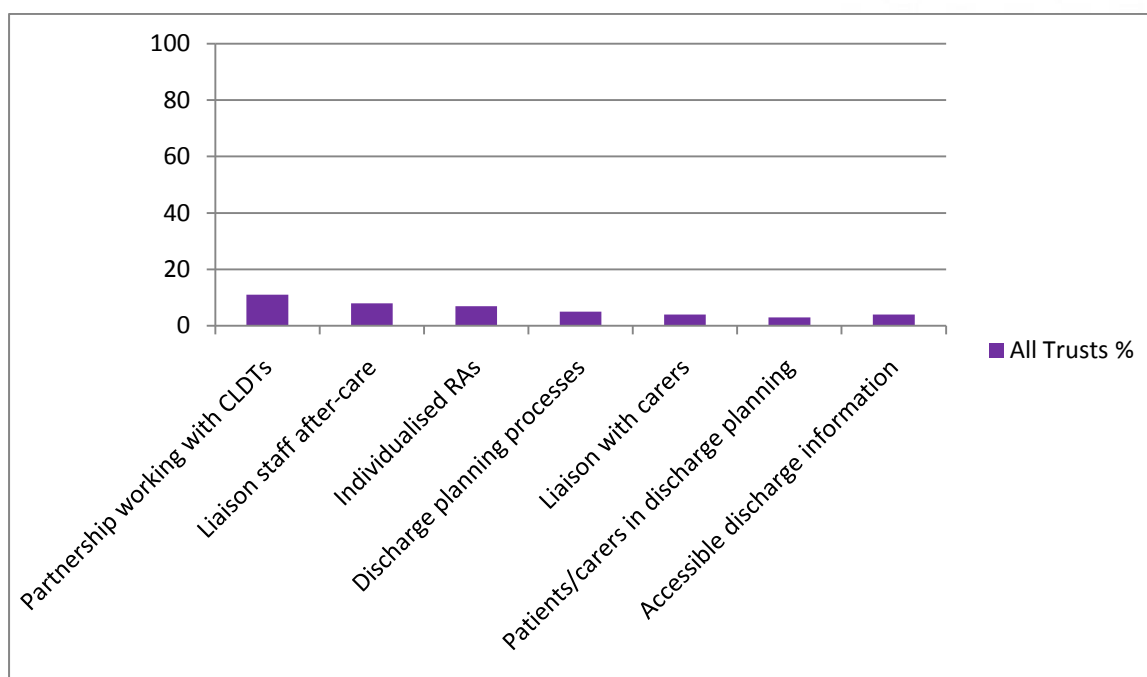


Airedale NHS Foundation Trust held an Open Day for patients with learning disabilities and their families where a ward was set up as a mock theatre, with a mock critical care area and a mock basic admissions ward. The event aimed to enable people with learning disabilities to have some prior understanding of what to expect if they were admitted to any of these areas.

Discharge and follow up

In relation to evidence of reasonable adjustments for discharge and follow up (see Figure 11; a detailed breakdown of responses is provided in Appendix 4), the only form of specific reasonable adjustment mentioned by 10 or more NHS Trusts concerned links between Trust staff and Community Learning Disability Teams (13 Trusts, 11% of Trust responders).

Figure 11: Reasonable adjustments made by Trusts for discharge and follow up




Use of liaison staff

Trusts were also asked whether they made use of liaison staff with a specific role in providing health facilitation, such as Learning Disability Liaison Nurses. Overall, 94% of Trusts (98 Trusts) responding to this question stated that they did make use of liaison staff with a specific health facilitation role. Responses by Trust type ranged from 95% of Acute Trust responders (55 Trusts) to 96% of PCT responders (24 Trusts) and 90% of Mental Health Trust responders (18 Trusts). (Responses where PCTs indicated that this question was not relevant to their operations were excluded from the data reported above.)

For provider Trusts:

- 12 Trusts (15 % of provider Trust responders; nine Acute Trusts and three Mental Health Trusts) said that they employed Learning Disability Liaison Nurses
- 12 Trusts (15%) stated that they employed Acute Liaison Nurses and six Trusts (8%) mentioned the use of Liaison teams
- 11 Trusts (14% of provider Trust responders) stated that they employed a health facilitation nurse or strategic health facilitator
- Four Trusts (5%) said that health facilitation was part of the Safeguarding Adults Lead or Co-ordinator role. Other forms of personnel identified by Trusts as having a liaison role include that of practice development nurse, paediatric outreach nurse and community psychiatric nurse
- Four Trusts (5%) stated that they engaged in partnership working with community or PCT health facilitation staff.

Much of the evidence for the use of liaison staff focused on the way in which they worked with other staff within the Trust as well as across other Trusts. Seven Trusts (9% of provider Trust responders)



said that liaison staff worked closely with Learning Disability Community Teams, with a further three (4%) stating that they worked well with a Learning Disability Health Liaison Nurse or lead Nurse from a PCT. Five Trusts (6%) stated that liaison staff were on Trust steering groups or other working group.

PCT responders emphasised the services they funded, with nine Trusts (36% of PCT responders) mentioning their funding of liaison staff, and seven Trusts (28%) giving examples of their funding of health facilitation as evidence for the use of liaison staff.

Service delivery – Summary and appraisal of evidence

- Trusts provided a range of forms of evidence for service delivery, including job descriptions, examples of protocols, meeting minutes and patient questionnaires. However, the majority of the examples reported by Trusts were anecdotal and focused on the ways that liaison and other Trust staff worked collaboratively with patients, carers and other services. The diversity of specific reasonable adjustments reported by NHS Trusts for people with learning disabilities in any area of service delivery meant that few reasonable adjustments were mentioned by 10% or more of NHS Trusts
- With regard to initial communications and first appointments, the most common reasonable adjustments mentioned by Trusts involved offering some flexibility in first appointments (in terms of the timing, duration and/or location of the appointment) (26 Trusts; 22%), and Easy Read or accessible appointment invitation letters (12 Trusts; 10%)
- With regard to the diagnosis / identification of health issues, no reasonable adjustments were mentioned by 10% or more of Trusts. Most commonly, 11 Trusts (9% of Trust responders) described collaboration between liaison staff and other services, including examples of joint and partnership working
- With regard to clinical and professional intervention, the only form of reasonable adjustment mentioned by 10% or more of NHS Trusts was a statement that they provided individual forms of reasonable adjustments in the area of clinical and professional intervention (15 Trusts; 13%)
- With regard to discharge and follow up, the only form of reasonable adjustment mentioned by 10% or more of NHS Trusts concerned links between Trust staff and Community Learning Disability Teams (13 Trusts, 11% of Trust responders)
- Almost all responding Trusts (98 Trusts; 94%) reported that they made use of liaison staff with a specific role in providing health facilitation, such as Learning Disability Liaison Nurses
- This highlights the extent to which NHS Trusts rely on staff with specialist knowledge, skills and role concerning people with learning disabilities to negotiate health services where reasonable adjustments are not embedded within routine service processes
- It also highlights the importance of partnership working across health services and or support services working with people with learning disabilities

Gathering, Monitoring and Reporting Information

In this section of the survey, Trusts were asked about the methods they used to gather, report and monitor information about people with learning disabilities accessing their services.

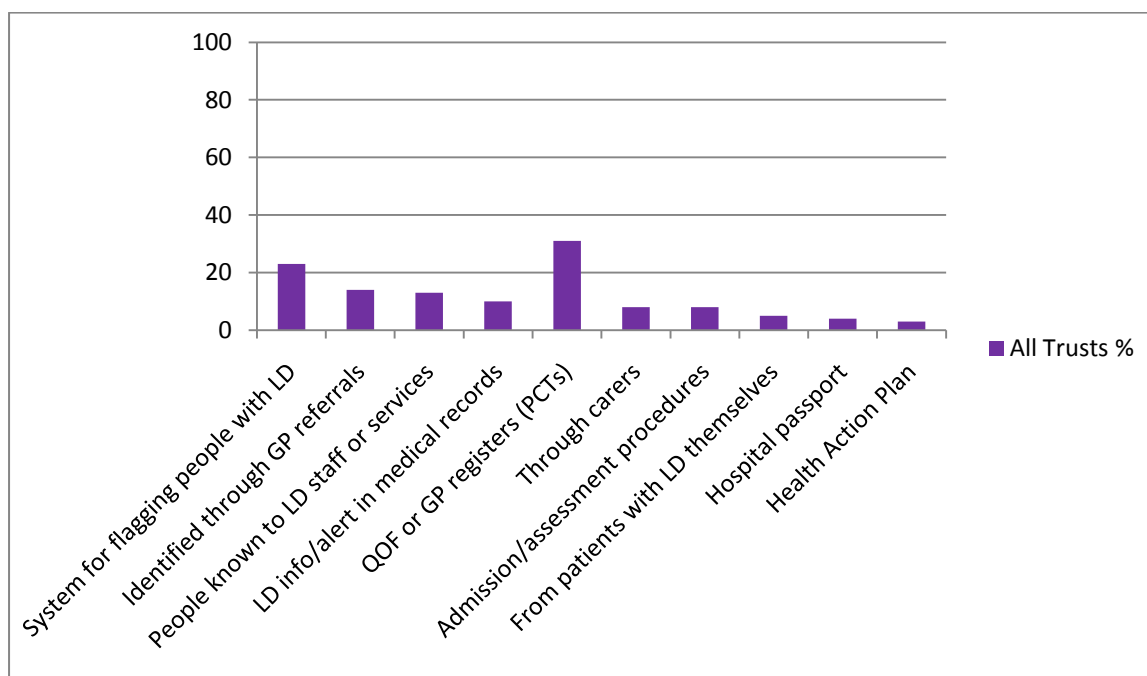
Finding out whether a patient has a learning disability

First, we asked Trusts were asked how they knew whether a patient had a learning disability. Methods for identifying patients with learning disabilities mentioned by 10% or more of Trusts were (see Figure 12; more detail is provided in Appendix 5):

- 27 Trusts (23% of Trust responders) gave an example of a flagging system that was in place as evidence for this question
- 17 Trusts (14%) stated that they knew patients had a learning disability through GP referrals
- 15 Trusts (13%) stating that patients were known to Learning Disability staff, teams or services
- 12 Trusts (10%) stated that some form of information or alert in medical records was used
- 10 PCTs (31% of PCT responders) stated that they knew whether patients had a learning disability through the use of the Quality Outcomes Framework or registers.

Six Trusts (5% of Trust responders) said that they had a system under development to identify patients with a learning disability, and four other Trusts (3%) said that there was no system in place

Figure 12: Methods for identifying people with learning disabilities



Number of patients with a learning disability making use of Trust services

As a follow up to this question, Trusts were asked how many patients with a learning disability made use of their services in 2009/10.

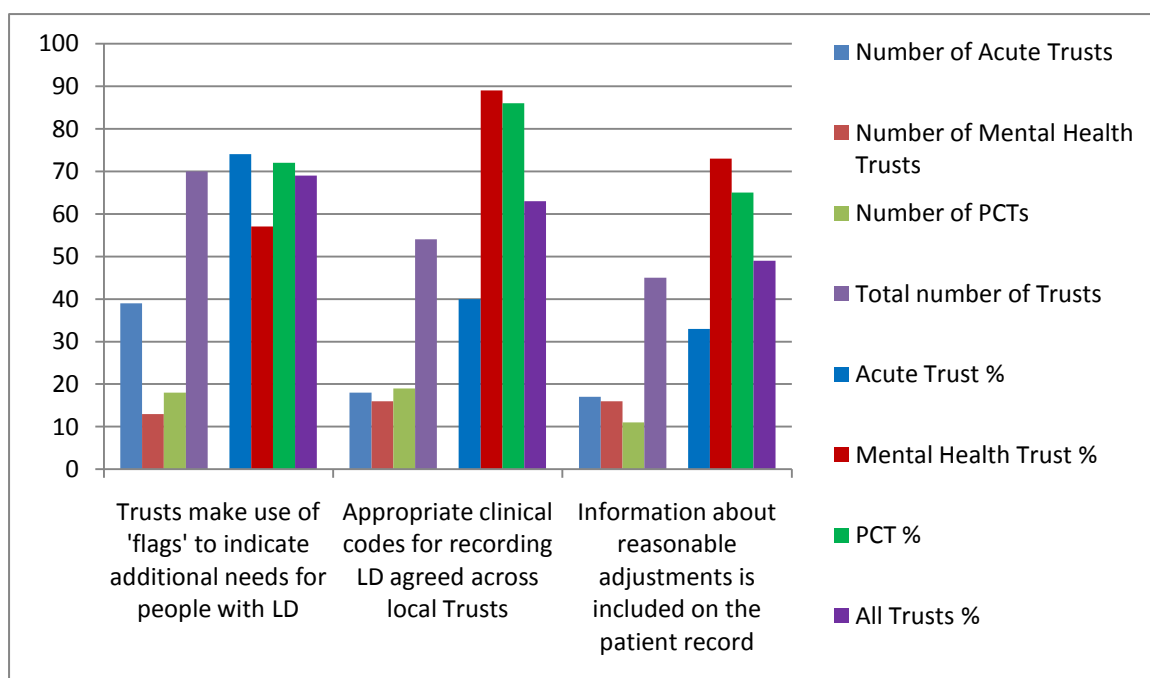
42 Trusts (35% of responders) gave some form of data for this question, although 18 Trusts (15%) qualified this information by stating that they had provided an approximate figure or covered only some Trust services or a shorter timescale. For the 24 Trusts where this information was not qualified in this way, responses ranged from 30 to 4,456, and averaged 891 patients.

24 Trusts (20% of responders) stated that the number of Trust patients with a learning disability was unknown, with a further 12 Trusts (10%) saying that this information was not recorded.

Use of 'flags' to indicate additional needs for people with learning disabilities

Trusts were asked if they made use of 'flags' to indicate additional needs for people with learning disabilities and whether appropriate clinical codes for recording learning disability (i.e. consistent codes within routine systems of clinical codes) had been agreed across local Trusts. Figure 13 shows that 70 Trusts (69% of Trust responders) stated that they made use of 'flags'. Rates of 'flag' use varied from 74% of Acute Trusts (39 Trusts), 72% of PCTs (18 Trusts) to 57% of Mental Health Trusts (13 Trusts; it is worth noting that specialist Learning Disability Trusts are included within this category but would not need to make use of 'flags' within their services).

Figure 13: Use of flags and appropriate clinical codes for recording learning disability



As evidence for their use of flags:

- 13 Trusts (13% of responders) mentioned some form of electronic flagging system
- Nine Trusts (9%) said that they used flags within the Patient Administration System
- Eight Trusts (8%) stated that flags were held in patient medical records
- Five Trusts (5%) stated that flags were in place in GP services (one Mental Health Trust and four PCTs)
- Four Trusts (4%) said that they use flags in Accident and Emergency departments.

Nine Trusts (not included in Figure 13) stated that a flagging system was under development, with a further nine Trusts stating that no flagging system was in place. In addition, three Learning Disability Trusts (part of the Mental Health Trust cohort) stated that this question was not relevant to their operations as all of their patients had learning disabilities.

At NHS South of Tyne and Wear PCT partnership working has been undertaken to introduce a flagging system which generates weekly reports by Acute Trusts shared with the PCT's Learning Disability Liaison Nurse.

Agreement of clinical codes across local Trusts

We also asked Trusts whether they had agreed with other local Trusts to record learning disability in a consistent way using standard sets of clinical codes used within Trusts (e.g. ICD10). As Figure 13 shows that, overall 63% of Trusts (54) stated that this was in place. 89% of Mental Health Trust responders (16 Trusts) and 86% of PCT responders (19 Trusts) said that appropriate codes had been agreed, with lower rates for Acute Trust responders (40%; 18 Trusts).

As evidence for the agreement of clinical codes, 16 Trusts (19% of Trust responders) mentioned the International Statistical Classification of Diseases and Related Health Problems (ICD 10) codes. Other forms of evidence provided were limited, but included codes within the Directed Enhanced Service (DES) (five Trusts, 6%) and the use of Read Codes (three Trusts, 3%).

Responses from Trusts that did not state clinical codes had been agreed (and so are not included in Figure 13) included that no agreement was in place (11 Trusts, 13%), that an appropriate agreement was under development (eight Trusts, 9%) and that there was agreement but that this was not consistently applied (two Trusts, 2%).

Recording information about reasonable adjustments on the electronic patient record

Trusts were also asked whether information about reasonable adjustments was recorded on the electronic patient record. Figure 13 shows that 73% of Mental Health Trusts (16 Trusts), 65% of PCTs (11 Trusts) and 33% of Acute Trusts (17 Trusts) responded positively to this question. Overall, 49% of Trusts responding to this question stated that information about reasonable adjustments was recorded on the electronic patient record.

Answers that provided evidence for this were again limited, but included information being recorded on care plans or care records (eight Trusts, 9% of Trust responders), information being recorded in free text boxes on the electronic patient record (two Trusts, 2% of responders) and information being recorded if agreed with the patient or in their best interests (two Trusts, 2% of responders).

Where Trusts had indicated that information was not recorded on the electronic patient record (and therefore not included in Figure 13 above), seven Trusts (8%) said that this was under development, 10 Trusts stated that information was kept on a paper or medical record, five Trusts (5%) said that an

electronic record was not kept, and three Trusts (3%) stated that information was not recorded consistently.

Use of Health Passports and Health Action Plans

Trusts were asked whether they made use of Health Passports, Health Action Plans or anything similar, and whether they accepted Health Passports they had not developed (see Appendix 5 for detailed findings).

The vast majority of those responding to the question said that they did make use of Health Passports, Health Action Plans or something similar (104 Trusts, 98%). Responses were at or nearly at 100% for Mental Health Trusts, Acute Trusts and PCTs. As evidence for this:

- 34 Trusts (32% of responders) stated that they used Health Action Plans
- 33 Trusts (31%) stated that they made use of Hospital Passports
- 14 Trusts (13%) said that they used the Traffic Light Assessment tool
- Seven Trusts (7%) said that they made use of the My Health Record booklet
- Six Trusts (6%) stated that they used the Hospital Communication Book
- Eight Trusts said that their use of Health Passports, Health Action Plans or something similar was under development.

The vast majority of responding Trusts (98%) stated that they accepted and used Health Passports not developed by their own Trust. When asked for evidence, four Trusts (4% of responders) stated that they accepted Health Passports for out of area patients, three Trusts (3%) said they did this for new referrals, two Trusts (2%) from neighbouring Trusts and two Trusts (2%) from community settings. Three Trusts (3%) provided a Health Action Plan or Health Passport as a form of evidence for this question.

Use of data about people with learning disabilities to contribute to service planning and development

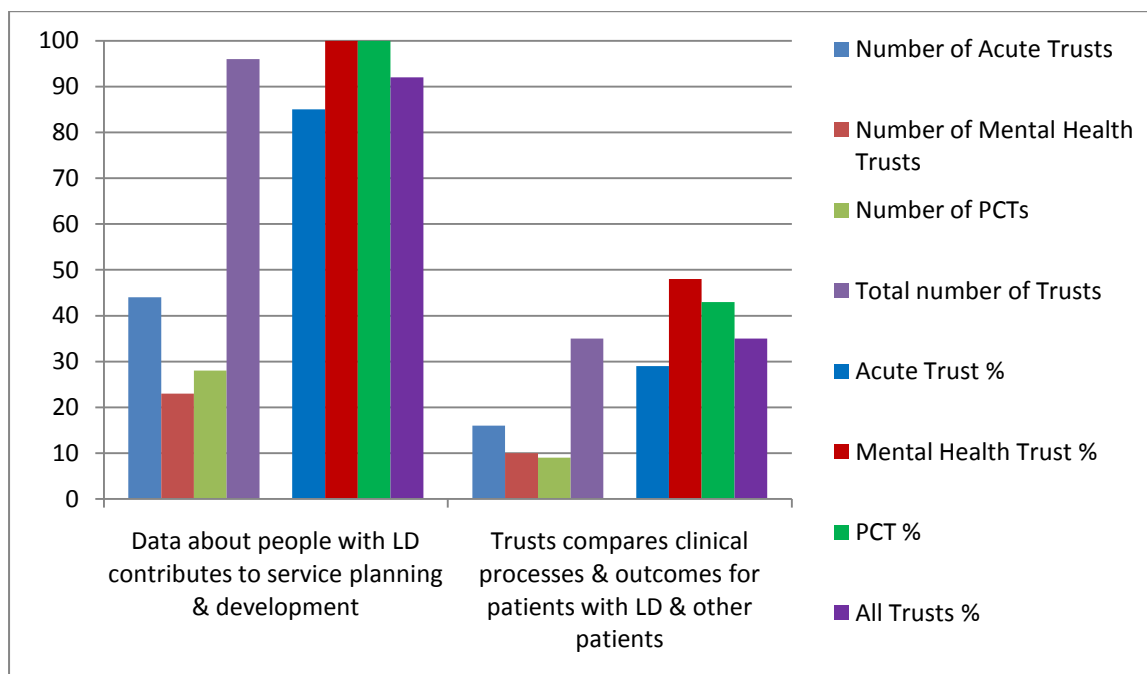
Finally, we asked Trusts whether data about people with learning disabilities were used to contribute to service planning and development, and whether the Trust compared clinical processes and outcomes for patients with learning disabilities with other Trust patients. Figure 14 shows that 92% of Trusts responding to this question stated that they used data to contribute to service planning and development, including all Mental Health Trusts and PCT responders to this question, and 85% of Acute Trust responders.

Evidence for this question was provided by a minority of Trusts (detailed Trust responses are provided in Appendix 5):

- 15 Trusts (14% of Trust responders) stated that they used some form of surveys or service user feedback that was acted upon
- Seven Trusts (7%) said that they made use of audit data
- Seven Trusts (7% of Trust responders) stated that data about people with learning disabilities was used for service planning and development through a Trust disability group or forum, five Trusts (5%) through Learning Disability Partnership Boards, four Trusts (4%)

through Health Action Groups or Health Task Groups, and four Trusts (4%) through patient equality and diversity groups.

Figure 14: Use of data for service planning and development and comparison of clinical processes and outcomes



Comparison of clinical outcomes and processes

Figure 14 also shows that 35% of Trust responders overall (35 Trusts) stated that they compared clinical processes and outcomes for patients with learning disabilities with outcomes for other patients; these statements were more likely for 48% of Mental Health Trusts (48%; 10 Trusts) and PCTs (43%; nine Trusts) than Acute Trusts (29%; 16 Trusts).

Small minorities of Trusts provided evidence in response to this question (see Appendix 5):

- Four Trusts (4% of Trust responders) mentioned the Learning Disability Self Assessment process
- Three Trusts (3%) stated that they compared clinical outcomes through the Strategic Health Authority, three Trusts (3%) through Good Health Groups, and three Trusts (3%) through specific forums
- Of those Trusts that stated that they did not compare clinical processes and outcomes (and thus not included in Table 15), eight Trusts stated that they did not currently do this but were aware of the need to do so, or that this was something under development.

NHS Bradford and Airedale scrutinise hospital admission data to identify disproportionate use of services by people with learning disabilities and cross reference disease registers with the Learning Disability register to understand prevalence and condition specific requirements.

- Most responding Trusts stated that they had some way of flagging a patient as a person with learning disabilities (69%), and that they used a set of clinical codes agreed upon with other local Trusts (63%)
- Almost half of responding Trusts (49%) stated that information on reasonable adjustments for patients with learning disabilities was included in the electronic patient record
- Almost all responding Trusts stated that they accepted and used Health Passports, Health Action Plans or something similar (98%), that they accepted and used Health Passports and Health Action Plans developed outside the Trust (98%), and that data concerning people with learning disabilities was used in Trust planning and development (92%)
- However, far fewer Trusts provided specific information or evidence to support these statements. Only 35% of responding Trusts stated that they used information specifically comparing clinical processes and/or outcomes for people with learning disabilities versus other patient groups, and only 20% of responding Trusts could provide specific information on the number of people with learning disabilities who had used the Trust's services in 2009/2010
- The quality of the information provided as evidence for the gathering, monitoring and reporting information section was mixed, with extensive anecdotal evidence for the use of monitoring systems for identifying patients with learning disabilities, but much more limited evidence that such information was actually available and used by Trusts.

Patient and Public Involvement

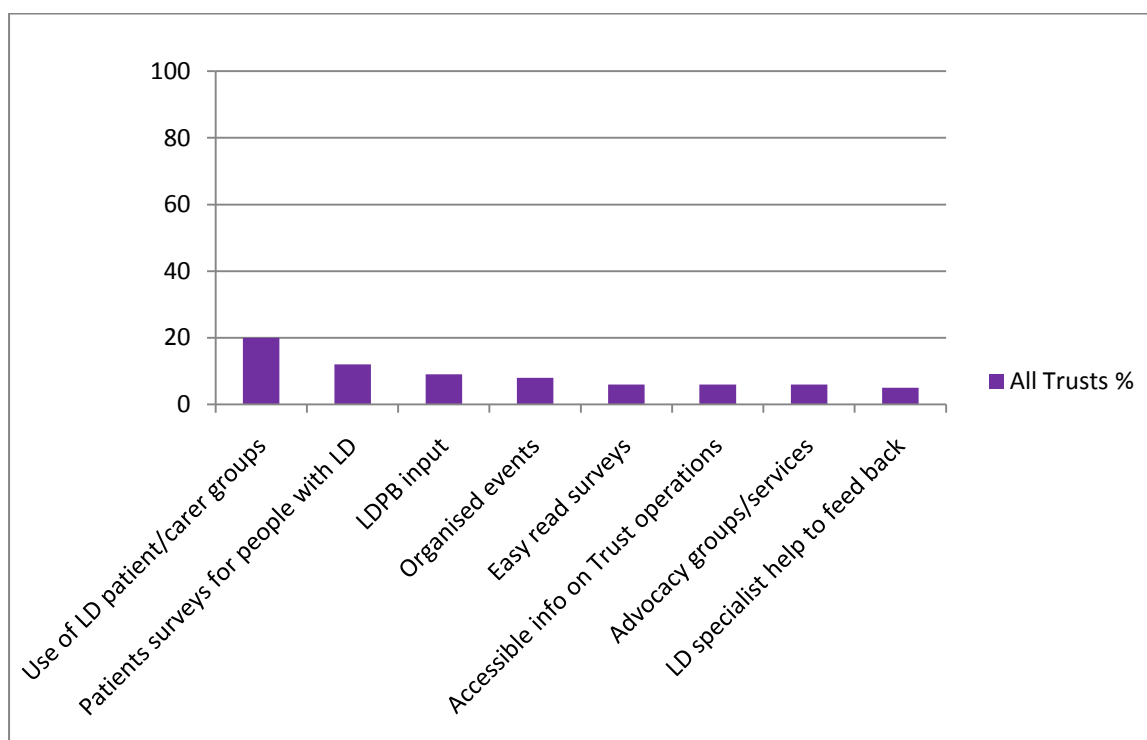
Trusts were asked a series of questions concerning how they involved patients with learning disabilities and their carers in monitoring, training and decision-making within the Trust. The first question asked what reasonable adjustments were in place to ensure that service evaluations and service reviews specifically included the views of patients with learning disabilities.

Including the views of patients with learning disabilities in service evaluations and service reviews

The evidence provided about service evaluations and service reviews was diverse, with only two forms of reasonable adjustment reported by 10% or more of Trusts (see Figure 15; a detailed breakdown of Trust responses is provided in Appendix 6):

- The most common Trust response referred to the use of groups, including Learning Disability groups, carers groups, forums and focus groups (24 Trusts, 20%)
- 14 Trusts (12%) identified patient surveys, questionnaires or interviews adapted for people with learning disabilities.

Figure 15: Including the views of patients with learning disabilities in service evaluations and service reviews

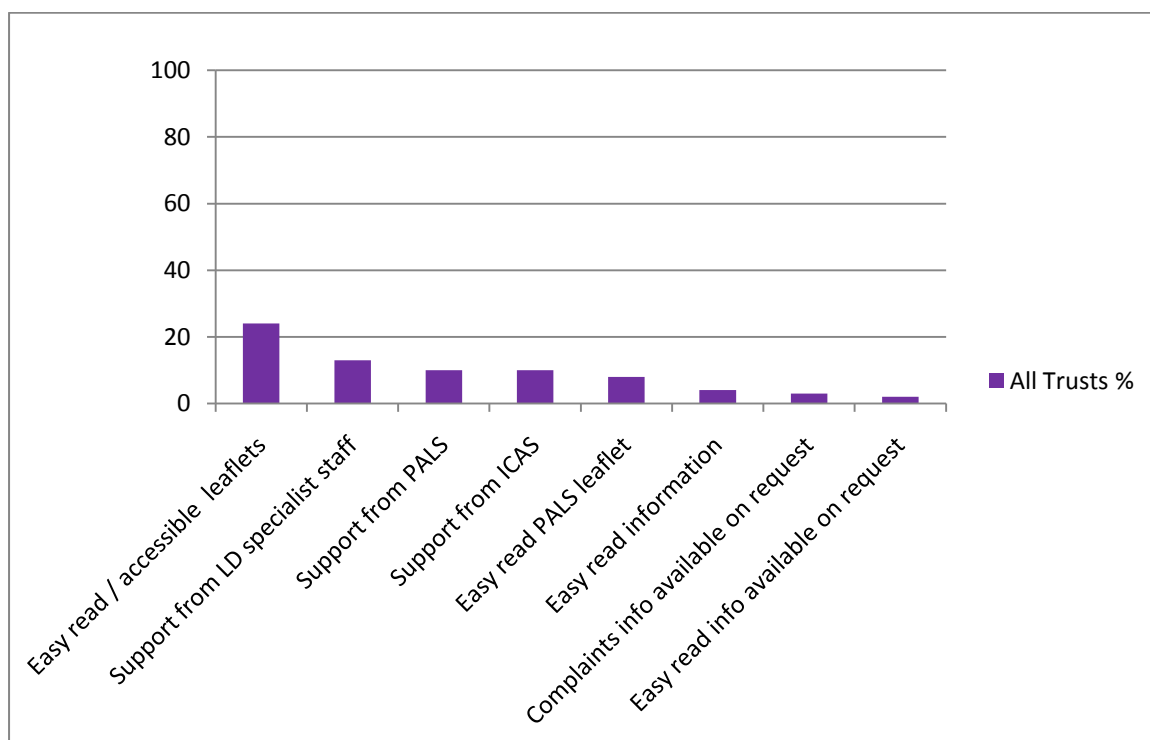


North Staffordshire Combined Healthcare Trust is currently introducing an experience based design initiative, a way of bringing patients and staff together to share the role of improving and re-designing services, across some of the Trust's Learning Disability Services. The initiative will support feedback from and involvement of clients with a Learning Disability in reviewing services.

Reasonable adjustments to allow access to Trust complaints procedures

In relation to evidence about access to Trust complaints procedures, the most common form of evidence provided was Easy Read or accessible complaints leaflets (29 Trusts, 24% of responders), with 10% or more Trusts reporting various sources of support in relation to accessing complaints procedures, including PALS (12 Trusts, 10% of responders), ICAS (12 Trusts, 10%), LD specialist or liaison nurses (16 Trusts, 13%) and LD teams (three Trusts, 3%) (see Figure 16; a detailed breakdown of Trust responses is provided in Appendix 6). Interestingly, one Trust said that it did not use the word 'complaints', as local LD partnership groups had advised that they felt concerns would encourage more useful feedback and usage of the complaints process.

Figure 16: Reasonable adjustments to allow access to Trust complaints procedures



Hertfordshire Partnership NHS Foundation Trust provides Easy Read complaints leaflets and Easy Read 'Have your say' forms, and an advocate presence in all in-patient services. Some in-patient units have patient experience tracker devices where service users can answer pre-defined questions around their care and treatment by pressing a sad or smiley face.

NHS Nottinghamshire County leads on a regionally and nationally awarded Pacesetters project called 'Healthy Hearts' that highlighted the needs and voices of adults with learning disabilities and coronary heart disease. The project consulted with over 150 men and women and their carers and recommendations from the Pacesetters project report have been actioned by 3 NHS Trusts in Nottinghamshire and supported by the NHS East Midlands Strategic Health Authority.

Ensuring the views and interests of people with learning disabilities are included at Board level

Trusts were asked about whether reasonable adjustments were in place to ensure that the views and interests of people with learning disabilities were represented at Trust Board level.

Overall, a big majority of responding Trusts (86%: 78 Trusts) stated that reasonable adjustments were in place to ensure that the views of people with learning disabilities were represented at Trust Board level. 90% of Mental Health Trust responders (18 Trusts), 85% of Acute Trust responders (41 Trusts) and 82% of PCT responders (18 Trusts) stated that these reasonable adjustments were in place.

However, overall responses rates were fairly low for this question, at 91 Trusts (76% of survey responders). In addition, specific evidence was only provided by a minority of Trusts, with 10% or more of Trust reporting the following (see Figure 17; see detailed breakdown in Appendix 6):

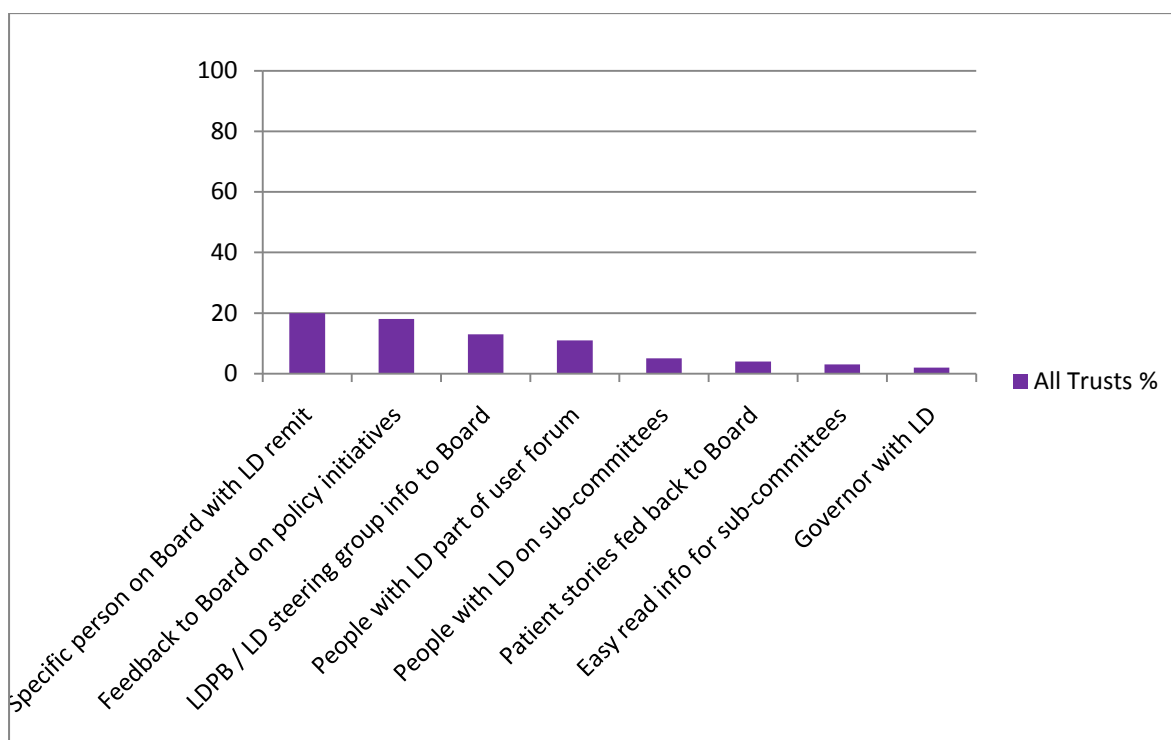
- 24 Trusts (20%) identified a specific person at Trust Board level, such as the Director of Nursing or non-executive Trust directors, who had a remit to consider the needs of people with learning disabilities at Trust Board level
- 21 Trusts (18%) discussed how regular reports from policy initiatives such as Closing the Gap were fed back to Boards
- 15 Trusts (13%) discussed how information from Learning Disability Partnership Boards or Learning Disability Steering Groups was fed to Trust Boards
- 13 Trusts (11%) stated that people with learning disabilities were included in the membership of a Patient Experience Group or a Service User forum that reported to the Board.

Involvement of people with learning disabilities and their carers as trainers for Trust staff

Overall, 67% of Trust responders (70 Trusts) stated that people with learning disabilities and/or their carers were involved as trainers for Trust staff, most commonly in Mental Health Trusts (83%; 19 Trust responders) compared to 64% (16 Trusts) for PCTs and 63% (21 Trusts) for Acute Trusts. Two methods for this were mentioned by 10% or more of Trusts (see Appendix 6 for more detail):

- 37 Trusts (35% of responders to this question) stated that people with learning disabilities or their carers were involved as trainers for Trust staff at specific training events
- 11 Trusts (10%) mentioned the involvement of outside organisations such as People First or theatre groups.

Figure 17: Reasonable adjustments to ensure the views and interests of people with learning disabilities are included at Trust Board level



Examples where feedback had changed a service

Trusts were also asked whether they could provide any specific examples where feedback from patients with learning disabilities and/or their carers had changed a service. A range of examples were provided as evidence for this question, with 10% or more of Trusts reporting the following (a detailed breakdown of Trust responses is provided in Appendix 6).

- 14 Trusts (13% of responders) mentioned a change or development in a policy, strategy, guidelines or action plans
- 12 Trusts (11%) discussed the development of Easy Read documents such as leaflets, complaint forms, menus or appointment letters
- 10 Trusts (10%) mentioned the development of resources used with patients, such as Hospital Communication Books and Hospital Passports as a result of feedback
- 10 Trusts (10%) identified changes in aspects of care, such as discharge or admission procedures and appointment times.

At *Your Healthcare* service users held a “Big Health Check Up Day” information awareness raising session, facilitated by the service users’ Parliament. A “problem wall” was created with issues which need to be addressed locally. These have been incorporated in to the annual plan of the health group and will help to change services.

Reasonable adjustments carried out by PALS

A further question asked by the survey was what reasonable adjustments were carried out by Patient Advice and Liaison Services (PALS) to support patients with learning disabilities and their families within the Trust. Evidence provided by 10% or more of responding Trusts included (a detailed breakdown of Trust responses is provided in Appendix 6):

- Easy Read or accessible leaflets (36 Trusts; 30%)
- 24 Trusts (20%) said that PALS provided individual or face to face support for patients with learning disabilities and their families
- 25 Trusts (21%) said that PALS refer to or liaise with other hospital contacts, such as Learning Disability Liaison Nurses or language support services.

Within Northumbria Healthcare NHS Foundation Trust, PALS have disseminated an easy read leaflet in A4 and A5 format explaining their role. Local NHS services and organisations, including Learning Disabilities services share one PALS service which enables a 'one stop' point of entry for service users. In addition PALS has a programme of talks, drop ins and other activities within the community and specialist services that explain the role of PALS and how to access the service.

Foundation Trust members

Finally, Foundation Trusts were asked how many Trust members were people with learning disabilities or their carers, and what percentage this was of total members.

Seven Trusts (17% of the 45 Foundation Trust responders to this question) provided a number and/or a percentage answer to this question. Of the four Trusts (9%) who provided a number of members, responses ranged from seven to 596 people, with an average of 222. For the five Trusts (12%) that provided a percentage of total members, this ranged from 1.8% to 16%, averaging 8.7%.

30 Trusts (73% of responders) stated this information was unknown or not collected.

Patient and public involvement- Summary and appraisal of evidence

In most areas of patient and public involvement, a minority of Trusts reported specific examples of reasonable adjustments concerning the involvement of people with learning disabilities or their carers in activities designed to influence the operation of the Trust.

- The most common Trust responses when asked for evidence about service evaluations and service reviews referred to the use of groups, including Learning Disability groups, carers groups, forums and focus groups (24 Trusts, 20%), or patient surveys, questionnaires or interviews adapted for people with learning disabilities (14 Trusts; 12%)
- In relation to evidence about access to Trust complaints procedures, the most common form of evidence provided was Easy Read or accessible complaints leaflets (29 Trusts, 24% of responders), with 10% or more Trusts reporting various sources of support in relation to

accessing complaints procedures, including PALS (12 Trusts, 10% of responders), ICAS (12 Trusts, 10%), and Learning Disability specialist or liaison nurses (16 Trusts, 13%)

- Regarding reasonable adjustments made by Trust Patient Advice and Liaison Services (PALS), 36% of responding Trusts reported PALS having Easy Read/accessible information for people with learning disabilities, 20% reported PALS offering individual face-to-face support for people with learning disabilities, and 21% reported PALS personnel liaising with specialist learning disability staff
- A majority of Trusts (78 Trusts; 86% of responders) reported that views from people with learning disabilities were considered at Trust Board level, although lower numbers of Trusts could specify how this happened, most commonly through identification of a specific person at Trust Board level with a remit for Learning Disability (20%), or reports from major policy initiatives being fed back to Boards (18%)
- Trusts reported examples of feedback from patients with learning disabilities or their carers changing a service through having an impact on Trust policies (13%), the development of Easy Read information (11%), other resources for patients with learning disabilities (10%), care practices (10%), the involvement of service users (9%) and changes to staff training/recruitment practices (4%)
- 17% (seven Trusts) of Foundation Trust responders could provide information on either the number or percentage of Trust members were people with learning disabilities
- Most Trusts (70 Trusts; 67% of responders) reported that people with learning disabilities and carers were acting as trainers within the Trust, most commonly at specific training events (37 Trusts; 35%) or through the involvement of outside organisations such as People First or theatre groups (11 Trusts; 10%).

Overall, a range of evidence was provided for the Patient and Public Involvement section, with several examples of accessible leaflets provided as well as documentation that included meeting minutes, and group terms and references. As mentioned above, response rates to the questions about the representation of the views and interests of people with learning disabilities at Trust Board level were relatively low. This may indicate that a greater proportion of Trusts do not carry out reasonable adjustments in this area than is indicated by the data in this section.

Employment

Trusts were asked about the recruitment and support they provide to employees and volunteers with learning disabilities, staff training regarding attitudes to people with learning disabilities and how they ensured that staff with learning disabilities were not treated unfairly in relation to career retention and development.

Recruitment and support to employees with learning disabilities

As evidence for the ways in which they recruited and supported employees and volunteers with learning disabilities (a detailed breakdown of Trust responses is provided in Appendix 7):

- 26 Trusts (22% of responders) mentioned their Human Resources recruitment policy
- 18 Trusts (15%) stated that they were part of the 'two ticks' disability award scheme
- A further 18 Trusts (15%) said that they used some form of supported employment scheme
- 16 Trusts (13% of responders) gave examples of volunteer schemes for people with learning disabilities
- 14 Trusts (12%) gave examples of where they had employed staff with learning disabilities
- Six Trusts (5%) stated that they did not employ anyone with learning disabilities
- Three Trusts referred to a guaranteed interview scheme.

The Queen Elizabeth Hospital King's Lynn NHS Trust have signed up to the Project Search programme of partnership work training, which is particularly suited to people with learning disabilities, and are currently supporting 8 young people to gain work experience and training.

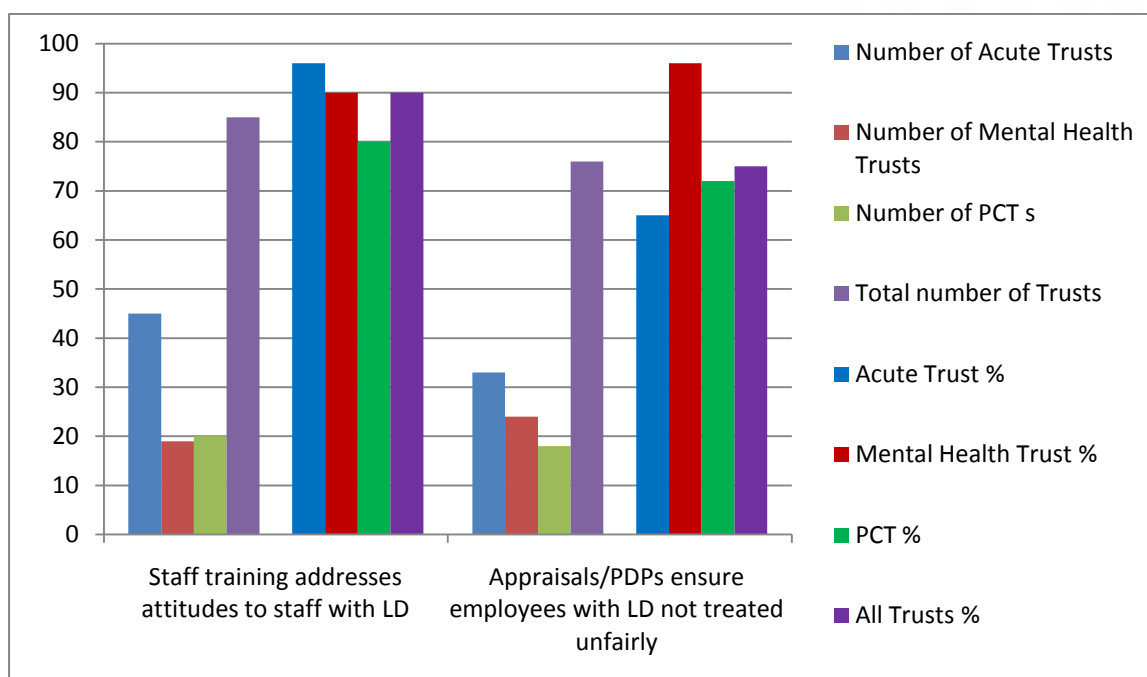
Staff training on attitudes to other staff with learning disabilities

Trusts were asked about whether staff training addressed attitudes towards other staff with learning disabilities. Of the 95 Trusts that responded to this question, Figure 18 shows that 91% (86 Trusts) stated that staff training did address attitudes.

When asked for evidence in relation to staff training Trust responses fell into two broad categories. 48 Trusts (51% of responders) said that staff attitudes were addressed to at least some degree in general equality and diversity training. 15 Trusts (16% of responders) said that they provided specific Learning Disability Training that included attitudes towards other staff with learning disabilities.

Ashford and St Peters NHS Trust's Equality and Diversity training covers bullying and harassment, including a DVD which details a woman with Down's syndrome who is bullied at work, followed by a group discussion.

Figure 18: Staff training on attitudes and use of appraisal and personal development plans (PDPs)



Fair treatment in relation to retention and career development within appraisals and personal development plans

We also asked Trusts whether appraisals and personal development plans ensured that people with learning disabilities were not treated unfairly in relation to retention and career development (see Figure 18). 93% of the Trusts responding to this question said that this was the case. Positive responses to this question varied by Trust type, from 95% (40 Trusts) of Acute Trust responders, and 95% of Mental Health Trusts (18 Trusts), to 84% of PCTs (16 Trusts).

When asked to provide evidence for the inclusivity of appraisal procedures and personal development plans, 12 Trusts (15% of responders) said that they had a policy in place to ensure this and eight Trusts (10%) stated that appraisals were designed to be individual. 14 Trusts (17%) said that some form of reasonable adjustment was in place, including modified appraisals or personal development plans. Seven Trusts who did not respond to this question stated that the information needed to answer it was not available or not collected.

Kettering General Hospital NHS Foundation Trust plan to provide access to printed information using Easy Read pictures and symbols to prepare individuals for their appraisal. Where appropriate, staff can be supported by an advocate at their appraisal.

Employment- Summary and appraisal of evidence

- The employment section had a high non-response rate, with 24 Trusts (20% of survey responders) failing to answer the employment questions on training and 38 (32%) not answering the question about appraisal and development plans

- Where evidence was provided, there was evidence of good practice in the form of supported employment schemes and individual case studies of how individuals with learning disabilities had been supported
- Of those who responded, reasonable adjustments in terms of the employment of people with learning disabilities included general HR recruitment procedures (22%), specific supported employment schemes (15%) or being signed up to the 'two ticks' scheme (15%), with a minority of Trusts giving examples of people with learning disabilities doing voluntary work (13%) or paid work (12%) in the Trust
- Most responding Trusts (93%) reported that their appraisal/PDP procedures were appropriate for employees with learning disabilities, but few could give specific examples of how these procedures had been altered
- A vast majority of Trusts responding to this section (91%) reported that staff training included training on attitudes towards people with learning disabilities, most commonly as part of general equality and diversity training.

Equality Impact Assessments

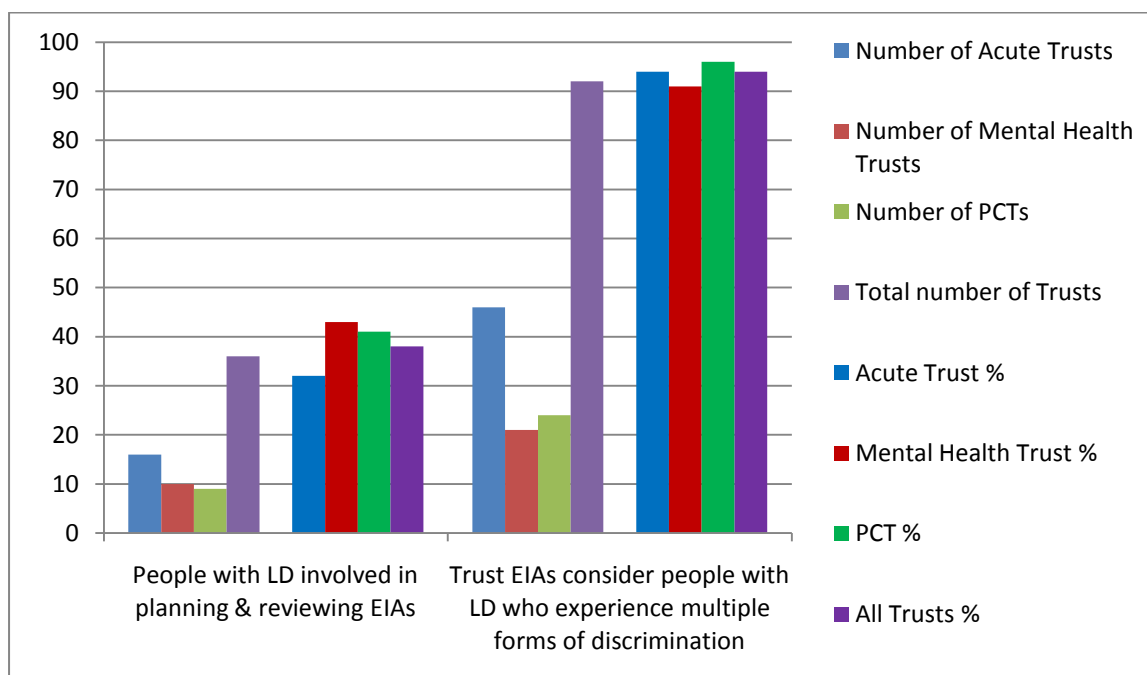
In relation to Equality Impact Assessments (EIAs), Trusts were asked whether people with learning disabilities were involved in planning and reviewing them. Trusts were also asked whether their EIAs considered people with learning disabilities who may experience multiple forms of discrimination, for example those from minority ethnic communities.

Involvement in planning and review of Equality Impact Assessments

Figure 19 shows that 38% of Trust responders (36 Trusts) stated that people with learning disabilities were involved in planning and reviewing EIAs. Rates were fairly similar for each Trust type (see Appendix 8 for full details).

As evidence for this question, 15 Trusts (16% of responders) highlighted the role of internal or external groups, such as advocacy or focus groups. Five Trusts said that people with learning disabilities were not, or not always, involved in planning and reviewing EIAs, and four Trusts said that they needed to increase participation by people with learning disabilities, or that this was something they planned to do in the future.

Figure 19: Equality Impact Assessments (EIAs)



Leeds Partnerships NHS Foundation Trust's Social Inclusion and Diversity Forum provides a platform for all staff, service users and carers, governors, and partner organisations to inform and influence the Trust's approach to inclusion and diversity, to act as critical friends and to monitor progress. Its membership includes a number of people with learning disabilities. The main focus of the quarterly meetings is decided by the membership and a 'live' equality impact assessment (EIA) process is used to enable members to identify areas of potential inequalities, through their knowledge and experience.

Equality Impact Assessments and multiple forms of discrimination

Almost all (94%) of responding Trusts (92 Trusts) stated that their Equality Impact Assessments for people with learning disabilities specifically considered people at risk of experiencing multiple forms of discrimination (see Figure 19).

As part of the evidence for this question, 16 Trusts (16% of responders) said that Equality Impact Assessments covered all groups, including people with learning disabilities. 14 Trusts (14%) stated that EIAs are used to ensure that multiple forms of discrimination can be highlighted. Nine Trusts (9%) gave some form of guidelines or policy as evidence for this question.

NHS Camden has carried out work with local Black and Minority Ethnic (BME) community groups to address perceived needs and access issues for people with learning disabilities. This resulted in a specialist project worker being commissioned from a community group to undertake detailed work with people with learning disabilities from the local Bangladeshi community. This work links with a wider BME Forum hosted by a local voluntary sector umbrella organisation.

Equality Impact Assessments – Summary and appraisal of evidence

- Response rates for this section were relatively low, at 96 responses for the question about the involvement of people with learning disabilities in EIAs and 98 Trusts responding to the question about multiple forms of discrimination. Specific forms of evidence for this section took the form of policy documents, Equality Impact Assessment documents, including EIA guidelines, and descriptions of the operation of groups
- A substantial minority of responding trusts (38%) reported that people with learning disabilities were involved in planning and/or reviewing Trust Equality Impact Assessments
- Almost all responding Trusts (94%) reported that their Equality Impact Assessment considered the potential for multiple forms of discrimination experienced by people with learning disabilities, although few Trusts (9%) provided specific examples of this.

Summary of results from audit of publicly available information

We also carried out an audit of the publicly available information on Trust websites in relation to the reasonable adjustments Trusts carried out for people with learning disabilities. This involved a key word search of a randomly selected sample of 10% of each major Trust type-Acute Trusts, Ambulance Trusts, Care Trusts, Mental Health Trusts and PCTs (the method is described in more detail in the Methodology section above).

Overall findings

The availability of information about reasonable adjustments for people with learning disabilities on Trust websites was variable. Some Trusts provided a comprehensive list of learning disability related information, including archives of accessible documents and with appropriate links to other organisations, whilst for others our searches gave no relevant information. The search did bring up examples where the needs of patients with learning disabilities were considered as part of a general guide to a clinical procedure, although this was not widespread. It is not possible to be specific about the nature of all of the reasonable adjustments found, as this would be highly likely to make individual Trusts identifiable.

It may be that our failure to find information on some Trusts' websites was because the search tools provided failed to locate resources that were actually provided. However, it is also the case that these are the web tools that may be used by people with learning disabilities and their carers, indicating that there may be a lack of appropriately accessible information available.

Acute Trusts

17 Acute Trusts were included in the random sampling process. Of these Trusts, seven (41%) had no results on their websites for reasonable adjustments for patients with learning disabilities. For seven Trusts (41%) their Disability Equality Scheme was returned, but just three (18% of the Trusts sampled) of these documents made any specific mention of reasonable adjustments that had been put in place for people with learning disabilities. A further five Trust websites (29%) returned the Trust's Single Equality Scheme, of which two identified reasonable adjustments for people with learning disabilities.

The other results that specifically highlighted reasonable adjustments for patients with learning disabilities were a Trust Quality Report, and two news stories about the launch of a Hospital Passport and a Trust signing up to Mencap's 'Getting it Right' campaign.

Care Trusts

Two Care Trust websites were selected as part of the audit. Of these, one returned a Disability Equality Scheme document, and one a Single Equality Scheme. Both documents made some reference to specific reasonable adjustments for people with learning disabilities. In addition, one Trust's website linked to a comprehensive website giving information about Joint Learning Disabilities Services in the local area.

Ambulance Trusts

Two Ambulance Trust websites were selected as part of the randomly selected sample but no results were found that specifically related to reasonable adjustments for people with learning disabilities.

Mental Health Trusts

Six Mental Health Trusts were selected as part of the audit. Two Trusts had used their website as a repository of accessible or Easy Read information, which included links to other Easy Read or accessible information. One of these Trusts included videos about the patient experience people were likely to have when they used Trust services. Two Trust Single Equality Schemes and one Disability Equality Scheme were returned in the results, although just one Single Equality Scheme made any specific reference to reasonable adjustments for people with learning disabilities. One Trust had a newsletter that gave information about an awareness campaign within the Trust for Learning Disability Week and advice on how to identify and work with people with learning disabilities. Another Trust indicated that Learning Disabilities Training had become mandatory on undergraduate and postgraduate clinical training courses.

Two Mental Health Trusts indicated that their reasonable adjustments for people with learning disabilities were under development, in relation to the recommendations of the Michael Inquiry and the creation of Easy Read information. For one Mental Health Trust website selected in the audit there was no specific information found about reasonable adjustments for people with learning disabilities.

Primary Care Trusts

Finally, we searched 15 Primary Care Trust (PCT) websites for the audit. Four Disability Equality Scheme documents were returned as part of the PCT audit, but only one of these made mention to specific reasonable adjustments for people with learning disabilities (including health checks). The audit also returned four Single Equality Scheme documents, of which two provided relevant information about reasonable adjustments.

Four PCT websites provided information about health checks, including one website that hosted an Easy Read leaflet giving information about health checks. A further Three Trust websites provided strategy or health information documents in Easy Read.

Other identified information related to reasonable adjustments for people with learning disabilities on Trust websites included details of consultation schemes or events (four PCTs), guides to the Mental Capacity Act or use of Independent Mental Capacity Advocates (two PCTs) and the use of or plans to improve staff training (two PCTs).

For three Primary Care Trust websites we were not able to find any relevant results related to reasonable adjustments for people with learning disabilities.

Limitations of the Survey

As we have mentioned in the introduction, this project was not designed to address all the important questions concerning how health services do or do not make reasonable adjustments for people with learning disabilities, and the impact of these reasonable adjustments. Consequently, there are a number of limitations to the survey.

This survey gives an indication of what three in ten NHS Trusts say they are doing in relation to providing reasonable adjustments for people with learning disabilities and their carers. A 30% response rate is reasonable for a postal survey, but this does mean that this report has not captured the practice of seven in ten NHS Trusts. It is impossible for us to know whether non-responding Trusts would have been more or less likely to report reasonable adjustments for people with learning disabilities compared to the NHS Trusts who did respond.

It was relatively common for Trusts not to answer particular questions, and this may have been because they preferred not to answer 'no' to a particular question. We decided to present data based on actual responses so as not to second guess Trust responses, and where non-responses were particularly high these have been highlighted in the report.

The difference between commissioning and provider NHS Trust functions was an issue for many PCTs who considered that some aspects of the survey were not appropriate for their operations as commissioners. There was also some confusion around whether PCTs were supposed to answer on behalf of the providers they funded. This links in to a further potential limitation of the survey, that as it was sent to individual providers it perhaps did not fully capture the funding, organisational and service links between NHS Trusts and how these can be best organised to ensure comprehensive and ongoing reasonable adjustments.

The focus on practice by NHS Trusts was an integral part of this research, but meant that information was not fully captured about other aspects of NHS provision for people with learning disabilities, such as partnerships with local authorities, GPs, dentistry and some other primary care services.

Due to the limited amount of time which the Learning Disabilities Observatory had to plan, deliver and analyse the NHS Trust survey, the consultation time was limited to three working weeks. Many Trusts found this timescale difficult to meet, although the IHAL team were as flexible as possible where Trusts had difficulties in meeting this deadline. It also seemed that surveys sent to Chief Executives did not always find their way to 'the right person' in the organisation; potentially an indirect indicator of the visibility of reasonable adjustments for people with learning disabilities at senior levels within the Trust. However, several Trusts commented anecdotally that completing the NHS survey had been a useful exercise and had helped them to improve their own practice.

Conclusions

This project has helped to identify many examples of reasonable adjustments that NHS Trusts state they provide for people with learning disabilities, and show some encouraging signs of innovation in the provision of reasonable adjustments within health services in England. There were examples of good practice in reasonable adjustments provided by some Trusts in all the areas we asked about in the survey; these examples will be made publicly available through the IHaL online searchable database in spring 2011.

Trusts most commonly reported making reasonable adjustments in terms of accessible information, with a substantial majority of responding Trusts providing Easy Read information for people with learning disabilities and reporting the use of Health Passports and/or Health Action Plans. It seems clear that this is often a first step for NHS Trusts in thinking about making reasonable adjustments for people with learning disabilities. However, we were not clear that this 'accessible' information was always specifically designed for people with learning disabilities, comprehensible to the people for whom it was intended, and proactively delivered to people with learning disabilities who become patients within the Trust. Many Trusts reported that information was available 'on request' or on Trust intranet sites, which do not seem optimal strategies for routinely ensuring access to such information.


Similar issues were apparent in Trusts' responses concerning support for carers, with accessible information for carers being commonly mentioned but robust evidence being more sparsely reported.

There were several other areas of reasonable adjustment where a vast majority of Trusts reported that they had reasonable adjustments in place, including: policies concerning mental capacity, staff training concerning communicating effectively with people with learning disabilities (including supporting non-verbal patients), having Trust patients with learning disabilities who have made use of an IMCA, using Health Passports and Health Action Plans, having staff training that addresses attitudes towards staff with learning disabilities, using information from people with learning disabilities in Trust planning and development, considering the views of people with learning disabilities and carers at Trust Board level, and having Equality Impact Assessments that considered multiple forms of discrimination for people with learning disabilities.

However, far fewer Trusts provided robust evidence to support their statements in these areas, and the extent to which these policies and procedures specifically addressed the needs of people with learning disabilities and family carers was sometimes unclear.

Areas of reasonable adjustments relating to the actual face-to-face treatment of people with learning disabilities and carers were only reported by a minority of Trusts, including support for carers (beyond providing accessible information), and all stages of the patient journey, from first contact through diagnosis to clinical intervention and discharge/follow-up.

The most common solution for Trusts concerning face-to-face contact with patients with learning disabilities and carers was to rely on staff with specialist learning disability training, skills or roles to act as liaison between the person with learning disabilities, the carer, the various parts of the Trust



and other learning disabilities services involved in the support of the individual. Many Trusts relied heavily on staff in Community Learning Disability Teams to perform these liaison and partnership working activities. It was often unclear whether such specialist support included a strategic role to enable Trusts to change their routine systems and procedures to become accessible for patients with learning disabilities, or whether such specialist support was solely concerned with working with individual patients with learning disabilities, leaving the Trust with ‘unadjusted’ routine systems and procedures. It was also sometimes unclear whether these specialist roles were seen as core to the effective functioning of the Trust, or as potentially vulnerable in times of resource constraint. There is also a question about how to make reasonable adjustments routine to Trust practice while at the same time ensuring they are personalised to the specific needs of individuals – this routine person-centredness may be a particular challenge to the standard operating procedures of many Trusts.

Finally, it was clear that only a minority of responding Trusts could provide us with specific information about people with learning disabilities using the Trust, for example in terms of the number of patients with learning disabilities who had used the Trust’s services or the number of patients with learning disabilities using IMCAs or accessing ICAS.

The results of this survey may seem to confirm the view of the Michael Inquiry that “There is a clear legal framework for the provision of equal treatment for people with disabilities and yet it seems clear that ... services are not yet being provided to an adequate standard” (Michael, 2008, p. 55). However, the findings of this survey also make clear that some forms of reasonable adjustment are being widely adopted in some Trusts, that work is underway to develop further provision, and that in all of the identified areas of reasonable adjustments there are some Trusts that have developed innovative, effective and low cost reasonable adjustments that have the potential to radically improve the experience of patients with learning disabilities and their carers.

These examples of good practice will be included in the forthcoming IHAL reasonable adjustments database, and some have been outlined in this report. A forthcoming IHAL report will also highlight the key guidance for commissioners that emerge from the results of this report. These should be a valuable addition to mechanisms of sharing good practice for NHS Trusts.

Potential developments of the work

Finally, there are several potential developments of the Reasonable Adjustments in the NHS project that would be useful to consider:

- How well reasonable adjustments in health services are working in terms of the experience of people with learning disabilities and their families.
- Whether they are equally effective for groups of people with learning disabilities known to be more likely to have a poor experience of health services, particularly those with complex needs, or from Black and minority ethnic communities.
- The extent and operation of good practice in reasonable adjustments within GP practices³.
- Their extent and operation in voluntary and private sector specialist services for people with learning disabilities.
- The extent and operation of good practice in reasonable adjustments within dental services.
- How progress in making effective reasonable adjustments for people with learning disabilities can be sustained in the context of exceptional resource constraints and at a time of major organisational change in health services.
- How to effectively encourage the spread of good practice throughout health services such that effective reasonable become routine for people with learning disabilities and their families.
- How referrals and clinical decision-making concerning clinical interventions with people with learning disabilities are made by health professionals.

³ Dr Umesh Chauhan at the University of Manchester is currently researching the operation and impact of health checks for people with learning disabilities within GP practices.

References

1. Disability Discrimination Act (1995). London: HM Government.
2. Disability Discrimination Act (2005). London: HM Government.
3. Equality Act (2010). London: HM Government.
4. Equality and Human Rights Commission (2010a). Equality Act 2010 guidance for English public bodies (and non-devolved bodies in Scotland and Wales). Volume 1: The essential guide to the public sector equality duty. Manchester: EHRC.
5. Equality and Human Rights Commission (2010b). Equality Act 2010 guidance for English public bodies (and non-devolved bodies in Scotland and Wales). Volume 5: Your rights to equality from healthcare and social care services. Manchester: EHRC.
6. Government Equalities Office (2010). Equality Act 2010: What do I need to know? A summary guide for public sector organisations. London: HM Government.
7. Emerson, E. & Baines, S. (2010). Health inequalities and people with learning disabilities in the UK: 2010. Lancaster: Improving Health and Lives Learning Disabilities Observatory.
8. Disability Rights Commission (2006). Equal Treatment: Closing the Gap. A formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems. Manchester: Disability Rights Commission.
9. Healthcare Commission (2007). A life like no other: A national audit of specialist inpatient healthcare services for people with learning disabilities in England. London: Healthcare Commission.
10. Mencap (2007). Death by Indifference. London: Mencap.
11. Parliamentary and Health Service Ombudsman and Local Government Ombudsman (2009). Six lives: the provision of public services to people with learning disabilities. London: The Stationery Office.
12. Michael, J. (2008). Healthcare for All: Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities. London: Department of Health.
13. Department of Health (2009). Valuing People Now: a new three-year strategy for people with learning disabilities. London: Department of Health.
14. Department of Health (2010). Six Lives Progress Report. London: Department of Health.
15. Robertson, J., Roberts, H. & Emerson, E. (2010). Health Checks for People with Learning Disabilities: A Systematic Review of Evidence. Lancaster: Improving Health & Lives Learning Disabilities Observatory.
16. Emerson, E. & Glover, G. (2010). Health Checks for People with Learning Disabilities: 2008/9 and 2009/10. Lancaster: Improving Health and Lives Learning Disabilities Observatory.
17. Mencap (2010). Getting it right: A campaign guide. London: Mencap.
18. Giraud-Saunders, A. (2009). Equal access? A practical guide for the NHS: Creating a Single Equality Scheme that includes improving access for people with learning disabilities. London: Dept of Health.