



Public Health
England

Protecting and improving the nation's health

Pharmacy and people with learning disabilities: making reasonable adjustments to services

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. We do this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. We are an executive agency of the Department of Health, and are a distinct delivery organisation with operational autonomy to advise and support government, local authorities and the NHS in a professionally independent manner.

About the Public Health England Learning Disabilities Observatory

The Public Health England Learning Disabilities Observatory (PHELDO) was set up in April 2010 to provide high quality data and information about the health and healthcare of people with learning disabilities. We are also known as Improving Health and Lives (IHaL). This name was suggested for the Observatory at a consultation with self-advocates organised for the Department of Health by Mencap. The information helps commissioners and providers of health and social care to understand the needs of people with learning disabilities, their families and carers, and, ultimately, to deliver better healthcare. PHELDO is a collaboration between PHE, the Centre for Disability Research at Lancaster University and the National Development Team for Inclusion. Since April 2013, the Observatory has been operated by PHE.

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Easy-read summary



Lots of people get medicines from pharmacists. Pharmacists are sometimes called chemists. The pharmacist is one of the people who works behind the counter in a pharmacy.

Most pharmacists work in shops and in hospitals. Some work in local doctors' surgeries.



A pharmacist is the person who can get you the medicines your doctor says you should take.

They can tell you about medicines to buy too.



Pharmacists need to know how to talk with people with learning disabilities and families. They will ask questions so they know how to help.

You can ask questions too. You can ask to talk in private.



Pharmacists need up-to-date information from your own doctor or hospital doctor about changes to your health or your medicines.



It is a good idea to show the pharmacist your health action plan or hospital passport. You can ask your doctor to share information with the pharmacist.



You can ask your pharmacist about ways to stay healthy.



You can ask your pharmacist about your medicines.

You can get help to remember when to take medicines and how to take them.



You can ask the pharmacist to check all the medicines you are taking.



The law says public services should put 'reasonable adjustments' in place to help people with learning disabilities use services.

Reasonable adjustments are changes to services so they are easier to use.

This report has examples of easy-read information. They can help people with learning disabilities use pharmacy services.

This report has examples of reasonable adjustments in local services so that people with learning disabilities find pharmacy services easier to use.

Pharmacy teams and learning disability teams should work together. This will help people with learning disabilities to get the support they need.

The pictures in this report are from Photosymbols: www.photosymbols.co.uk

Foreword

Pharmacy teams in community, primary care and acute hospital settings see many people with learning disabilities. You may not have attached that label to an individual, but you know that you need to use easy words and short sentences for this person, or take longer to show another person how to take their medicine. You will know the people who have complex repeat prescriptions – or you will recognise the family member or support worker who hurries in to collect medicines.

There are about a million people with learning disabilities in England. This diverse group have both poorer health than others and worse access to healthcare. Only about one in four people with learning disabilities are identified as such in their GP practice registers.

Pharmacists' skills – listening, explaining, advising, questioning – are highly relevant to the needs of people with learning disabilities. Many people living independently or with just a little support will benefit from advice about healthy lifestyles and remedies for common health problems. Some people take a variety of prescribed medicines; keeping these under review and advising on ways of remembering what to take (and when and how) can be very helpful. A small percentage of this population have more complex and significant physical and/or mental health problems that demand close multidisciplinary collaboration.

Improving health and wellbeing and helping to reduce health inequalities are major priorities for pharmacy. This guide offers practical suggestions and examples to support pharmacists and their teams in making reasonable adjustments to their practice. It is a very useful tool that complements the CPPE e-learning materials.² The guide also aims to inform people with learning disabilities, family carers and support staff about getting the best from their pharmacy teams. The common 'high impact' theme from both perspectives is around communication:

- for pharmacy teams to feel confident about engaging with people with learning disabilities, family carers and support staff
- for people with learning disabilities and their supporters to see pharmacy teams as people they can talk to about medicines and other health matters



Robbie Turner
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Introduction

This guide is for staff working in either pharmacy teams or learning disability teams and for anyone who supports people with learning disabilities. It summarises what the research tells us about the needs of this diverse group of people in relation to pharmacy services and what are the best approaches to use when working with them.

The focus of the guide is on pharmacy in community, primary care and acute hospital settings rather than on pharmacy in services specifically for people with learning disabilities or in mental health services. There is a programme led by NHS England, supported by the Royal Pharmaceutical Society and other professional bodies, that aims to reduce inappropriate use of psychotropic drugs for people with learning disabilities (see <https://www.england.nhs.uk/2016/06/over-medication-pledge/>) and this guide will avoid duplication.

This report is the fourteenth in a series of reports looking at reasonable adjustments in a specific service area (see Appendix A). The aim of these reports is to share information, ideas and good practice in relation to the provision of reasonable adjustments.

We searched for policy and guidelines that relate to people with learning disabilities and pharmacy services. A summary of this information is below. We looked at websites to find resources that might be of use. There is a brief description of these and information about how to obtain them in the resource tables.

We put a request out for examples through the UK Health and Learning Disability Network, a major email network for people interested in services and care for people with learning disabilities. This request was also circulated through Royal Pharmaceutical Society and PHE networks. We asked people to send us information about what they have done to improve pharmacy services for people with learning disabilities. We were sent some examples of resources and good practice case studies. Examples that have proved useful are given at the end of the report.

What we mean by learning disabilities

A person with learning disabilities will have:

- a significantly reduced ability to understand new or complex information and to learn new skills (impaired intelligence)
- a reduced ability to cope independently (impaired social functioning)
- which started before adulthood, with a lasting effect on development

This does not include conditions like dyslexia, which cause a specific difficulty with one type of skill but not a wider intellectual impairment.

We estimate that 1,087,100 people with learning disabilities, including 930,400 adults, were living in England in 2015. The number of people with learning disabilities recorded in health and welfare systems is much lower; for example, GPs identified 252,446 children and adults as having learning disabilities on their practice-based registers.¹ Those on the registers are likely to be people with more significant learning disabilities.

What we mean by reasonable adjustments

Under the Equality Act 2010ⁱ public sector organisations have to make changes in their approach or provision to ensure that services are accessible to disabled people as well as everybody else. Reasonable adjustments can mean alterations to buildings by providing lifts, wide doors, ramps and tactile signage, but may also mean changes to policies, procedures and staff training to ensure that services work equally well for people with learning disabilities. For example, people with learning disabilities may require clear, simple and possibly repeated explanations of what is happening, and of treatments to be followed, help with appointments and help with managing issues of consent in line with the Mental Capacity Act. Public sector organisations should not simply wait and respond to difficulties as they emerge: the duty on them is ‘anticipatory’, meaning they have to think out what is likely to be needed in advance.

All organisations that provide NHS or adult social care must follow the accessible information standardⁱⁱ by law. The standard aims to make sure that people who have a disability, impairment or sensory loss are provided with information that they can easily read or understand with support so they can communicate effectively with health and social care services.

PHELDO has a database of examples of reasonable adjustments made by health services

(<http://webarchive.nationalarchives.gov.uk/20160704150527/http://www.improvinghealthandlives.org.uk/adjustments/>)

ⁱ www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga_20100015_en.pdf

ⁱⁱ <https://www.england.nhs.uk/wp-content/uploads/2015/07/access-info-spec-fin.pdf>

Pharmacy and people with learning disabilities

The Centre for Pharmacy Postgraduate Education (CPPE) published distance learning materials² for pharmacy professionals in mainstream settings to support active engagement with people with learning disabilities and their carers. The aim is to ensure that pharmacy teams are able to support the health needs of people with learning disabilities and optimise their use of medicines. Pharmacists will find more detail in those materials; what follows is aimed at a mixed audience. Some sections will be of more interest to pharmacy teams and some to readers who support people with learning disabilities.

What you might notice if someone has learning disabilities

Like the rest of the population, people with learning disabilities come in all shapes and sizes. Some people look a little different (for example, a member of the pharmacy team might notice a person with Down syndrome); lots of people do not. The CPPE e-learning materials² suggest using pharmacy consultation skills with everyone to listen, observe and check the person's understanding. It will usually be relatively easy to identify someone with more significant learning disabilities (and information may well be passed on by the GP, family carers or support staff). Pharmacy teams need to be alert to the larger number of people with mild learning disabilities, who may still need some support. A team member might notice someone who has difficulty with:

- reading and/or writing and forms
- explaining symptoms or a sequence of events
- understanding new information or taking information in quickly
- remembering basic information such as date of birth, address, health problems
- managing money
- understanding and telling time

Noticing pointers such as these could prompt a conversation with the person to ask more questions about any communication or support needs, and also to check understanding and recollection of information.

Understanding the roles of pharmacy

In order to get the best from pharmacy services it is important for people with learning disabilities, family carers, support staff and learning disability community teams to understand the roles that pharmacy can play. About 70% of pharmacists work in community pharmacies, with teams that include pharmacy technicians and counter staff. Some pharmacists work as part of the team in GP surgeries and in care homes, and

around 20% work in hospitals (see <https://www.ilovemypharmacist.co.uk/what-do-pharmacists-do/>).

Hospital pharmacists work as part of the multidisciplinary team, managing caseloads of patients, providing treatment programmes and helping patients to manage their care (particularly in relation to managing medicines).

Pharmacy in community settings has changed considerably in the 21st century. The 2008 white paper 'Pharmacy in England' set out a vision for pharmacies as community hubs for leading healthier lives. The public would be able to get their medicines optimised and supplied, and also receive some public health services and a wide range of advice on health issues. Progress against this agenda was described in a 2016 report,³ which noted the development of proactive outreach from many pharmacies through schools, workplaces and community centres. Examples included promoting healthy lifestyles and providing a range of public health services, such as smoking cessation support, flu vaccination and NHS health checks. Some pharmacies focused on healthy living, employing health champions as part of the team.

Despite these developments, a survey in March 2016 (described in the same report) showed that many members of the public still thought of pharmacy as just to do with dispensing prescriptions, in a high street pharmacy or general hospital. The survey also showed that members of the public were unsure about the capabilities and capacity of community pharmacy to provide more health advice or health care.

People with certain health problems (such as asthma or diabetes) who are prescribed a medicine for the first time may be able to get extra help and advice from the pharmacist through a free scheme called the 'new medicine service' (<http://www.nhs.uk/NHSEngland/AboutNHSservices/pharmacists/Pages/medicine-service-qa.aspx>). The pharmacist can offer initial information and advice and will then offer two appointments during the first month to check progress and help to resolve any problems.

An easy read leaflet produced as part of the 'Making time' pharmacy project in West Yorkshire (see <https://easyonthei.worldsecuresystems.com/get-checked-out-making-time-pharmacy>) listed a range of ways that pharmacy teams can help people with learning disabilities:

- tell you how to be healthy
- tell you about other services that can help
- tell you how to look after yourself better
- help you to make the best of the medicine you take
- learn about your medicine
- ask questions about your medicine
- make your medicine work better

Core 'essential' and 'advanced' services are commissioned by NHS England (see <http://psnc.org.uk/contract-it/the-pharmacy-contract/>); extra services may also be commissioned by NHS England, clinical commissioning groups and local authorities. For example, in some areas public health have contractual arrangements to run regular public health campaigns jointly with community pharmacies. An independent review of community pharmacy clinical services commissioned by NHS England's Chief Pharmaceutical Officer in 2016⁴ recommended further development of clinical pharmacy as part of an integrated system of public health and NHS services (including greater digital interconnectivity). Alongside this the Department of Health announced a new community pharmacy contractual framework and NHS England introduced a fund to support the development of clinical pharmacy practice in a wider range of primary care settings, including embedding clinical pharmacists in GP surgeries. A new commissioning framework focused on healthy living is aimed at improving the health and wellbeing of the local population and helping to reduce health inequalities through community pharmacies (see <http://psnc.org.uk/services-commissioning/locally-commissioned-services/healthy-living-pharmacies/>).

Health of people with learning disabilities

Just as people with learning disabilities and those supporting them need to understand what pharmacy can offer, pharmacy teams need to be aware of the common health problems experienced by people with learning disabilities and the factors that can cause problems with access to health information and health care. PHELD0 publishes regular reports^{1,5} on the data that is available on people with learning disabilities in England, including numbers of people, what types of support people get, health inequalities and uptake of health care. In summary, people with learning disabilities:

- make up about 2% of the population; as noted in the introduction, only around a quarter are identified in GP learning disability registers and/or are known to specialist learning disability services
- are likely to be at risk from the determinants of health inequalities even if they have mild learning disabilities, yet they may not have access to support
- live with family, friends or on their own (the majority); in addition in 2015/16 about 34,000 lived in residential homes and another 30,000 in accommodation with some degree of support (this may be very limited)⁶ – thus only about 6% of adults with learning disabilities live in residential care or supported living
- are at increased risk, compared to the general population, of a variety of health problems;ⁱⁱⁱ people often have several co-existing conditions and some people have behaviour that challenges (which may or may not be linked to an identifiable health problem)

ⁱⁱⁱ Common health problems include: obesity, diabetes, epilepsy, sensory impairments, sleep disorders, mental ill health, thyroid problems, dysphagia, asthma, gastro-intestinal problems, poor oral health, dementia, chronic pain and heart failure⁵

- are at increased risk of early avoidable mortality⁷
- often have limited access to health information; access to health care can be compromised by communication difficulties, low expectations, lack of support, poor understanding of mental capacity and lack of reasonable adjustments by health services
- very often rely on others (such as family carers^{iv} or support workers) for help with access to health care; access can be poor if those people are not well informed themselves or there is high turnover of workers
- aged 14 or over who are on their GPs' learning disability registers are entitled to an annual health check and health action plan;⁸ in 2014/15 just under 50% of those on registers had a health check
- may not make connections between the development of signs or symptoms (such as putting on weight or developing nervous disorders) and medications they are taking
- are commonly prescribed multiple medications for both physical and mental health conditions, often for long periods

A 2016 study by NHS Digital with PHE⁷ provided detailed data from almost half of all GP practices in England on the health of people with learning disabilities and their use of health services. The report confirmed differences, as outlined above, in the treatment, health status and outcomes of people with learning disabilities compared to the rest of the population.

Family carers are often the people who hold detailed knowledge about a person's health, how this affects the person's life (and the rest of the household), successful ways of communicating with and supporting the person and what the person will or will not accept. Some support workers also build up such knowledge of an individual, but high turnover of staff and limited support hours mean that this is not always the case. Community learning disability teams (including health professionals and social workers) often have good knowledge about the health and lives of the people with learning disabilities who are known to them. However, many people with learning disabilities are not known to specialist services. People with learning disabilities who attend hospital appointments regularly may have a 'hospital passport' that captures vital information about them and their needs and preferences (see <http://webarchive.nationalarchives.gov.uk/20160704150527/http://www.improvinghealthandlives.org.uk/gsf.php5?f=313856&fv=21547>)

^{iv} In this report we use the term 'family carers' to mean family members (or close friends) and 'staff' or 'support workers' to mean people who are paid to provide support. Support workers do not usually have any professional qualifications

Summary care records

The NHS in England is using an electronic record called the summary care record (SCR) to improve the safety and quality of patient care. The SCR is a copy of key information from GP records. It provides authorised care professionals with fast, secure access to essential information about people when they need care. The record contains important information about:

- allergies and adverse reactions
- acute medications
- repeat medications
- repeat medications that have recently been stopped

With the person's consent (or a best interests decision for a person who lacks capacity to consent) it is possible to add information, such as:

- details of a learning disability
- details of associated physical and sensory disabilities
- communication needs
- contact details for family carers
- details of the annual health check results or health action plan
- support workers and care services involved
- details of anyone with relevant decision-making powers (for example, a deputy or attorney for health and welfare)

There is clearly potential to improve the sharing of information that will enable services to make reasonable adjustments. People with learning disabilities and those who support them should ask about SCRs and how to add the information they think is important. By December 2016 50% of community pharmacies were using the SCR, according to NHS Digital (see <http://content.digital.nhs.uk/article/7546/Summary-Care-Record-now-used-in-50-of-community-pharmacies>). More information about SCRs is given in the section on resources.

Pharmacy services and people with learning disabilities

Work has been done both nationally and by local teams in a number of areas to find out about the experiences of people with learning disabilities (and their supporters) using pharmacy services, and the experiences of pharmacy teams in contact with people with learning disabilities. Some common themes recur and these are described below.

Understanding medicines

People with learning disabilities often want more help to understand medicines – what they are for, how they are supposed to help, how to take them and any side-effects. A 2004 study⁹ showed that few of the people with learning disabilities interviewed were

clear about the medicines prescribed for them; some had a general idea about the purpose and that the prescriber concerned had said the medicine was 'safe', but there was heavy reliance on other people to ensure that medicines were taken in the correct dose and at the right times. Not everyone did want more information, but it was unclear whether truly informed consent had been given. Similar concerns were reported by the National Patient Safety Agency in 2004,¹⁰ with a focus on the adverse consequences of inadequate information. Examples were given of people taking the wrong tablets or the wrong dose, or missing their medication. A focus group held in 2015¹¹ reported that most participants did not fully understand why they were taking medicines and they did not know they could ask a pharmacist for more information. A survey of people with learning disabilities in Lancashire in 2016¹² found that most respondents had received no information from the pharmacy. Those who had received information said it was about dosage and when to take their medicines. Most had struggled to read leaflets or to remember verbal information.

People with learning disabilities usually need more time to take in and process information, and need information in different formats (such as practical demonstration, easy read leaflets using pictures and simple words, or video clips). Participants in a 2016 Disability Alliance project¹³ described written information as "*too small, too wordy, too complex*", while those in the 2004 research cited above⁹ had only been given verbal information and did not remember it. Instructions (for example about timing, taking a medicine with or without food) and contraindications need to be communicated in ways that the individual can understand and retain. People with learning disabilities may need very clear information about any over the counter remedies they should avoid and whether they should avoid drinking alcohol. The benefits of making reasonable adjustments to support self management have been described in a number of individual case studies (for example, work to help one man understand his diabetes and its management¹⁴).

One of the common adjustments offered is supply of medication in multi-compartment compliance aids (sometimes referred to as dosette boxes). These can be useful, but also carry certain risks.² For example, medicines may not be as well protected from the environment or from interacting with each other, compared to keeping them in the original packaging, and the aids cannot accommodate all the necessary information (such as dosing or side-effects). There are other approaches, such as calendar charts, some of which are described in the case studies and resources referenced in this guide. It is important to choose the most suitable approach for each individual.

Involving family carers and support staff

As noted above, many people with learning disabilities rely on support from family members or staff for information about health, for access to health care and for support with medication. It is therefore important that "*supporters of people with intellectual*

*disabilities [are] knowledgeable and well equipped to effectively help them coordinate, manage and proactively address their health needs".*¹⁴ Yet family carers and staff may not be given adequate information about prescribed medicines (including side effects to watch out for and over the counter remedies to avoid).⁹ Those whose first language is not English or who struggle themselves with literacy also need information that is very easy to understand. Family carers and staff may not know that a pharmacist would value the information they hold about the person.

The Confidential Inquiry into premature deaths of people with learning disabilities¹⁵ identified a number of frequently reported problems with medication, including:

- the person not taking or not being given prescribed medicines, or not being given the correct dose
- medicine being prescribed in a form the person could not take (due to swallowing difficulties) and family carers or staff devising unsafe solutions
- lack of monitoring for side-effects or unreliable monitoring

A number of these examples demonstrated lack of adequate communication with family carers or staff.

Some pharmacies will print out medication administration record (MAR) sheets for residential care homes. As noted earlier the vast majority of people with learning disabilities do not live in residential care; where printed MAR sheets are offered there should be a consistent approach for people who get support in other ways with taking their medication (for example, from visiting support workers).

The Disability Alliance project¹³ found that families often do not know that they can ask a pharmacist for advice and information. Family carers may also have very little time or energy¹⁶ and can benefit from a proactive offer.

Co-ordinating advice and treatment

People with learning disabilities are sometimes prescribed treatments from different sources that may not be well co-ordinated (for example, from several different hospital departments as well as primary care). Clinic and discharge letters can take time to arrive. It is important for pharmacists to know promptly about any changes in prescription, as there may be unforeseen interactions. The summary care record has considerable potential to improve communication; for this to be effective the GP surgery need to add new medicines promptly and remove old ones. There may still be a delay in new information being available to a pharmacy (for example, if a prescription has been changed during a hospital visit and there is delay in notifying the surgery). Hospital pharmacists dispensing medicines for a person to take home may not be fully aware of new or changed prescriptions from other sources. Pharmacists may also be unaware of any over the counter remedies the person is taking, unless they ask the person and/or

family carers and staff. Tools such as 'My medication passport' can help to improve communication about all the medicines an individual is taking.¹⁷

People with learning disabilities do not always take (or may not be given) prescribed medicines, or may not be following the right timings or methods of taking medicines; the results can be very serious.^{10,15} For example, staff supporting a person with swallowing difficulties might crush a tablet, not knowing that that could be dangerous. A person's medicines may be collected by a family member or staff, so the pharmacist may not see the person and notice potential difficulties. Information from the summary care record may help to alert the pharmacist to the questions that should be asked.

Stopping the overmedication of people with a learning disability, autism or both

Research undertaken by Public Health England and others in 2015^v showed that at any time between 30,000 and 35,000 people with learning disabilities are prescribed an antipsychotic, an antidepressant or both by their GP without having the conditions that the medicines were designed to treat. This is about one in every six people known to their GP as having a learning disability. As well as these medicines, concerns were also raised about overmedication with other psychotropics such as mood stabilisers, benzodiazepine, sedatives and stimulants.

Out of the research came the launch of the NHS England STOMP campaign ("Stopping the overmedication of people with a learning disability, autism or both"). If people with learning disabilities (or their families or staff) are concerned that too many medicines are being prescribed, they are advised not to stop the medicines but to seek advice from a pharmacist. Pharmacists are ideally qualified to discuss any concerns with the prescriber.

As a part of the learning disability annual health check GPs are being asked to review more closely the purpose of the medicines prescribed to ensure that only those medicines that are clearly beneficial continue.

Understanding the person and their circumstances

Pharmacists need a clear picture of a person's health problems, lifestyle and circumstances in order to be able to give helpful advice and information or to raise questions about prescribed medicines. This should include the support that is or is not available to the person with learning disabilities: as noted above, it should not be assumed that an individual will have 24 hour support, nor that any support available is

v

<http://webarchive.nationalarchives.gov.uk/20160704150527/http://www.improvinghealthandlives.org.uk/gsf.php5?f=313881&fv=21599>

from staff with health qualifications. A summary care record should contain the most important medical information, but will not necessarily include much about the person's wider lifestyle. The person themselves and their family or support workers will often be the best source of such information. Some people will be able to show pharmacists their health action plans or hospital passports, with 'My medication passport' if they are using that tool.

Events run for people with learning disabilities by the Safer Communities Partnership in one area found that many people were confused about whether they could drink alcohol with the medication they were taking. This issue has also been raised in research;^{18,19} there is potential for people to mix prescribed medicines with the consumption of alcohol or use of recreational drugs. Examples were also given of people with learning disabilities stopping taking prescription drugs if they wanted to drink alcohol. This highlights the need for prescribers and pharmacists to ask questions about lifestyle and to give clear information about what needs to be avoided and what can happen if a person stops taking a prescribed drug.

Pharmacists also need to understand the interactions there may be between the needs of the person and those of others in the household, such as family carers. For example, an individual might not be concerned about their sleep patterns, but disturbed sleep might be having a very serious impact on the rest of the family (or other people in a shared house) and the ability of family carers to continue providing support.

Pharmacy teams sometimes need support to improve their confidence in communicating with a person with learning disabilities, understanding mental capacity and making reasonable adjustments. In some areas pharmacies have been offered advice and training by local groups of people with learning disabilities, or by an acute liaison nurse in hospital. The CPPE distance learning materials² cover communication and consultation skills thoroughly.

What do we know about what works?

As noted in the introduction, this guide does not cover the issues relating to prescription of psychotropic drugs (see <https://www.england.nhs.uk/2016/06/over-medication-pledge/>).

There is limited research evidence about access to pharmacy services by people with learning disabilities. However, the literature does identify some approaches and strategies that may be helpful.

For pharmacy teams:

- use the CPPE distance learning materials² and advice on consultation skills¹¹ to enhance the team's skills and confidence around communicating with people with learning disabilities and assessing mental capacity
- use the same materials and also advice on the family carer's perspective¹⁶ to enhance the team's skills and confidence around working with family members and support workers
- sign up to use the summary care record and encourage people with learning disabilities, family carers and support staff to ask for important information to be added
- encourage people with learning disabilities to have an annual health check and associated health action plan⁸
- encourage people with learning disabilities or their supporters to ask their GP to review their medication if they appear to be taking overall combinations of medication (particularly mental health medications) that seem inappropriate, or appear to be having important side effects
- help and encourage people with learning disabilities and their carers to recognise side-effects of medications they are taking and to ask if prescriptions can be changed to reduce or eliminate these
- ask people with learning disabilities, or their supporters, to share their health action plans or their hospital passports with the pharmacist
- encourage people to use 'My medication passport' or one of the easy read tools available¹³ to keep track of their medication (both prescribed and over the counter)
- encourage people with learning disabilities and family carers to ask for advice about promoting good health and common health problems as well as advice about medicines; offer accessible information
- use the medicines optimisation materials from the Royal Pharmaceutical Society and CPPE^{20,21} to enhance the management and regular monitoring of medication
- find out how to contact your local community learning disability team if you need extra advice or support about someone who may have learning disabilities
- consider making people with learning disabilities a focus for any local public health campaigns

For people with learning disabilities, families and support staff:

- talk to your pharmacist: you can ask for advice about keeping healthy and you can ask all sorts of questions about medicines
- ask your pharmacist about any side-effects of the medicines you take: ask what you should watch out for and what you should do
- check with the pharmacist that any medicines you buy yourself will be all right to take with any medicines prescribed by your doctor
- if your medicines get changed by your GP or a hospital doctor, ask for a letter you can take to the pharmacist
- use tools like health action plans and 'My medication passport' to keep information about your health and health care up-to-date

- ask for your medicines to be reviewed every year if this has not been done
- ask your GP practice to add important information about you to your summary care record
- ask your pharmacist to look at your summary care record

The common 'high impact' theme from both perspectives is around communication:

- for pharmacy teams to feel confident about engaging with people with learning disabilities, family carers and support staff
- for people with learning disabilities and their supporters to see pharmacy teams as people they can talk to about medicines and a variety of other health matters

Some examples of what works in terms of adaptations to systems and individual approaches are given later in the report.

Resources

The four tables that follow list all the information and resources we have found in relation to pharmacy services.

- Table 1 lists guidance and policy about pharmacy services. The information about general pharmacy policy may be of use to learning disability professionals
- Table 2 lists websites and resources about learning disability that may be of use to pharmacy teams
- Table 3 lists resources about pharmacy and people with learning disabilities for family carers and for staff (both in pharmacy teams and in learning disability services)
- Table 4 lists the easy-read resources we have found. This is where you can find information to use with people with learning disabilities
- Table 5 lists all the relevant free apps we have found about managing medicines. None of these are designed for people with learning disabilities

Some resources may be available from more than one site, but we have only given one link. We have only included resources that are free to download, although some of the websites may also include resources you can buy.

Table 1: Policy and guidance relevant to pharmacy services

Theme	Description	Provider	Link
Summary care records	An overview of the implementation of summary care records, with a specific section on the roll out of summary care records in community pharmacy	NHS Digital	https://digital.nhs.uk/summary-care-records https://digital.nhs.uk/summary-care-record/community-pharmacy
Healthy living pharmacy	A new commissioning framework aimed at improving the health and wellbeing of the local population and helping to reduce health inequalities, through community pharmacies	Pharmaceutical Services Negotiating Committee	http://psnc.org.uk/services-commissioning/locally-commissioned-services/healthy-living-pharmacies/
Building capacity: Realising the	Report on the role of community pharmacy in promoting the	Royal Society for Public Health and Public Health	https://www.rsph.org.uk/our-work/policy/wider-workforce/pharmacies-in-the-

Theme	Description	Provider	Link
potential of community pharmacy assets for improving the public's health	public's health, exploring what makes pharmacy an appropriate location for health promoting interventions, the opportunities and the challenges experienced by pharmacy teams	England	community.html
Managing medicines for adults receiving social care in the community	Guideline NG67 aims to ensure that people receiving social care are supported to take and look after their medicines effectively and safely	National Institute for Health and Care Excellence (NICE)	https://www.nice.org.uk/guidance/ng67

Table 2: Resources about learning disability for pharmacy teams

Theme	Description	Provider	Link
Public health observatory for learning disabilities	This website has information about numbers of people with learning disabilities, their health and health care, and reports on making reasonable adjustments in relation to a range of health problems that are common in people with learning disabilities	Public Health England	https://tinyurl.com/ihalarchive
People with learning disabilities and pharmacy	Distance learning programme for pharmacy teams	Centre for Pharmacy Postgraduate Education	https://www.cppe.ac.uk/programmes/l/learndislc-d-01/
Medicines optimisation and people with learning disabilities	Briefing and article with key messages for pharmacy teams	Royal Pharmaceutical Society and Centre for Pharmacy Postgraduate Education	https://www.cppe.ac.uk/programmes/l/mobrief-p-03/
Communication and consent	Summaries of issues from the perspective of people with learning	General Medical Council	http://www.gmc-uk.org/learningdisabilities/

Theme	Description	Provider	Link
	disabilities and their families, together with resources		
Supporting patients with learning disabilities and their families	Presentations from an event 20.9.16, including case studies and video clips	Specialist Pharmacy Service	https://www.sps.nhs.uk/meetings/supporting-patients-with-a-learning-disability-and-their-carers-what-non-specialists-need-to-know-2/
Resources on a wide range of topics that are relevant to people with learning disabilities	Resources on consultation skills, vulnerable adults, long term conditions	Royal Pharmaceutical Society	www.rpharms.com

Table 3: Resources about pharmacy and people with learning disabilities for family carers and staff in both pharmacy and learning disability services

Theme	Description	Provider	Link
Making reasonable adjustments in pharmacy services	Making time project, which aims to make sure people with learning disabilities get the best service they can from their community pharmacy	NHS Leeds North Clinical Commissioning Group, Community Pharmacy West Yorkshire, Leeds City Council, Leeds and York Partnership NHS Foundation Trust	http://www.cpwy.org/pharmacy-contracts-services/local-services-enhanced-/making-time.shtml
Person-held record of medication	My medication passport: explanation of the document, link to order paper copies, and download app	National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care, Northwest London	http://clahrc-northwestlondon.nihr.ac.uk/resources/mmp
Access to pharmacy services	Project report and resource pack from project that explored issues in accessibility of pharmacy services	Disability Alliance (Mencap, National Autistic Society, Scope and Sense)	https://www.mencap.org.uk/pharmacy-project
Summary care records	Information (including videos) about what summary care records	NHS Choices	http://www.nhs.uk/NHSEngland/thenhs/records/healthrecords/Pages/overview.aspx

Theme	Description	Provider	Link
	are and how to use them		
Summary care records	Presentation showing how including extra information can help; includes an example for a person with learning disabilities	NHS Digital	Scroll to end of this page https://digital.nhs.uk/summary-care-records/additional-information#Resources
Swallowing difficulties and medicines	Website offering advice and information for patients and prescribers	Prof David Wright (funded through an unrestricted educational grant from Rosemont Pharmaceuticals)	http://www.swallowingdifficulties.com/
Preparing for hospital appointment	Medicines information leaflet for people attending hospital – what information to bring, ideas about what to ask	Chelsea and Westminster Hospital NHS Foundation Trust/Specialist Pharmacy Service	Select 'v10 LD leaflet' listed under presentations https://www.sps.nhs.uk/meetings/supporting-patients-with-a-learning-disability-and-their-carers-what-non-specialists-need-to-know-2/
Supporting family carers	Short video showing interaction between a pharmacist and a family carer: "What would be helpful to you right now?" Making a difference in a short consultation	Centre for Pharmacy Postgraduate Education	https://player.vimeo.com/video/150664602

Table 4: Easy-read resources about pharmacy

Please note that the easy-read resources available via the websites listed here are from a variety of sources and some may not have had any input from pharmacy professionals. Some are also quite old, so you may wish to check them yourself (if you are a pharmacist) or show them to a pharmacist before offering them to someone with learning disabilities.

Theme	Description	Provider	Link
Community pharmacy and medicines	Easy-read leaflets about what community pharmacies do, about taking medicines, and about some types of medicines. Developed as part of the 'Making	Easy on the I and Your Health Matters	https://easyonthei.worldsecur.esystems.com/get-checked-out-making-time-pharmacy

Theme	Description	Provider	Link
	time' project		
Pharmacy and help with medicines	Easy-read resources (some in the downloadable resource pack and two near the bottom of the web page) about what pharmacies do, medicines reviews, and how to take medicines	Disability Alliance (Mencap, National Autistic Society, Scope and Sense)	https://www.mencap.org.uk/pharmacy-project
Summary care record	Easy-read leaflet can be downloaded from this page	NHS Digital	https://digital.nhs.uk/summary-care-records/additional-information#Resources
Managing long term pain	Easy-read leaflet that is free to download from this page. Other pain management leaflets are also available: search for 'easyread' in the website search box	Royal College of Nursing	https://www.rcn.org.uk/professional-development/publications/pub-005590
Information about health problems and medicines	Easy-read leaflets developed with a pharmacist – can be requested by telephone	Elfrida Society	https://elfridasociety.wordpress.com/publications/
Information about different health problems and treatments	Large collection of easy-read leaflets that have been developed by a variety of organisations	Easyhealth	http://www.easyhealth.org.uk/
Information about mental health problems and medicines	Easy-read leaflets on a number of mental health problems and a number of different medicines (some written for this website and some based on older work from Birmingham University)	Royal College of Psychiatrists	http://www.rcpsych.ac.uk/healthadvice/problemsdisorders/learningdisabilities.aspx

Table 5: Apps related to managing medicines

There are various free apps for both iPhone and Android to remind people when to take medication. New apps become available all the time, so rather than listing specific

medication reminder apps we offer two links that offer advice on choosing an app. There is advice in the first link about what to consider in relation to such apps.

Theme	Description	Provider	Link
Medication reminder	Advice about medication reminder apps and description of 'Pills on the go' app	Shaw Trust	http://www.livingmadeeasy.org.uk/personal%20care/medication-reminder-apps-p/pills-on-the-go-0110420-3824-information.htm
Medication reminders	Review (2013) of ten medication reminder apps for iPhone. The reviews set out which features are regarded as helpful. Some apps are also available for Android	Capsulepen	http://pillcontainers.com/index.php?route=blog/article&article_id=2
My medication passport	App to support use of 'My medication passport'	National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care, Northwest London	https://www.networks.nhs.uk/nhs-networks/my-medication-passport/my-medication-passport-on-smart-phones

Examples of reasonable adjustments and case studies

Below are some examples of where services have worked to make changes to their systems and pathways or to develop the workforce or resources with the aim of improving outcomes for people with learning disabilities.

Pharmacy-led improvement project

NHS Leeds North Clinical Commissioning Group and Community Pharmacy West Yorkshire led establishment of the 'Making time' project in 2015, in partnership with Leeds City Council and other NHS bodies in the city. Based on consultation with people using learning disability services, the project aims to ensure that people with learning disabilities get the best service they can from their local pharmacies:

"It's about making sure that pharmacy services can offer the kind of person centred service that people with a learning disability really need to stay safe and well."

<http://www.cpwpy.org/pharmacy-contracts-services/local-services-enhanced-/making-time.shtml>

Starting with 24 pharmacies across the south and west of the city, supporting around 200 individuals, the project provided training and resources for pharmacy teams. Each pharmacy has individual rooms for private consultations and signed up to giving people with learning disabilities more time when they visit. This is not about providing new services, but making services already offered by pharmacy (such as medicines use review, signposting and health promotion) more accessible for the patient and easy to understand. Where appropriate, the project also enables community pharmacy to help the family carers and social care staff who support the patient. The approach is expected to help with the identification of new conditions and ensuring that the correct medicines are being dispensed and used in the best possible way.

The project is based on a year of care approach, which is about a proactive process of planning the care and services offered to patients. This includes improved patient involvement and a personalised approach that supports self-management. Contacts are recorded via the PharmOutcomes information system. A one page summary and a longer guide are available to download free from <http://www.cpwpy.org/pharmacy-contracts-services/local-services-enhanced-/making-time.shtml>

Working with Your Health Matters and Easy on the I, the project also developed new easy read literature, to help people with learning disabilities understand what pharmacies can do for them and to learn about their medications and how to take them.

These resources are free to download from

<https://easyonthei.worldsecuresystems.com/get-checked-out-making-time-pharmacy>

The pharmacies involved also had training to become part of the Leeds City Council safe places scheme. This identifies shops and other premises where a disabled person can be sure of being welcomed if they feel unsafe out and about in the city.

The project has already won two national pharmacy awards. The interim evaluation report sets out progress and includes a number of stories illustrating the benefits to individuals: <http://psnc.org.uk/our-news/service-case-study-community-pharmacy-teams-in-leeds-engage-with-patients-with-learning-disabilities/> .

For further information, please contact Community Pharmacy West Yorkshire info@cpwy.org

Training pharmacy students

Opening Doors (formerly People First Norfolk) have been training student nurses at the University of East Anglia (UEA) for nine years and sit on UEA's disability forum. In 2016 they were invited to provide some training for fourth year pharmacy students at UEA, as one of the pharmacy course lecturers realised how much people with learning disabilities rely on a wide range of pharmacy services.

Two people with learning disabilities and different health problems, each with supporters, talked to the students about what they go to pharmacies for and about good and bad experiences. They asked the students to discuss the experiences and what they could have done that might have been different. They showed the students examples of health passports.

The pharmacy students said the session gave them a better understanding of the lives of people with learning disabilities, the barriers to good health and what pharmacists can do. They learned more about the importance of good listening and of accessible information; they asked lots of questions about the kinds of support people get and how to find out about a person's capacity to understand information and make decisions. One of the concerns the students expressed was about seeming patronising.

Opening Doors were asked to repeat the session in 2017, again receiving excellent feedback about the usefulness. Students commented particularly on the insights they gained on communication skills.

Opening Doors had to work with UEA to ensure access for disabled people and to agree fair payment to the experts by experience – and payment to the organisation to help with preparation, support in the session and debriefing afterwards. Opening Doors

wrote an explanation about why this was needed and are willing to share this with other organisations.

For further information, please contact Ian Hubbard at Opening Doors
ianh@openingdoors.org.uk

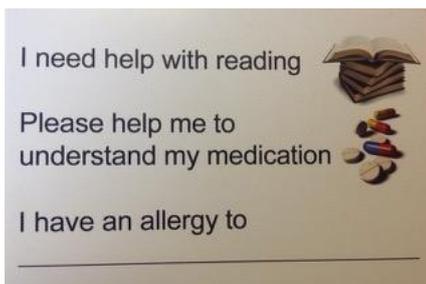
Quality checking pharmacies

The health quality checking team from Greenwich check GP surgeries and pharmacies to make sure that they are giving a good service to people with learning disabilities. They checked eight pharmacies (out of 50) during 2016 and plan to continue until all have been reached. They also offer "I'm a person too" learning disability awareness training, though this has not yet been taken up by pharmacies.

The health quality checkers talked to people with learning disabilities at health forums and citizen forums. Some people said that they found it difficult going to a pharmacy. The team came up with the idea of a pharmacy card as a reasonable adjustment. The aim is to encourage pharmacy staff to help people understand their medicines and how to take them, ensuring that people understand and checking if they have any questions.

Printed on one side is "I have a learning disability and need some help"; there is space to write the patient's name, the GP practice and GP number. The other side is shown in Figure 1.

Figure 1. Reverse side of the Greenwich pharmacy card



The pharmacy card is free and comes in a plastic wallet to keep it safe. Copies were given out to people with learning disabilities at health forum and citizen forum meetings; people say they have been useful.

For further information, please contact the Health Quality Checking Team, Advocacy in Greenwich
healthcheckers@advocacyingreenwich.org.uk

Top tips, training and easy read materials

The learning disability strategic health facilitation team in Derbyshire did a survey of local pharmacists, which showed that they were not aware of easy read resources available and were not routinely offering reasonable adjustments such as medication labels in different formats. The team is working on top tips for pharmacists regarding people with learning disabilities and is planning to offer training. The acute liaison nurse for people with learning disabilities, based at Derby Royal Hospital, has worked with hospital pharmacists to ensure that they are aware of any issues relating to people with learning disabilities attending the hospital.

The nurse consultant (learning disabilities and mental health) at Derbyshire Healthcare NHS Foundation Trust led work to develop a booklet for carers and staff about neuroleptic medication. The purpose of the booklet is to support monitoring of side-effects and their impact on the person, with plans about what to do, as part of the person's health action plan. The team are developing a work sheet to support discussion with an individual about the possible side-effects of different antipsychotic drugs, with the aim of finding out which would be of most concern. This information can be used alongside other factors, such as family history, to inform clinical decisions. Further work is under way on accessible information about different medicines. Straightforward advice on reasonable adjustments and materials such as the booklet described above are available to download

<http://www.derbyshirehealthcareft.nhs.uk/services/learning-disabilities/>

For further information, please contact Jackie Fleeman, strategic health facilitator
Jackie.Fleeman@derbyshcft.nhs.uk

Improving communication in hospital

Chelsea and Westminster Healthcare NHS Foundation Trust embarked on a programme to improve care and treatment for people with learning disabilities. A lead nurse for learning disability was appointed and a flagging system for patients with learning disabilities was embedded into the existing electronic patient record; this allows important information about patients to be recorded and hospital staff can prepare for the next admission. A hospital passport for learning disability has been produced; this contains key information such as likes and dislikes, how to communicate with the person and a small section about medicines. The plan is to add 'My medication passport' to this. A pharmacy student led development of a leaflet for people with learning disabilities and their carers about medicines. Monthly training sessions to improve learning disability awareness are run by the lead nurse for learning disability, with support from care workers from local support groups and patients. The training session is aimed at all clinical and non-clinical staff; pharmacy staff can link this with

their professional development of consultation skills and reflect on ways to improve communication with people with learning disabilities and their carers.

Summarised from a blog by Ibrahim Abbadi <http://www.pharmaceutical-journal.com/opinion/blogs/how-we-are-trying-to-make-hospital-visits-better-for-patients-with-learning-disabilities/20069425.blog>

Training about reasonable adjustments in pharmacies

The healthier lives group, part of Bradford People First, and the strategic health facilitator (SHF) for Bradford District Care Trust received funding from health commissioners to offer education and training to various health professionals, as part of the local plans to improve access to healthcare for people with learning disabilities. The healthier lives group talked to members about their experiences with medication. Discussion with a local pharmacist revealed that pharmacists could offer an annual review of medication to regular customers who were taking two or more medicines. This was a surprise to most of the healthier lives group.

The pharmacists' regular professional development sessions were all booked up, so an evening event was arranged (with refreshments) and advertised via the local community pharmacists' network and within the local hospitals. Posters were also given to local pharmacies.

The hour started with an introduction to the healthier lives group; members then explained that they did not always understand why they were taking medicines or when to take them. They noted that sometimes they did not want to bother people and therefore did not ask for help. Some members asked what they should do with old medicines. The SHF added information about health problems that are common in people with learning disabilities and some examples of reasonable adjustments, such as dosette boxes, giving people longer to explain or understand things, having a quiet space available, accessible information and considering carers' needs.

Discussion followed the presentation. Some of the pharmacists wanted to check what terminology people found acceptable: all the trainers said they would prefer someone to ask if they needed extra help because of their learning disability, rather than saying nothing for fear of causing offence. The group talked about large print labels, medication management aids, having medicines delivered at home and easy read information. Examples were shared and the pharmacists learned about local help to make information accessible. The pharmacists agreed that they could make a note on their computer system to alert them to someone needing extra support; this could include details of the reasonable adjustments needed by that individual.

The pharmacists evaluated the session positively, commenting on the power of hearing directly from people with learning disabilities. Bradford People First followed up by writing an easy read letter that pharmacists could use to invite people for a medication review. The group also planned to raise awareness amongst people with learning disabilities about using their local pharmacists and decided to investigate development of easy read information about medications in other languages (given Bradford's diverse population).

For further information, please contact Vicky Donnelly, strategic health facilitator, Bradford District Care NHS Foundation Trust

victoria.donnelly@bdct.nhs.uk

Reasonable adjustments training

The purple star strategy project team has been working in the Welwyn-Hatfield area of Hertfordshire since January 2015 to deliver equitable and accessible health services for people with learning disabilities. The purple star is a kitemark symbolising a high standard of support for adults with learning disabilities. The quality standards that a service requires in order to be awarded a purple star are outlined at

www.hertfordshire.gov.uk/purplestar

In order to get a purple star at least 50% of the service staff must be trained on the TEACH tool (time, environment, attitude, communication and help), which reminds staff about ways of making reasonable adjustments for people with learning disabilities. Services have to prove that they are recording and evidencing the use of reasonable adjustments in order to stay accredited.

One pharmacy in Hatfield has been awarded its purple star and another is about to receive its award. These pharmacies are helping to raise the quality of care given to people with learning disabilities.

For further information, please contact Megan Roberts, Purple Star Strategy Nurse, Hertfordshire County Council

megan.roberts@hertfordshire.gov.uk

Advice and support from a pharmacist

The Learning Disability Partnership in Islington has included a half time clinical pharmacist for over 18 years. This role has four main elements:

- information, advice and support to people with learning disabilities
- advice and support to family carers and to social care staff teams
- advice to health and social work colleagues in the integrated community team
- liaison with community pharmacists

The pharmacist undertakes some direct clinical work, such as medicines usage reviews and helping people with learning disabilities to understand the medicines prescribed for them. She will develop information that is accessible to the individual and will help people to explore treatment options. For example, there might be different treatments available that have different side-effects – understanding individual preferences and risks is important in arriving at the right option for the individual. Some people need to have their medicines administered in specific ways to reduce the risk of choking, or have multiple health problems with different treatments that have to be carefully co-ordinated. The pharmacist will work with clinical colleagues to optimise the person's treatment.

She also works with a local voluntary organisation, the Elfrida Society, to help them develop a range of accessible information materials. These are kept under review to ensure they are up-to-date.

Family carers and social care staff are offered support from the pharmacist to help them understand the medicines prescribed for individuals and also to ensure that they are aware of possible interactions with over the counter products. Another example of the advice available was support to a staff team to develop guidelines for 'as needed' medication, in collaboration with the community psychiatrist and linked to positive behaviour support plans.

As noted in the section on co-ordinating advice and treatment, it is important for community pharmacists to have timely information about changes (to the person's health or treatments) when they are dispensing medicines to an individual. The Learning Disability Partnership pharmacist helps to ensure that community pharmacists are alerted promptly to any changes resulting from medicines usage reviews or as a person is discharged from hospital. She will also support people with learning disabilities to attend and get introduced to their local community pharmacy and will talk to the pharmacist there about any reasonable adjustments that may be needed.

For further information, please contact Athena Mesaritis, Islington Learning Disability Partnership

athena.mesaritis@islington.gov.uk

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Appendix A

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