

The Disability Partnership



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Evaluation Report of the 2015-16
Mencap-led Pharmacy Project

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Introduction

The Disability Partnership is a consortium of 4 national disability organisations, working with the Department of Health, NHS England & Public Health England within the Strategic Partners programme to highlight and address issues affecting disabled people and their families within health and care services.

The Disability Partnership brings a breadth and depth of reach into local communities, working with around 1 million disabled people and their families throughout the UK. The Disability Partnership is one of 22 partners within the Department of Health's Voluntary Sector Strategic Partnership Programme.

The Health and Care Voluntary Sector Strategic Partner Programme

The Strategic Partner Programme brings together expertise from the voluntary and community sector. Those involved work together on key aspects of health, social care, and public health policy with organisations including the Department of Health, Public Health England and NHS England – on behalf of patients, services users and the wider public.

Partners reach hundreds of thousands of voluntary and community sector organisations, interacting with a broad range of people, groups and communities.

Accessible Information Standard

The NHS England 'Accessible Information Standard' – directs and defines a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents, where those needs relate to a disability, impairment or sensory loss.'

This is emphasised in the five stages that must be implemented in all health provider settings: identification, recording, flagging, sharing and meeting of needs.

This project has set out, as one of its key objectives, to explore awareness of the Standard amongst pharmacists and steps they have taken to meet its requirements.

Acknowledgements

We would like to thank former Mencap staff member Lara Burnett, who worked on this project. The project is also indebted to the National Pharmacy Association (NPA), the Royal Pharmacy Society (RPS), the Centre for Pharmacy Postgraduate Education (CPPE), the various community pharmacists and the hundreds of disabled people, their family members and carers, who have provided the insight and lived experience that have informed the project's recommendations.

Executive Summary

This project set out to achieve three broad outcomes:

1. To speak to disabled people, their families and carers, and professionals working in pharmacies, to confirm what barriers, issues and concerns exist in relation to the accessibility of pharmacy services.
2. To create, co-create, adapt and collate resources that would support and guide the above groups to create and maintain more accessible pharmacy services.
3. To work with pharmacy bodies such as the National Pharmacy Association (NPA), the Royal Pharmacy Society (RPS), the Centre for Pharmacy Postgraduate Education (CPPE) and NHS England to ensure that recommendations from the project and resources can be utilised and acted on as widely as possible.

Interview, survey and focus group work

The project worked with local groups of Disability Partnership organisations, local pharmacy associations and self-advocacy groups in Sheffield and Greenwich.

The project interviewed, surveyed, and held focus groups with over 500 people (comprising 506 disabled people and professional support staff, 56 pharmacists, and 35 family carers) gathering information about key concerns, and recording solutions to the barriers identified.

In both areas we conducted **surveys of disabled people**, both in-depth **interviews and top level questionnaires** to gather views, not just about the barriers that exist, but what solutions they might find useful to overcome the barriers. Each Location Lead ran a **focus group with pharmacists** in the area to gather their opinions on barriers about which we had learnt and to consider possible solutions to these barriers.

Creation of resources

Following this, the project began **creation of resources** pharmacists and disabled people, or their family and carers, might use to overcome or mitigate barriers. The project also looked to the adaptation of existing resources for the purposes of pharmacists, and the co-creation of resources with pharmacy organisations where the project had made links to maximise the efforts of all organisations involved.

The project created or co-created 16 individual resources, collated into a single booklet, and gathered best practice examples which are available on the Mencap website.

Key findings

The in-depth questionnaire responses from disabled people (103) contained interesting data:

In the pharmacy:

- *57% of respondents thought that signage was not clear in the pharmacy*
- *Fewer than 10% of respondents used a quiet room to communicate to staff and nearly half (48%) did not think their pharmacy had a quiet room at all*
- *30% wanted their pharmacist to be more patient.*
- *The average frequency for visits to pharmacists was monthly.*
- *15% stated that they did not know why they took their medication*
- *Survey work with disabled people, family carers and professional support workers in Mencap services shows that negative experiences of pharmacy services are not the norm. However, it is clear that a number of barriers exist, such as access to information, clear communication and explanation of the purpose of medicines.*
- *Survey work for this project has shown that a common experience of pharmacy services for disabled people and their supporters is one that is neither good nor bad. This is supported by feedback from pharmacists, with a third stating that their pharmacy is 'neither good nor bad' in meeting the needs of disabled people. Clearly there is significant room for improvement to make use of pharmacy services for disabled people a positive and empowering experience in relation to managing their health.*

Outputs

The key output from the project has been the 16 resources that have been produced and co-produced. They are broken down into four areas:

- *Resources for people with a learning disability*
- *Resources for family carers and family members*
- *Resources for pharmacists*
- *Resources for external agencies to audit or support pharmacies*

The resources are available on Mencap's website www.mencap.org.uk/pharmacy-project, and are now being widely utilised by the pharmacy organisations we have been working with, as well as local areas we have worked with (Sheffield and Greenwich).

The role of a pharmacy and the pharmacist

Pharmacists are increasingly being seen as central to local communities. Often seeing their customers far more frequently than GPs and frequently knowing the individual far better.

There are 1.8 million visits per day to community pharmacies for health related reasons. One of the reasons for the more frequent contact with pharmacists is that they are easily accessible; 99% of the population can get to a pharmacy within 20 minutes by car and 96% by walking or using public transport.

Pharmacists have a key role to play in helping people with a learning disability and other disabled people to increase independence by managing their own medicine.

One pharmacist reported: “Once, I supported a service user who was not allowed to administer his own medicines without supervision because of a history of overdosing, but he wanted to take charge of it himself. I developed tailored medication administration recording sheets and medicines information to enable him to understand what he was taking and to show his carers that he had taken his medicines correctly. When he reached his goal he made a heart-warming comment: ‘Ajay, now that I can take charge of my own medicines, I feel like a grown-up’.”

This example shows that reasonable adjustments can make a large difference in ensuring disabled people are better equipped to protect, manage and promote their own health. However there is a need for training and support for more pharmacy staff to know how to work with disabled people and make reasonable adjustments.¹

Best practice

There are examples of best practice already in existence up and down the country, and the purpose of the project was not to replicate existing resources, but to highlight them. Bradford District Care Trust for example has developed training and resources, including Easy Read guides, bespoke training, and a variety of resources to help pharmacists support their patients and customers. Other examples were also highlighted to us during the course of the project.

Leeds – Making Time project

New easy read literature, in relation to pharmacies and medication, has been created as part of the ‘Making Time’ project. This was launched by NHS Leeds North Clinical Commissioning Group and Community Pharmacy West Yorkshire in June 2015 for a 12 month period, supporting around 200 individuals. The objective of the project has been to ensure people with learning disabilities receive the best service possible from their local pharmacy, and sufficient time given to patients when visiting to support with correct prescriptions, explanations of usage and identifying conditions.

<http://www.leedsnorthccg.nhs.uk/your-health/making-time-pharmacy-project.htm>

1. <http://www.pharmaceutical-journal.com/career/career-feature/pharmacists-role-in-learning-disability/10982413.article>

London Borough of Lambeth – Enter and View project (Healthwatch/Lambeth Mencap/ Lambeth Learning Disability Assembly)

Adults with learning disabilities were trained with Lambeth Mencap and Lambeth Learning Disability Assembly to become enter and view visitors, visiting healthy living pharmacies with a list of healthy living questions to see the type of responses they received, and the quality of service that they were provided. Objectives of the project included increasing the confidence of people with learning disabilities to use their pharmacy, and reduce what could be unnecessary visits to doctors, where a pharmacist could help.

The project resulted in five main recommendations to support development of best practice:

1. all pharmacists should receive learning disability awareness training
2. all should have easy read materials available
3. links should be made between pharmacies and local community places to support the public's understanding about what pharmacies can offer and to encourage use
4. improve physical accessibility of pharmacies
5. clear information be made available about health check charges.

<http://www.healthwatchlambeth.org.uk/news/first-wave-enter-and-view-visits-healthy-living-pharmacies-gets-flying-start>

http://www.healthwatchlambeth.org.uk/sites/default/files/hwl_pharmacies_enter_and_view_pilot_report_june15_0.pdf

Methodology of project delivery

The project worked with local groups of Disability Partnership organisations, local pharmacy associations and self-advocacy groups in Sheffield and Greenwich.

Survey work

In both areas we conducted **surveys of disabled people**, both in-depth **interviews and top level questionnaires** to gather views, not just about the barriers that exist, but what solutions they might find useful to overcome the barriers. Each Location Lead ran a **focus group with pharmacists** in the area to gather their opinions on barriers about which we had learnt and to consider possible solutions to these barriers.

Creation of resources

Following this, the project began **creation of resources** pharmacists and disabled people, or their family and carers, might use to overcome or mitigate barriers. The project also looked to the adaptation of existing resources for the purposes of pharmacists, and the co-creation of resources with pharmacy organisations where the project had made links to maximise the efforts of all organisations involved.

Accessible Information Standard

As a result of the links and relationships the project has forged, the Project Leads were also invited to take part in the co-creation of other support mechanisms around the Accessible Information Standard for pharmacists and supported the CPPE to write their on-line training module.

Seeking initial feedback

We have taken the opportunity to double check the findings of the project and the resources that have been created with disabled people at conferences and similar events, including the final Disability Partnership/NHS England participation event in Liverpool.

Findings from the project

The accessible information materials, resources, and concepts the project presented at meetings attended by professionals have been extremely well received. Attendees have commented on how useful they would be. It has been of concern that a significant number of those attending meetings appeared totally unaware of their existence, despite most of them being produced by the NHS, and a smaller, but significant, number still being unaware that the Accessible Information Standard existed. All of the findings have been taken from the surveys and interviews conducted throughout the project, the highlights of which can be found in appendix A and the full transcripts are available on request.

General findings from survey work

- *The number of disabled people who have had specific negative experiences with their pharmacist have been very small in number (around 5%). A number of the barriers that have been cited have been experienced by some of those interviewed or surveyed, but these are not universal.*
- *The number of disabled people who have described their experience of pharmacy services as 'good' or 'very good' numbers fewer than a quarter.*
- *The number of pharmacists who rate themselves as good or very good at supporting the needs of disabled people was 45%.*
- *Nearly half of disabled respondents (48%) stated that they were unaware of any disabled person they knew being asked for feedback about the service of the pharmacy.*

A third of pharmacists acknowledge that their services for disabled people are neither good nor bad. This shows that improvement is needed to ensure that pharmacies can deliver the best quality health service within their own community.

It was further found in the Greenwich area that 'pharmacists do not seem to raise awareness of other services that could be beneficial to vulnerable people, and only a small minority use resources that could improve the understanding and communication of people with limited capacity or communication skills.'

In addition, the survey that was conducted for families and carers of people with disabilities found that 'only nine people out of thirty five have heard of the medication use review which [might] suggest this service is not being promoted effectively'.

It is worth noting that, although the total number of people the project spoke to numbered 597, of which 500 were disabled people, and 56 were pharmacy professionals, this is not a significantly high enough a figure to justify whole-scale conclusions for a workforce of 43,665 pharmacists.

The specific findings have been categorised into three areas; issues for disabled people, issues for pharmacists, and the ideal situation.

Issues for disabled people:

The following were the reported barriers to access to information about healthcare, medicines, or other issues that affected health care:

- *Access to information – information presented in ways that were too small, too wordy, too complex, or not suitable*
- *Physical barriers - poor accessibility to health care facilities;*
- *Administrative barriers - short appointments and long waiting times*
- *Communication barriers - inability to describe symptoms, with differential diagnosis difficult and diagnostic overshadowing possible*
- *Attitudinal barriers - negative assumptions and attitudes about disabled people*
- *Knowledge barrier - limited theory and practice experience of the health needs of disabled people*

Issues for pharmacists

The following issues were raised by pharmacists during workshops, focus groups, and by survey:

- *Health Reviews are often completed by practice nurses so medication not being checked by a GP and can therefore go years without being changed*
- *There is a lack of communication between secondary and primary care especially between GP and pharmacy, and then to service providers or families*
- *There can be fear amongst families of reducing medication. If they've had bad experiences in the past and have finally got the situation to a manageable point, they can be scared to alter it. Pharmacists feel they need to build up trust, help the families' understanding of the situation and give them information*
- *Community pharmacists do not have the skills or confidence to support better communications between healthcare professionals - to take a role in linking families in with specialists if there is a red flag, rather than sending patients back to GPs. Families don't want to have to deal with too many professionals, so there needs to be decision making and coordination on a local level*

A shared vision of an accessible and inclusive pharmacy service

During the project, in surveys, interviews, workshops, and consultations, the following was suggested:

- *Families should use the pharmacist as a knowledgeable professional to go to, to get advice and information about medication instead of pouring through large amounts of information about illnesses and medication themselves, and to talk issues through, such as when two medicines cause a negative effect.*
- *Pharmacists need to be proactive rather than reactive, taking small steps to improve the patients' understanding of medication – for example.*
- *Pharmacists should not just be able to hand over the prescription if it is the first time, they have to give some accessible guidelines (just a simple document) that outlines issues.*
- *Steps could be taken such as production of a laminated card with information about what steps need to be taken before medication is given.*

Recommendations

In conversation with all of the stakeholders the project interviewed, as well as with national organisations, specifically the National Pharmacy Association, the Royal Pharmacy Society and the CPPE, the following questions and suggestions were posed and answered. These are not exhaustive, but cover a wide range of the concerns that have been raised during the project, and were used as a basis for the resources that were then collated and produced by the project (an outline of these can be found in appendix B, the full list can be found on the Mencap website).

How can pharmacists know (from their systems) that a patient has communication needs?

- *Patients with learning disabilities might record their communication needs separately or within a 'health passport'. One might add it to the ICE (in case of emergency) card information. Another might be to encourage patients to ask their GP to record the information on the 'additional information' section of their Summary Care Records (SCRs)*
- *Pharmacists need to highlight their need for the SCR and to be able to edit it so that they can add to the additional information, especially now that the Accessible Information Standard makes the sharing of information between professionals mandatory*
- *Including a tool for gathering information about people's communication needs as part of implementation guidance*
- *For each patient a Reasonable Adjustment Plan to be completed, a 'blue dot' sticker could be applied to the Patient's case notes / patient folder and an annotation regarding the communication needs documented*
- *Information about the diagnosis of medication needs to be included in the records (at the moment it is only the medication that is recorded, so the pharmacist is not able to use their knowledge about whether overshadowing or misdiagnosis is taking place). If more information is included about why certain medications are being used, pharmacists may be able to raise concerns*
- *Having a service user held 'information alert card'*

How can disabled people and their carers be empowered?

- *Ask their GP to record the information on the 'additional information' section of their Summary Care Records (SCRs). Nationally, pharmacists and pharmacy technicians are in the process of training to access SCR by April 2016.*
- *Patients to ask if the pharmacies provide Medicine Use Reviews at the pharmacy or in their home, and if so to let the disabled person know that they can request them. Broaden the criteria for the review to include those with disabilities as an automatic patient to offer the service to. Also the suggestion to lift the contractual restrictions so that it could be offered to parents and carers – for this to happen, a simple consent form would be need to be produced*

How can pharmacists be supported to implement the Accessible Information Standard?

- *Allow for flexibility within services to ensure that each individual's needs can be addressed, and ensure that all professionals have access to a range of different resources that can be tailored to individual patient needs*
- *Address the need for staff training and awareness building sessions*

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- *A sliding scale tool of what you can do/have time to do, at least to sign post them on to other specialists or help. Need to make the most of their local, community role*
 - *Recognise the benefit of involving clinical staff in the assessment and development of accessible information resources, whilst also acknowledging the impact on capacity*
 - *A single source, laminated book containing some of these resources would be useful for a whole host of health organisations and pharmacies throughout the country. We recommend this be a piece of work for an organisation to create.*

What training should pharmacists be offered to implement the Accessible Information Standard?

- *Training in supporting patients, for example those with cognitive impairments, with support to provide an accurate description of their communication needs.*
- *Whole staff training (of any member of staff who is public facing), including awareness-raising, local policies and knowledge or skills*
- *Mandatory communication skills, safeguarding and equality and diversity training, dementia awareness training, caring for patients and service users with learning disabilities training and Deaf awareness training. Much of this could be delivered through e-learning*
- *Raising awareness of the importance and impact of accessible information; delivery of accessible information to individuals, resulting in improvements in their health and wellbeing, and enabling people to fully participate in their healthcare, including empowering them to be part of decision-making.*

How can national organisations support pharmacists to implement the Accessible Information Standard?

- *National standards for easy read information and quality assurance*
- *Create a directory of useful services and organisations*
- *A national network for sharing good practice and experiences (and avoiding duplication of work)*
- *Need to make big changes across the country – to copy the Dementia ‘Call to Action’ which had a large impact and reduced the level of psychotic drugs prescribed by 52% from 2008-2015*
- *There needs to be a general public campaign so that the public fully understand how pharmacist can help them – ‘this is what pharmacists can do for you’, to raise awareness of pharmacists’ responsibilities*
- *Encouraging pharmacies to be proactive rather than reactive – The majority of general practices function on a largely reactive rather than proactive basis, relying upon people with disabilities, their families or care workers to identify problems and actively seek a consultation - which can be problematic if communication or access difficulties are present.*

What other examples of good practice should be recommended?

- *Community pharmacists should ask patients about the last annual medicine review they had and encourage them to have one if not recently.*

For more information

Mencap will continue to review and check the work of this project by ensuring that the resources and findings generated by this project will be on the Mencap website. For further details please email ProductsLegacy@mencap.org.uk or look at the resources that this project has generated, collated or contributed to at www.mencap.org.uk/pharmacy-project

Questionnaire and survey responses highlights

The in-depth questionnaire responses from disabled people (103) contained interesting data:

In the pharmacy:

- *57% of respondents thought that signage was not clear in the pharmacy*
- *Fewer than 10% of respondents used a quiet room to communicate to staff and nearly half (48%) did not think their pharmacy had a quiet room at all*
- *30% wanted their pharmacist to be more patient.*
- *The average frequency for visits to pharmacists was monthly.*
- *15% stated that they did not know why they took their medication*

External survey responses from pharmacy professionals (56)

- *45% felt their pharmacy to be good or very good at meeting the needs of disabled people.*
- *33% felt their pharmacy to be neither good nor bad at meeting the needs of disabled people.*
- *6% felt their pharmacy to be not good at meeting the needs of disabled people*
- *16% did not know*

Survey results from Mencap services on the experience of pharmacy services for people with a learning disability (403):

- *20% felt their pharmacy to be good*
- *75% felt their pharmacy to be neither good nor bad*
- *5% felt their pharmacy to be not good*

The survey conducted of families and carers (35) found:

- *22% of respondents had experienced a poor service, but these were found to be administrative in nature*
 - *10% of respondents felt it would be useful to have information in easy read*
 - *75% had not heard of the medication use review*
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Appendix B – resources the project has created

A number of resources were created to support the data collection process to gather a clear picture of what the current situation is regarding accessibility and pharmacies. These resources included:

- *A questionnaire, and an easy read version of the questionnaire, for pharmacy staff on what adjustments they make currently.*
- *An easy read observation form for what to look for when visiting a pharmacy regarding accessibility.*
- *Qualitative questionnaire for pharmacy staff to find out the perceptions of pharmacists about their settings' accessibility, if they have solutions on how to make it more accessible and what support they felt they needed to meet their customers' needs.*
- *Qualitative questionnaire, and an easy read version of the questionnaire, for people with disabilities to understand their current experience of using a pharmacy and their feedback on changes that could be made to improve.*
- *Qualitative questions for parents and carers to collect their experience of supporting an individual with a disability or impairment to use their pharmacy and their feedback.*
- *Focus group questions for pharmacy staff to gather feedback about the current situation in their setting regarding accessibility.*

Using the feedback the project received, and research into what resources currently exist, new resources were created to support people with disabilities and communication needs and their families and carers when accessing their local pharmacies. These included:

- ***My Communication Rights at the Pharmacy**, an easy read document, which gives a summary of what the Accessible Information Standard is and the key information people with disabilities and communication needs should know.*
- ***Communications Rights at the Pharmacy** document for parents and carers to summarise the key points from the Accessible Information Standard, information particularly useful for them to be aware of, and some hints and tips when supporting someone to access their pharmacy.*
- *We created two resources which have been endorsed by the Royal Pharmaceutical Society. These resources are easy read guides to explain what the New Medicine Service is and the Medicine Use Review.*
- *An easy read document explaining what pharmacies are, that can be used to give people with disabilities a clearer understanding of what these facilities are, why you would use one and how they work.*

The project shaped two resources directly for pharmacists to support them with implementing the Accessible Information Standard.

- *A list of reasonable adjustments that pharmacists can put in place to make their pharmacy accessible, and*
- *a checklist for pharmacists to make sure that they are following the Accessible Information Standards, with a list of suggestions they can follow, on areas such as communication methods, to improve their customers' experiences of using their local pharmacy.*

Additionally, the project worked with the CPPE to support the shaping of their on-line training module for pharmacists in how to implement and support the AIS for individual settings.

Appendix C – further ideas for resources

During this project we have identified a number of future resources that could be developed to further meet the needs of pharmacists, patients and parents and carers. These are:

- *Flowcharts for pharmacists to follow on how they can make their settings accessible for certain disabilities or impairments*
 - *A leaflet in a variety of formats (easy read, braille, audio etc.), that describes the Accessible Information Standard for patients / service users, which encourages them to request information in alternative formats if required, asks for their feedback if alternative formats are provided and also tells them how they can raise comments, concerns or complaints within the providing organisation*
 - *Poster templates for Trusts to advertise their commitment to the Standard and the services available*
 - *Case studies showing 'how to follow the Accessible Information Standards' in a practice, hospital, community facilities etc. to help with implementation*
 - *Access to the Widget health pack – 62 pages of flash cards for health settings*
 - *A laminated pack of existing resources that can be distributed to pharmacists to support them with their communication with service users*
 - *A template letter that can be used for patients to fill in to be handed into their GP detailing their additional communication needs and how they preferred to be supported. RNIB currently have a template letter for people with sight impairments to support them to do this. Potentially, a template could be developed suitable for all service users to complete and hand in*
 - *Emergency contact cards that highlight medical conditions and the individual's preferred communication method*
 - *Further e-learning training sessions*
-