



## #MyGPandMe - Little things make a massive difference

An interim report on training for GP practices on learning disability and autism



# Introduction

Dimensions, in partnership with Beyond Words, has delivered #MyGPandMe training to GP surgeries up and down the country. This report sets out the learning from #MyGPandMe training and evaluates its impact.

The report outlines good practice and makes recommendations to inform approaches to learning disability and autism training for health services. This is an interim report based on 23/50 total sessions.

We want to empower clinical practitioners, patients, families and other professionals so that all can work together for better health outcomes for people with a learning disability and autistic people.

## Little things make a massive difference

The health inequalities faced by people with learning disability and autism are profound.

The problems is not just lack of awareness. Attitudes, stereotypes and myths about people with learning disability and autism , along with judgments about their quality of life and ‘benefits’ of treatment, can bias the healthcare someone will receive.

Effective training should give professionals the knowledge and tools they need to deliver good patient care and to make reasonable adjustments that, alongside challenging and changing attitudes, will ensure that people with learning disability and autism are treated fairly by services.



# Changing culture and attitudes



There has been a lot of work progressed in the health and social care sector to better understand the inequalities faced by people with a learning disability and autism.

As a consequence, there are a great deal of resources and guidance for professionals to help support people to access health services.

## **So why are there still such stark inequalities for people with learning disability and autism?**

Too often guidance and best practice is not followed, adjustments aren't made, and tools that can help to reduce barriers are overlooked.

This is not to criticise individual professionals and practitioners, but it speaks to a lack of awareness and a culture in health services that doesn't always prioritise the needs of an individual patient with a learning disability and/or autism.

All people learning disability and autism, including those with multiple disabilities and complex health issues, must have equal and fair access to good health care services.



Changing this culture and challenging attitudes that disadvantage patients with learning disability and autism should be at the heart of training to tackle inequality.

We believe there are 4 key elements to do so.

1. Meaningfully involving people with learning disability and autism.
2. Training professionals with different roles together.
3. Focussing on reasonable adjustments and person centred thinking in services.
4. Introducing communication tools designed to empower health professionals.



# Meaningfully involving people with a learning disability and autism



Our #MyGPandMe training sessions were co-led by people with lived experience; people with a learning disability and/or autism.

During #MyGPandMe training sessions the co-trainers:

- shared personal experience and brought sessions to life
- highlighted generic and specific reasonable adjustments
- led practical exercises around accessible and person centred communication
- outlined how their rights had been ignored and the impact this could have
- answered questions in a supportive environment.

“Very helpful to have experience and insights of lady with learning disability”

“Very interactive and good to have the co-trainer so involved and helpful”

“Meeting the co-trainer and hearing true experiences was the best part of the training”

Co-led training puts people with learning disability and autism in a position of power and challenges the assumptions of professionals who normally only see people with learning disability and autism as patients.

It also creates a forum to ask important questions and to say things that professionals do not feel empowered to ask of patients and their supporters.

The strongest feedback on co-trainers in #MyGPandMe training was about trainers employed by Dimensions to work on health issues, this meant they had a strong understanding and expertise around the issues, as well as lived experience.



## Reflections from Jordan Smith, Dimensions Health Equalities Lead

I think it's really important that myself and other people with learning disabilities and/or autism have been fully involved in designing and delivering the #MyGPandMe training alongside our colleagues.

We have unique experiences of health services and we can influence health professionals so that they learn and understand how to improve the health and wellbeing of people with learning disabilities and/or autism.

In training sessions doctors and nurses have taken the time to tell me the difference I have made. They said it was good to have someone involved telling it how it is for them, not just hearing it from a third person.

People in the training also said it was good to have a human touch and not just read about problems in reports and see them in statistics. One practice manager said that they are usually just focused on the paperwork and that I had made them think about the person behind the paper work.

From this I would like to see mandatory training delivered to health professionals and others across all sectors in the NHS by people with learning disabilities and/or autism.

### Case study: Communication tools help

In one training a patient of the practice was involved as a co-trainer and has reported friendlier, more understanding and responsive staff during subsequent contacts with the surgery.

His GP said the part of the training which changed people's attitudes, as opposed to providing information, was the short reading of a few pictures from the Beyond Words book, *Going to the Doctor* by one of the self-advocates and one of the training team.



# Training professionals with different roles together and making it work for surgeries

#MyGPandMe training sessions were:

- two hours long - they could fit into practice closing periods for Protected Learning Time
- aimed at all staff - the impact and reach of training was maximised
- interactive - participants shared their thoughts, asked questions and tried new techniques

Training people with different roles was a valuable approach that helped professionals to focus on a person's journey through a visit to the GP and not just their individual role within it.

The whole practice approach supports a shift in culture when it comes to patient care across the surgery. This is particularly important as multiple surgery staff will interact with a patient and may need to be aware of or use the tools and resources that will help a patient at the surgery, such as health passports and health stories in pictures...

## Case study: Involve all GP practice staff in training

In one session GPs were concerned about offering 20 minute appointments because of the pressure that this would put on time. The doctors asked if 15 minute appointments would be appropriate and whether all patients with a learning disability would need a longer appointment.

The trainer talked about the value of having time to communicate and how this could be difficult for someone who is anxious at the doctor.

The group began to discuss how they could tackle this issue. If a patient got the right adjustments when they arrived at the surgery, then perhaps they would be more relaxed and better able to communicate with the GP in the appointment.

The conclusion of discussion was that reception staff could make adjustments for people coming to the practice, so that patients could feel more relaxed when going into an appointment. Whilst some people would still benefit from longer appointments, adjustments earlier on could help to make time with the doctor as effective as possible.





## Focusing on reasonable adjustments



In order to access services, many people with learning disability and autism will need reasonable adjustments.

These are small changes that can make a big difference to an individual's experience. They might include things like making the lighting dimmer, the waiting space quieter or providing information like *Going to the Doctor\** and helping the patient and those supporting them to prepare for the appointment.

Reasonable adjustments are a legal obligation, set out in the Equality Act (2010) but they are not always implemented.

**60%** People say their GP surgery does not make adjustments for them\*\*

**48%** GPs say they're unclear on when to use reasonable adjustments\*\*

One of the reasons that reasonable adjustments are not put in place is because they are not seen as an integral part of good patient care.

In feedback from our training we found that most surgeries made some general adjustments, but few had initiated conversations with patients and their supporters about the specific things that might help a particular patient to feel less anxious and to participate in health appointments.

Fewer still had recorded adjustments somewhere that all practice staff could access, so that an individual would not have to repeatedly ask for them.

A key learning point was that putting in place reasonable adjustments will normally require joined up thinking between surgery staff, the patient and their supporter and pro-activeness from the surgery to find out what works best for each patient.

**“Staff are more aware of the challenges faced by patients attending with learning difficulties. Instead of speaking to patients through the Perspex screen at reception, staff go around the desk and have face to face conversations.”**



# Training results

#MyGPandMe training led to a range of innovative and practical changes in practices to support patients with learning disability and autism.

To date, we have delivered training to 23 practices across England, training around 250 professionals.

Feedback from #MyGPandMe training\*\* underlines positive improvement in surgery staff's confidence working with people who have a learning disability and autistic people.

94%

said they were either confident or very confident they understood what having a learning disability and autism might mean when someone accesses primary care.

94%

said they were confident or very confident around making reasonable adjustments for patients with learning disabilities and/or autism.

89%

said they were either confident or very confident communicating effectively with patients who have learning disability and autism.

## Looking ahead

We welcome the government's consultation on mandatory training on learning disability and autism.

We hope that our learning from working with primary care professionals will support good practice in delivering training and supporting great health outcomes for people with a learning disability and/or autism.

This is an interim report based on 23/50 total sessions. We will publish a full report soon.

All GP practices at our #MyGPandMe training received free copies of Books Beyond Words: Going To The Doctor.

This is a very useful resource for patients with a learning disability and/or autism, and we highly recommend GP practices have a copy available.

[Purchase yours from booksbeyondwords.co.uk](http://booksbeyondwords.co.uk)



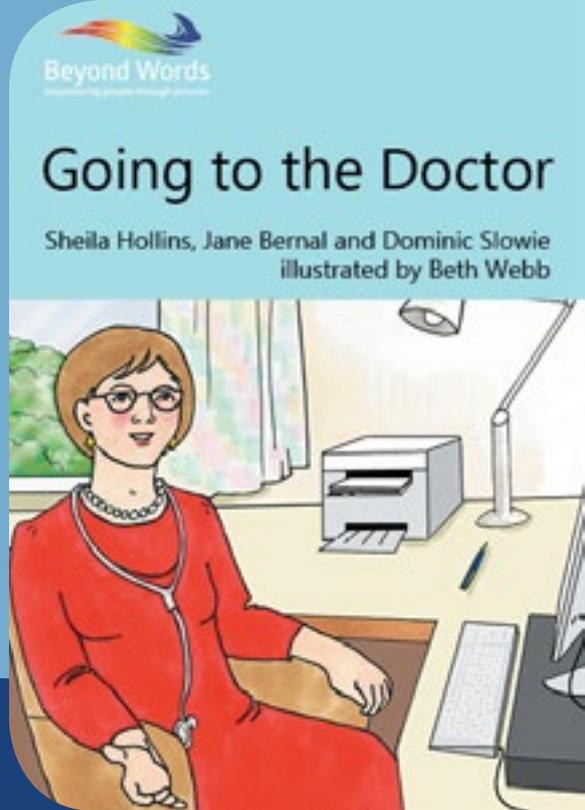
Contact us to find out more:

[www.dimensions-uk.org](http://www.dimensions-uk.org)

0300 303 9001

[mygpandme@dimensions-uk.org](mailto:mygpandme@dimensions-uk.org)

Find us on social media @DimensionsUK



## Dimensions

2nd Floor, Building 1430, Arlington Business Park, Theale, Reading, RG7 4SA