



#MyGPandMe
Making primary care fair



Foreword

Dimensions and Books Beyond Words would like to thank all those who participated in this primary healthcare research, shared their experiences and gave their time to inform the report.

Everyone has the right to good healthcare. But, our findings make it clear that there is room to improve the health of people with learning disabilities and autism and, in turn, their quality of life overall.

They also highlight that many healthcare professionals are working hard to deliver quality care but are not getting the training and support they require; in order to improve health outcomes for patients with autism and learning disabilities.

For most of us, a GP is the starting point when it comes to managing our health and receiving treatment when we get ill. Very often, our GP can resolve a health issue without the need to go to hospital or see more doctors. But research shows that people with learning disabilities are five times more likely to end up in hospital for an issue that would normally be treated by primary healthcare practitioners¹.

We hope that through #MyGPandMe we can bring together the skills, knowledge and passion of all those who have a responsibility for people's health and make sure primary care is fair and accessible for people with learning disabilities and autism.

Professionals working in general practice have told us they need support to deliver good care to people with learning disabilities and autism, but there is no mandatory training around this in primary healthcare.

Good health outcomes for people with learning disabilities and autism rely on collaborative working between all those who support people with their health, including GPs, nurses, practice staff, families, support workers and patients themselves.

Without training, many practices are finding it difficult to support people with learning disabilities and autism to achieve good health and consequently too many people experience a reduced quality of life.

Crucially, GPs are joining our call for tailored support and training. #MyGPandMe is connecting GPs, nurses, practice managers, receptionists, support workers, patients and families to overcome health inequalities and support better health outcomes. Together, we can achieve real change.



Steve Scown,
Chief Executive,
Dimensions



Professor Baroness Sheila
Hollins FRCPsych,
Chair and founder of
Books Beyond Words

¹ Being disabled in Britain: A journey less equal, Equality and Human Rights Commission, 2017



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Key findings



Cancer screenings

Eligible women in the general population who have had recent breast screenings and in the last 3 years.



Women with autism and learning disabilities who have had breast screenings in the last two years.



Eligible women in the general population who have had recent cervical screening.



Eligible women in the survey who have had a recent cervical screening.



Nearly half of the GPs surveyed said they want additional training on how to make reasonable adjustments to support improved rates of cancer screenings.

Up to 35,000 people may be wrongly prescribed psychotropic medication. Over 80% of GPs agree that over-prescription of medication is a particular problem. Half of GPs would like more training on prescribing and assessing psychotropic medication.

Behaviour changing medication

About half of people with learning disabilities and autism suffer from long-term constipation. This is due to poor diets and limited physical activity, some medications and finding it difficult to monitor their bowel movements.

Annual health checks should help tackle these issues, but less than half of the people on the learning disability register have one.

Nearly half of the GPs surveyed said they want additional training in delivering good annual checks.

Communication

Compared to other people, people with learning disabilities and autism are: 30% less likely to feel listened to by their GP. 28% less likely to feel treated with care and concern. Only half feel involved in decisions about their healthcare.

Over half of the GPs surveyed agree that communication issues between patients, support workers and GPs are an obstacle to meeting the needs of people with learning disabilities and autism.

Reasonable adjustments



Health inequality

29 Years

On average, women with a learning disability die 29 years younger than other people, and men with a learning disability 23 years younger, from generally preventable causes².

Training

64% of GPs surveyed have had less than 1 day's training on meeting the needs of patients with learning disabilities and autism.

98% of GPs surveyed want more training.

#MyGPandMe research findings

There's a resounding message that more needs to be done to ensure people with learning disabilities are receiving the quality of care that they urgently need.

Our research shows that people with learning disabilities and autism are less satisfied with their healthcare and often experience numerous barriers when it comes to accessing primary healthcare. Just **53%** of people with a learning disability or autism rated the service they get from their GP positively, compared to **85%** of the general population³.

We surveyed our support teams and found that many people experience difficulties accessing timely and effective care. Some areas require urgent attention, such as the very low number of people accessing cancer screenings and the high number of people experiencing constipation.

Other areas underline the long-term reduction in quality of life that occurs when people aren't supported to maintain their health and make healthy lifestyle choices.

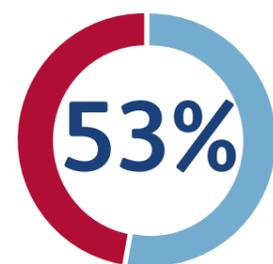
This is just one side of the coin, so we asked GPs about working with people who have learning disabilities and autism to gauge their training and confidence.

Two thirds (64%) of GPs told us that they had received less than a day's training on how to meet the needs of patients with learning disabilities and autism and **7%** of GPs have received no specific training. **60%** of GPs say that additional training is necessary, and that more could be done to ensure patients with learning disabilities and autism are getting the best possible care from the primary healthcare system.

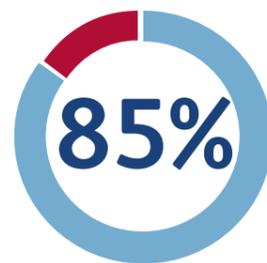
Most importantly, **98%** of GPs told us that they would benefit from a short training session, led by people with learning disabilities and autism, on how to meet the individual needs of patients with these disabilities to improve their health outcomes.

No wonder then, that people with learning disabilities and autism are less satisfied with their primary healthcare.

GPs, support teams and people with learning disabilities and autism are all in agreement. Our research shows a clear need to deliver better healthcare for people with learning disabilities and autism, supported through effective training.



Respondents with a learning disability or autism rated the service from their GP positively.



Respondents from the general population rated the service from their GP positively.

Health inequality

If you are a man with a learning disability you can expect to live 23 years fewer than a man in the general population. If you are a woman with a learning disability, this rises to 29 years fewer than a counterpart in the general population⁴.

The mortality gap shows just how difficult it can be to access healthcare when you have a learning disability. It is the clearest indicator of health inequality.

The learning disability mortality gap is the result of multiple systemic inequalities and barriers in the healthcare system. This means you are more likely to experience poor health and a reduced quality of life if you have a learning disability, and for poor health to go undiagnosed and untreated.

Health inequalities and barriers arise in multiple ways:

- If communicating is difficult, then it might take time to identify that someone is ill or in pain, delaying their access to health care.
- If accessible information about maintaining good health isn't available, or the doctor explains a diagnosis and treatment in a way that's hard to understand, it can mean effective health interventions aren't made.
- If the focus is on someone's disability and how that impacts on their life, known as diagnostic overshadowing, then the signs that someone might be ill or experiencing changes in their health can be missed.
- If someone finds tests and procedures difficult or has had a bad experience in the past, then it can mean diagnostics are delayed and access to the right healthcare denied.

⁴ NHS Learning Disabilities Mortality Review, 2017

³ GP Patient Survey, NHS England, 2017

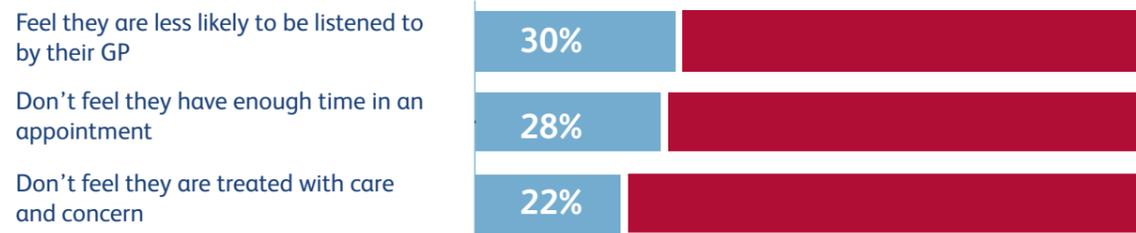
Research has also found that many learning disability deaths are preventable⁵.

“Not only is the mortality gap an injustice to those people with learning disabilities who die early, it sustains low expectations when it comes to longevity for people with learning disabilities that can impact on the care they receive.” Dave Robinson, Health and Wellbeing Programme Manager.

The idea that people live on borrowed time, or that quality of life is a reason to withhold treatment from someone with a learning disability, is still far too prevalent.

Our research shows that people with learning disabilities and autism feel this inequality. Compared with the general public, respondents with a learning disability or autism are **30%** less likely

Compared with the general public, respondents with a learning disability or autism...



to feel listened to by their GP, **28%** less likely to feel they have enough time in an appointment, and **22%** less likely to feel treated with care and concern.

The persistence of health inequalities and the resulting mortality gap demands that everyone comes together to deliver better outcomes for people with learning disabilities and autism.

Practitioners, support workers, patients and families need to know how best to support people to access effective and timely healthcare that meets their needs. This includes making reasonable adjustments for every individual and using best practice approaches to maintain good health.

“Not only is the mortality gap an injustice to those people with learning disabilities who die early, it sustains low expectations when it comes to longevity for people with learning disabilities that can impact on the care they receive.”

Dave Robinson, Health and Wellbeing Programme Manager

⁵ CIPOLD (Confidential inquiry into premature deaths of people with learning disabilities), University of Bristol, 2013

Reasonable adjustments

Reasonable adjustments are small changes that are made for someone with a disability so they can access a service that would otherwise be inaccessible.

The Equality Act 2010 created a legal obligation to make reasonable adjustments, but they are not put in place as often as they should be. **60%** of respondents to our primary healthcare survey said their GP did not make reasonable adjustments for them.

Not only are reasonable adjustments a right, they are crucial to ensuring someone gets the healthcare they need.

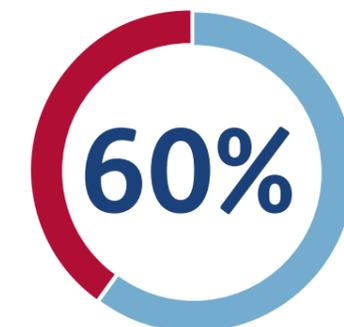
Some adjustments can be specific and technical, such as finding alternative diagnostic tests that are less invasive and that reduce a person's anxiety.

Other adjustments might be more general, like providing accessible, easy read information and making sure there is a quiet place for someone to wait in the practice for an appointment.

“Reasonable adjustments will be different for every individual, but many people will benefit from simple adjustments like avoiding jargon and providing longer appointments so people have more time to explain and understand their health and treatment.” Dave Robinson, Health and Wellbeing Programme Manager.

Currently, student GPs receive no mandated face-to-face training around caring for people with learning disabilities, and little training around implementing reasonable adjustments to make services accessible.

This has a direct impact on their ability to provide reasonable adjustments. **Half of GPs** have identified that a lack of training on making reasonable adjustments stops them meeting the needs of patients with a learning disability or autism.



Respondents said their GP did not make reasonable adjustments for them.

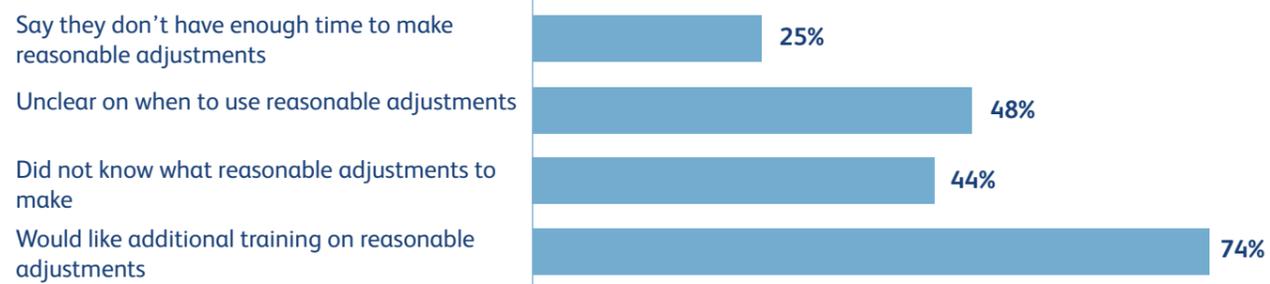
“Reasonable adjustments will be different for every individual, but many people will benefit from simple adjustments like avoiding jargon and providing longer appointments so people have more time to explain and understand their health and treatment.”

Dave Robinson, Health and Wellbeing Programme Manager



Notably, **25% of GPs** say they don't have enough time in their appointments to make reasonable adjustments, but these are a right not a privilege. We can tackle this by giving GPs more support to make reasonable adjustments. **Almost half (48%)** identified a lack of clarity on when to use reasonable adjustments and **44%** said they didn't know which reasonable adjustments to make.

GP survey



Encouragingly, GPs themselves are calling for further training to tackle the issues they've identified and **almost three quarters (74%)** of GPs would like additional training on reasonable adjustments to ensure people with learning disabilities and autism receive care and treatment that meets their individual needs.

Case study

Paul has never liked being in unfamiliar surroundings with unfamiliar people. This can cause Paul great anxiety which can result in some very challenging behaviour.

But it's important that Paul gets used to going to his local surgery for his appointments and health checks.

To help prepare, staff book a taxi for Paul every Friday for 11am to the surgery and book another from the surgery for 11.20am.

To make him feel at ease, Paul's support staff prepare a flask of tea, a couple of biscuits and Paul's favourite mug.

At first, the staff at the surgery arranged things so as soon as Paul walked in, there was a chair straight in front of him next to the water cooler. Paul would sit down and have his tea and biscuits.

Then after six weeks of visits the support staff began to guide Paul straight through the waiting room and into the consultation room to have his tea, making sure that Paul can see his flask as he goes.

Once in the room Paul has his tea and biscuits - his support staff and the surgery staff chat to Paul and make sure that he is relaxed and comfortable.

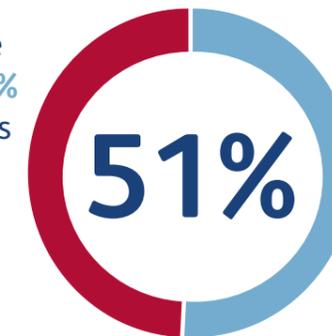
The staff at the surgery have Paul's communication plan – they understand that as Paul is registered deaf, he takes most of his communication from facial expressions and body language. The staff know to over exaggerate their facial expressions when they are smiling and welcoming Paul.



59% of the GPs we spoke to identified communication issues between patients, support workers and GPs as an obstacle to meeting the needs of people with learning disabilities and autism.

#MyGPandMe training tackles these obstacles - to support strong relationships and good communication between patients, GPs, support teams and other practice staff.

GPs also highlighted the need for further training to ensure patients are getting the most out of annual health checks, and 44% of GPs would like additional training in this area.



Respondents with learning disabilities and autism felt involved in decisions about their healthcare.

Annual health checks

Free annual health checks are available to anyone with a learning disability that has registered on their general practice's learning disability register.

The annual health check can help people to maintain their health and develop a relationship with their general practice in case they fall ill or need treatment.

Whilst practitioners currently receive no mandatory training around learning disability and autism, there is a lot of guidance to support good health checks and they can be a very valuable part of someone's healthcare.

But there is still room for improvement. In 2014-15 just 46% of people on the learning disability register had an annual health check, and many more not on the register will not have had one.

Our research shows that the quality of health checks can vary, often depending on the adjustments that practices make and the relationship that exists between the person and professionals in their general practice.

Only half (51%) of people with learning disabilities and autism felt they were involved in decisions about their healthcare. GPs are mirroring these concerns.

Case study

Dimensions supports a large group of people in one town where we provide support and has regular contact with the local GP surgery. The staff team there have worked hard for a number of years with the practice to improve the relationship between the people supported and the GP.

Negative perceptions, lack of communication and poor treatment were all issues having a detrimental impact of the people supported in the town. Often, the doctors relied too much on contact with the support workers and didn't engage with the people themselves. Reasonable adjustments weren't made to make visiting the practice easier.

The practice liked to group all of the people's annual health checks together, meaning people didn't get enough time individually to discuss their health. Staff explained the importance of having time to communicate and understand health issues to the practice. Now each person has an individual appointment with the correct amount of time allotted to them.

Now people are seen as individuals and treated in a person-centred way, including better adjustments to help visits to the practice and greater flexibility to make the patients feel listened to and understood.

Key areas of concern

Our research has identified some key areas of learning disability and autism health that need urgent attention.

Overmedication, cancer screenings and constipation are clear areas for improvement when it comes to improving health outcomes for people with learning disabilities and autism.

All three not only threaten people's overall quality of life, but also present a real threat to longevity and contrast starkly with the experience of the general population.

Spotlight on... psychotropic medication

Psychotropic medication is any medication that changes the way your brain works. Common examples include anti-depressants and anti-psychotics.

It is estimated that 30,000 – 35,000 people with learning disabilities or autism are at risk of being wrongly prescribed psychotropic medication. Often these drugs are used to reduce and control challenging behaviour, in the past this has been referred to as chemical restraint.

Over medication as a response to challenging behaviour is wrong and reduces quality of life.

Challenging behaviour can often be the result of environmental factors, which can be changed and adjusted. Better support and better environments provably lead to

a reduction in challenging behaviour, with far better outcomes for individuals than chemical intervention.

Overmedication can lead to other health issues, such as increased risk of constipation, weight gain and even organ failure. Beyond this, there is the fundamental point that no one should be taking drugs they do not need, when other interventions can improve their quality of life.

Over 80% of GPs identified over-prescription of medication as a problem confronting people with learning disabilities and autism. **Almost half (48%)** of GPs would like additional training on prescribing and assessing psychotropic medications.

Anyone on psychotropic medication should have a multidisciplinary review of their prescription every six months, but many people still don't receive regular reviews. This is a clear area for action and one that GPs must be aware of.

Dimensions works within the NHS Stopping the Overmedication of People with learning disabilities (STOMP) initiative, developing practical tools and guidance to make sure people have their prescriptions reviewed regularly.

We want to see more people receiving regular reviews of their prescriptions and, where possible, reducing their use of psychotropic medication.

Case study

In 2016 John was unsettled and his behaviour was quite unpredictable. He was lashing out at staff, pulling hair, and throwing objects.

John was on a medication called Lorazepam. He would have this administered when his behaviour became 'challenging'.

New staff in his new home took a different approach and tried alternatives to using medication as a way to calm John, such as giving him space and time to work things out for himself. The team were also given SCIP Training which helped them to understand John's behaviour better.

As a result of this continued effort the team did not need to administer Lorazepam. So at John's next psychiatry review it was decided that the Lorazepam would be discontinued and other medications to counter aggression and anxiety would be reduced. Six months later, John's prescription was reviewed again and his medication further reduced.

With the guidance of healthcare professionals and the Locality Manager, John now appears to be a completely different person. He is happy-go-lucky, friendly, sociable and an absolute pleasure to be around. His staff team truly believe that the gradual reduction in John's medication has contributed to him having a better quality of life.

Spotlight on... cancer screenings

National cancer screening programmes are a crucial part of public health, identifying cancers early on to give the best chance of positive treatment outcomes.

Developing the knowledge and understanding to check your own body can be more difficult for people with learning disabilities and autism. Some will have support workers to help spot any changes or abnormalities that need attention, but overall, people with learning disabilities and autism are at a high risk of late diagnosis. This makes screening programmes particularly important for people with learning disabilities and autism, as an opportunity to spot potential cancers at regular intervals.

Nonetheless, screenings for breast, cervical and testicular cancer can be challenging for people who experience anxiety when they attend the doctors.

Evidence shows that people with learning disabilities and autism are routinely missing out on cancer screenings.

“ Screenings for breast, cervical and testicular cancer can be challenging for people who experience anxiety when they visit the doctors. ”

*Dave Robinson,
Health and Wellbeing
Programme Manager*



Spotlight on... constipation

As of March 2016, **75.5%** of eligible women in the general population had a breast screening with a recorded result within three years. But **only 47%** of women with autism and learning disabilities in Dimensions' survey had a breast screening within the last two years.

Even more shockingly, **19%** of eligible women in Dimensions' survey had had a cervical cancer screening, compared to **73%** of eligible women in the general population – a gap of 54%.

The cervical screening statistics are particularly concerning and are, in part, due to false assumptions that many women with learning disabilities are not sexually active and so don't need screenings.

Almost 45% of GPs would like additional training on cancer screenings and **41%** of GPs would like additional training on sexual health in relation to people with learning disabilities and autism.

Reasonable adjustments can help to ensure people get the screenings they need. Furthermore, considering the least invasive route for tests, and taking the time to explain these tests and preparing someone for a procedure – sometimes over months – can make the difference between spotting cancer, or the potential for cancer, early and spotting it too late.

Case study

Sarah has a real fear of any medical professionals - she needed to have a health check as she was showing signs of possible gynaecological issues.

Her support staff helped Sarah to understand what would happen at the check up by finding easy read literature that explained how she would be examined on the day.

Sarah was supported to get familiar with the building and the medical staff over time – this really helped.

On the day, the support worker even went as far as getting on the table and having gel on her own stomach to reassure Sarah.

All of the work that went into preparation paid off and Sarah was able to have her examination.

It is estimated that half of people with a learning disability are at risk of suffering from long-term constipation.

Poor diet, limited physical activity, over medication and poor bowel movement monitoring are all risk factors for constipation, to which people with learning disabilities are more susceptible.

Long-term constipation is symptomatic of poor health and causes ongoing reductions in quality of life, through discomfort, pain and the need to take medication. Currently, **97%** of the people Dimensions supports with constipation are prescribed laxatives.

It is vital that people are supported to make healthy lifestyle choices that support bowel health. This helps to improve quality of life and reduce the risk that someone might be hospitalised for constipation.

Case study

Tom has Down's syndrome and severe learning disabilities. When Dimensions started supporting him he had violent tendencies, and had just been evicted from his house. He suffered from severe constipation.

At his old house, he would stay up all night then sleep through the day and he was taking a cocktail of medication. But when he got a house on his own, with his own dedicated staff team, things began to change.

His support team started to make sure that his evening meal was always cooked fresh and included lots of vegetables. His team made sure his medication was given on

Managing the risk of constipation is a clear area where those supporting people with learning disabilities must work with healthcare professionals effectively.

Using tools such as Health Action Plans can help to co-ordinate someone's healthcare across different practitioners and make sure that everyone has understood the steps that are needed to maintain or improve someone's health. **46%** of respondents to our primary healthcare survey did not have a health action plan.

When everyone works together, long-term problems such as constipation can be very well managed, meaning people can lead healthier, happier lives.

time and at the right intervals, so Tom was up before 8am for his medication. Then he was always offered a healthy breakfast, normally porridge with fresh fruit.

The results were so good that Tom started to sleep around eight to nine hours a night, his bowel movements were more regular and his aggression was virtually gone.

This change in behaviour meant he didn't have any medication for aggression after six months of this programme. His psychologist, on seeing him after about a year in his own home, stated that he had known Tom for 24 years and never seen him looking so good.

The solution

There is a resounding consensus amongst the people we spoke to that more needs to be done to tackle health inequalities for people with learning disabilities and autism.

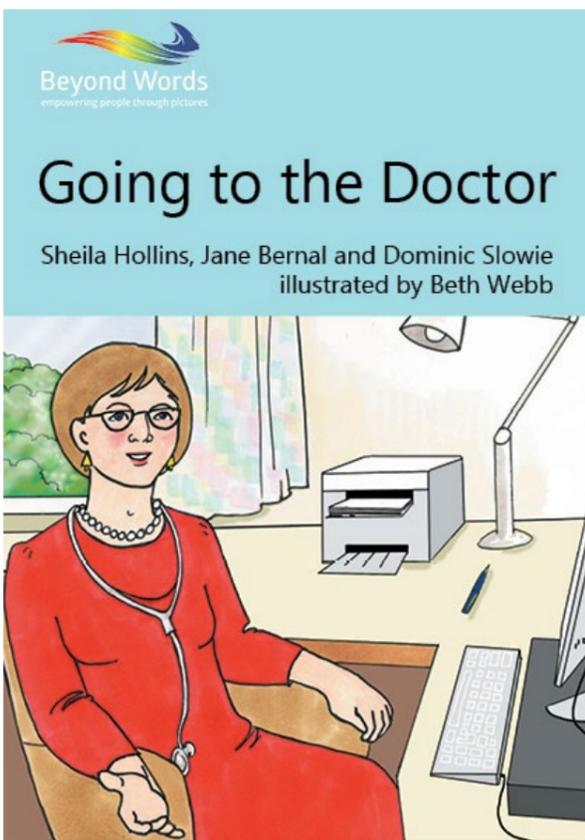
#MyGPandMe is calling on everyone to work together to tackle this head-on and make better primary care a reality.

What is Dimensions doing?

As part of the #MyGPandMe campaign, Dimensions will be running **50 free 'whole practice' training sessions**. These sessions will be co-led by people with autism and learning disabilities who are 'experts by experience'.

The training is developed in consultation with key partners including Books Beyond Words.

The first 50 practices that participate will receive a copy of Beyond Words' accessible health resource *Going to the Doctor* to support communication with people with learning disabilities across the practice.



What can policymakers do?

Reducing inequalities for people with learning disabilities and autism is rightly being prioritised within national health policy. Closing the mortality gap and removing barriers to access will mean all those working with patients have the skills, knowledge and confidence to make adjustments that meet individual needs.

The Department of Health and Social Care's Think Autism strategy focuses on closing the life expectancy gap for people with autism. A key area of the strategy is supporting tailored communication and reasonable adjustments to help people with autism access services.

The health of people with learning disabilities remains a clinical priority within the NHS Five Year Forward View. This includes ensuring that NHS staff are equipped with the knowledge and skills they need to meet patient needs, particularly around annual health checks.

Through #MyGPandMe we are calling for national policy to be supported by:

- **Mandatory training for professionals working in primary healthcare on learning disability and autism, to be co-delivered by trainers with learning disabilities and autism. This will support GPs, nurses and other practice staff to meet patient's individual needs, and increase confidence to make effective reasonable adjustments.**
- **Greater emphasis on quality of life, focusing on key areas of improvement such as overmedication, cancer screening and constipation. This will be in line with Best Practice, including high quality Annual Health Checks; Health Action Plans; and STOMP tools.**



The details

The #MyGPandMe report draws on three datasets:

1. Dimensions GP survey

This data was collected in March 2018 through an online survey for GPs across the UK. The survey received 252 responses and captured their experiences of caring for people with learning disabilities, the level of training they've received, and their thoughts on what more can be done to address health inequalities.

2. Dimensions primary healthcare survey

This data was collected through an open survey for people with learning disabilities and autism, in July and August 2017.

The survey received 434 responses and captured data relating to satisfaction with GP services, use of learning disability health services, including the learning disability register, annual health checks, health action plans and reasonable adjustments.

Comparisons have been made with identical questions asked to the general public in NHS England's 'GP patient survey 2017.'

3. Dimensions support team survey

This data was collected through an internal survey to Dimensions staff teams. The survey received 168 responses from managers, covering the experience of 1,842 people Dimensions supports with health. The survey collected data on key health issues, including overmedication, access to cancer screenings and constipation. The survey captured anecdotal evidence of people's experience with health services, including particular barriers and success stories in supporting people to access healthcare.

What can General Practices do?

Through #MyGPandMe we are calling for:

- GP practices to take part in the #MyGPandMe training, co-developed and delivered by people with learning disabilities and autism.
- GP practices across the country to sign up to become a 'learning disability and autism friendly GP practice' once they have taken part in the #MyGPandMe training.
- GP practices across the country to purchase a series of accessible health books from Beyond Words, which include resources for specific health issues such as breast screenings, testicular checks and cancer.

Good health and quality primary healthcare is a key part of leading a happy and active life and it's imperative that we make this a reality for people with learning disabilities and autism.

At the heart of this is the relationship that develops between health professionals, support workers, families and patients themselves.

The #MyGPandMe campaign will support great relationships in primary healthcare, through effective training, awareness raising and positive collaboration around the health of people with learning disabilities and autism.



Proving life can get better

Dimensions provides evidence-based, outcomes-focused support including sector leading positive behaviour support for people with learning disabilities, autism and complex needs. We help the people we support to be actively involved in their communities.



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