#MyGPandMe

Building Better Together

Accessibility and inclusion in primary care buildings and environments

dimensions

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Executive summary

This report provides an insight into the experience of people who have disabilities in primary care settings, with a focus on how the building and environment impact on people receiving health services and the relevance of the physical space to the health inequalities experienced by people who have a disability.

Dimensions surveyed around 600 people to collate views on primary care, including GP services and community health centres. This included people who have a range of disabilities, as well as people who support someone with a disability to access healthcare, such as family members and paid social care workers.

Our report finds 4 key themes:

- **Independence, choice and control**
  The design of buildings and environments impacts on people's ability to get around independently and access services without needing more support than they normally would. This includes signage, ramps, railings and automatic doors.

- **Dignity**
  Access to private space and technologies can ensure people access healthcare with dignity and are not left in difficult or compromising situations. This includes access to Changing Places facilities and equipment that is used in a wheelchair.

- **Feeling relaxed**
  Décor, sensory inputs and furnishings can reduce anxiety and help people to access health services in the right state of mind. This includes adjustable lighting, using plants and sound proofing.

- **Customer service and patient care**
  Whilst the environment and building design are important, the skills, knowledge and attitude of health professionals and non-clinical staff have a significant impact on people's experience in primary care settings.

Our report finds that, overall, people who support someone to access primary care have a lower level of satisfaction with services than people with disabilities.

Feelings of stress and anxiety are prevalent amongst people who say that their primary care building does not meet their needs, as well as amongst supporters who say the primary care building does not meet the person they support's needs.

In light of COVID-19, our report also finds that people who have a disability greatly value opportunities to access physical primary care environments. Planning in the wake of the pandemic should have regard to the ongoing need for primary care buildings to meet people's needs safely.

Our report recommends:

- **Flexibility**
  Buildings should be designed to offer flexibility, including the ability to change the space with wall partitions and screens; to adjust the sensory environment and enable technologies that assist people.

- **Involvement**
  People who have disabilities should be involved in planning and design processes and in renovation in primary care settings to provide insight from their lived experience.

- **Regulation**
  Accessibility and the suitability of the built environment should be considered within the existing inspection regime and viewed as an essential part of understanding patient care.

> **"I know from personal experience that people can get a fear of doctor's surgeries and hospitals – but I know that if those places could get things right for me, then I might be a bit more forthcoming."**

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1. Introduction

Primary care services are often the beginning of a person's pathway to improved health and wellbeing and, where prevention and early intervention are effective, they can also be the end of that pathway.

Primary care settings are vitally important to everyone and should be able to meet the needs of the whole community they serve. This includes eliminating the barriers that people who have disabilities often experience when it comes to accessing a physical space.

#MyGPandMe: Building Better Together draws together the voices and experiences of people who have disabilities and those that support them – including family, friends, and paid support workers. In setting out both quantitative and qualitative data gathered from around 600 people who have disabilities and their carers[1], we hope to highlight good practice and areas for change so that everyone with a disability can access primary care services on an equal basis.

The findings of this report are set against a backdrop of substantial health inequalities for people who have a disability.

Current research shows that people with a learning disability die, on average, 25 years earlier than their counterparts in the general population[2].

People with a learning disability are also 5 times more likely to be treated in hospital for issues that would typically be dealt with through primary care services[3].

Despite longstanding equality legislation, people with disabilities often have to advocate for changes and adjustments so as to access a space equally, or simply at all. This can be incredibly difficult when it comes to accessing primary care settings at a time of need – when one is likely to be experiencing ill health, pain or distress.

Fundamentally, barriers in primary care settings and primary care buildings mean people do not access health services when they need them and have poorer health and wellbeing outcomes as a direct consequence. Whilst it was evident in our research that the attitude, skills and training of people working in primary care are vitally important, it was also clear that the spaces themselves can make the difference in terms of achieving good patient care and better patient outcomes.

At a time where primary care services are becoming ever more important – through social prescribing, health and care integration and the development of Primary Care Networks, the needs of patients who have a disability must be considered at every level. This includes the development of the primary care estate and in innovation within existing buildings to improve the experience of people who have a disability and those that support them.

We believe that patients should be afforded independence, choice, control and dignity in primary care settings and we know that these elements can be both enhanced and diminished by the physical environment in which primary care services are delivered. Being able to stay relaxed, get around easily and use services in a simple and efficient way were all viewed as important aspects of good primary care buildings amongst participants in our research.

We would like to thank everyone who has contributed to **#MyGPandMe: Building Better Together**... through our online survey, workshops and site visits.

Above all, this report underlines the need to involve people with lived experience in the development, design and improvement of services, so that their voices are not lost where they matter most.

> "Sometimes you don't feel like speaking up if you're unwell."

[1] Through an online survey, workshop and site visits
[2] LeDeR 4th Annual Report, Learning Disability Mortality Review, University of Bristol, 2020
[3] Being Disabled in Britain: A journey less equal, Equality and Human Rights Commission, 2017

2. How people feel about their primary care settings

The following insights were gathered through consultation with people who have disabilities before the start of the COVID-19 pandemic. Reflections on the experience and impact of the pandemic can be found at the end of the report.

Encouragingly, 65% of disabled respondents felt that their primary care setting met their needs.

A significant proportion of people stated that they **felt happy** (48 %) in their primary care setting.

Importantly, 14 % of people who have a disability said they **felt unsafe** in primary care settings.

Levels of satisfaction were generally lower amongst people who supported someone in health services.

Only **43%** of supporters felt that the physical environment met the needs of the person they supported and only **39%** felt it was easy to support the person they supported whilst at the surgery or health centre.

22% of supporters did not feel any elements of the primary care setting were good in relation to meeting the person they support's needs.

There are number of possible explanations for the disparity in perception and satisfaction between patients and those supporting them...

1. The survey was structured with different sections for different groups.

People supporting someone in primary care will most likely be supporting someone who has a higher need for support and is thus more likely to encounter significant barriers to access in services.

The response of supporters to our survey may be slanted towards this cohort of people, who may be more likely to have negative experiences in health services on account of those barriers.

2. Research recognises the potential for influence and bias in the views of people with intellectual disabilities.

People may be more suggestive or open to persuasion - to say things to please people or say what they think people want to hear.

3. Some people may not be asked for their views very often and will be unsure due to the lack of experience of being asked to have their say.

Patients may have had negative experiences with primary care buildings that supporters have observed and highlighted in their responses, but that patients themselves have not.

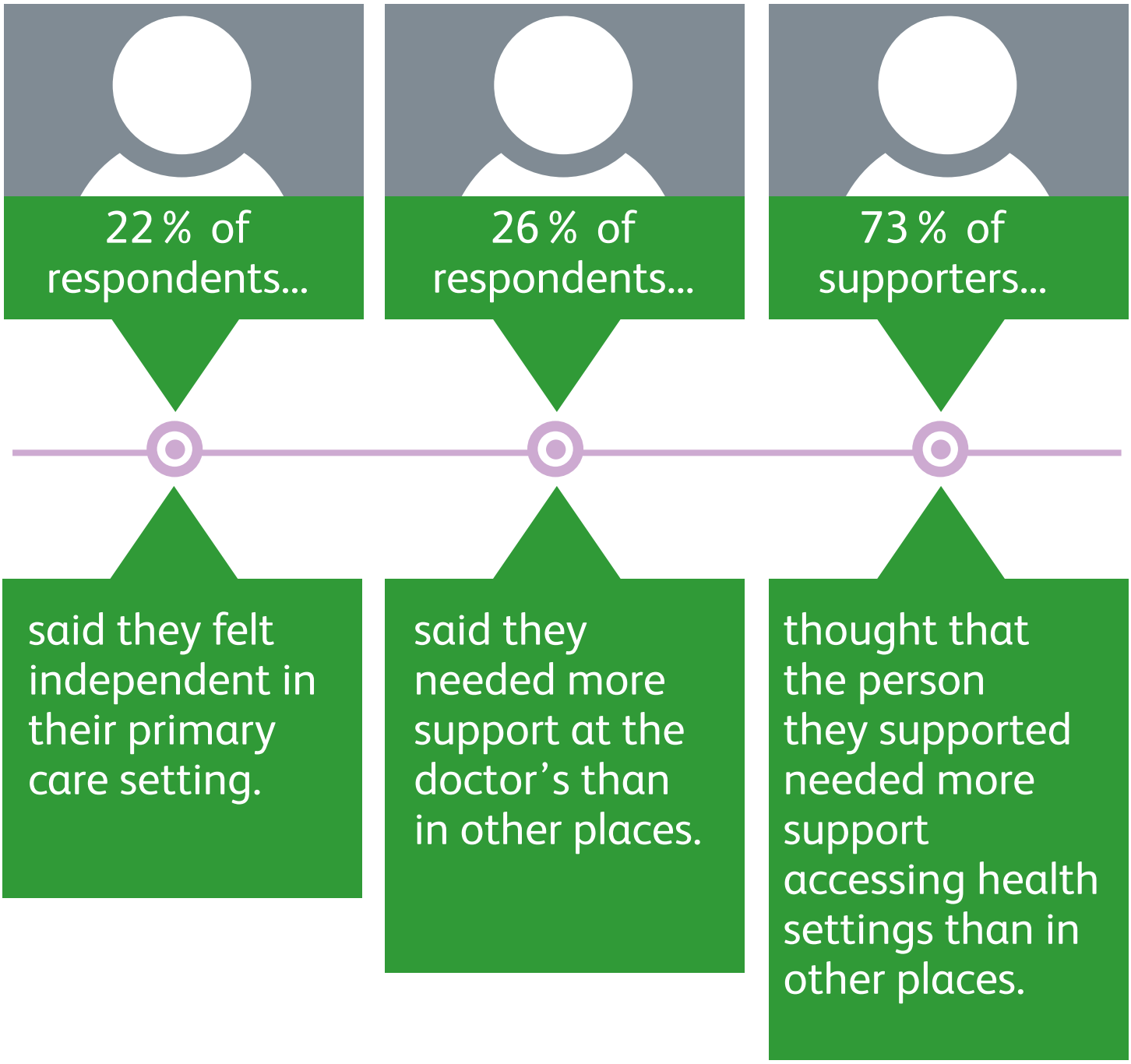
Nonetheless, consistent themes arose within the feedback that was provided by people who have a disability and their supporters, despite some disparities between the two groups in the quantitative analysis of each cohort's perception of and satisfaction with services.

The following section of this report outlines these key themes and highlights examples of good practice in primary care settings.

Independence, choice and control

A strong theme in feedback from people who have a disability and their supporters, was that primary care settings should ideally enhance, and certainly not limit, patients' independence, choice and control.

Participants in our research highlighted examples of difficulty in navigating a primary care setting without support, and of finding themselves reliant on others to access primary care spaces.



Signage

Clear signage is an important part of building design when it comes to enhancing independence.

Only **18%** of supporters thought the person they supported could understand the signage in their practice.

Half of disabled respondents said they could not understand the signage at their GP practice or health centre.

Feedback included good practice examples of large print signage, colour coding and effective announcement systems that enabled people to make their way round the primary care setting with more independence. Other participants noted that more symbol-based signage would support them to get around and that notice boards could be too small and difficult to read.

We asked people what the issues were at their primary care setting and what could be improved:

"Make it easier to know when I am called – with a display. I NEVER hear when I am called or where to go. The doctor has to waste my 15 minutes coming to find me!"

"Much larger text on visual displays to say who the next patient is and where they need to go!"

"The signs can be small and confusing at the doctor's."

"There is not enough easy read leaflets or information for disabled people."

Getting around

Another key element of enhancing independence is ensuring that patients can get around a setting easily. Encouragingly, 71% of disabled people said that it was easy for them to get around their practice on their own.

Participants raised the need for handrails in corridors so that they could guide themselves around when they had a visual impairment.

A significant number of participants highlighted the need for automatic doors that would enable them to move around in a wheelchair, without relying on others to open and hold doors or to support them to manoeuvre through awkward spaces.

We asked people what the issues were at their practice and what could be improved:

"Automatic doors, indicator monitors to help people with hearing issues."

"The doorways into the building not ideal, no automatic door. The doctors or nurses doorways not good for wheelchairs."

"Someone always needs to hold the door so they can get in the building in their electronic wheelchair. This lack of independence leads to a lack of dignity. It's not something I want to go through."

Dignity

It was evident from feedback that people did not always feel like they were treated with dignity and respect when they accessed primary care settings.

This theme is closely linked with independence, where patients can exercise choice and control over what happens to them in primary care buildings. Participants also highlighted situations where the physical environment left them feeling exposed or embarrassed.

It was clear that there was an overarching indignity that can arise when people are unable to receive the right treatment at the right time on account of the physical environment.

For example, some patients could not move out of their wheelchair because a hoist was not available, meaning they couldn't receive appropriate treatment and investigations.

These barriers underline a fundamental inequality for people purely on account of them having a disability.

> "People did not always feel like they were treated with dignity and respect."

Privacy

Availability of private space was cited regularly by participants. Given that many patients and supporters experienced anxiety and stress when accessing primary care, the availability of private space to speak to reception staff was important.

"Open reception – no privacy when there are communication challenges."

Some participants explained that stress and anxiety could lead to them finding it hard to cope, resulting in them leaving the practice all together and missing their health appointment.

For people who experience communication difficulties, a private space where they could engage with primary care staff and communicate at a pace and in a way that works for them was vitally important.

"At the reception you feel like you can talk to people in private but at the same time it is visible and approachable."

"The doctors have a room where I can chat to the doctor and he supported me by writing a letter to support my PIP. Doing this meant less stress for me and made me feel supported."

Reception facilities

Alongside privacy, the setup of reception could leave people in undignified situations. For some, there were barriers to communication and important interpersonal connection with staff because the building was not set up to meet their needs.

Not being able to make eye contact with reception staff, or having to engage with someone looking down at them, were issues that undermined people's dignity in primary care settings.

Overall, 37% of supporters agreed that the reception in their primary care setting was good, compared to a considerably higher number of disabled people (72%).

"Desk level has recently been lowered at a GP surgery, allowing staff to talk directly to the person in a natural way."

"Staff are behind a high desk so not face to face with wheelchair user - it's non accessible."

"Counter is too high for wheelchair user's comfort."

Toilet facilities

A further clear theme was the lack of appropriate toilet facilities within primary care settings. A gold standard for facilities would be the availability of Changing Places toilet facilities.

Less than half the survey respondents felt toilet facilities met people's needs, undermining dignity.

Some participants highlighted having to rely on supporters in order to use toilets, or simply having to wait until they got home as the facilities at the primary care building could not meet their needs. This is clearly an unacceptable position for patients with disabilities to be in.

"No suitable toilet facility. Not enough space for wheelchair to manoeuvre."

"Toilets have been too small to use – often I've just waited until home."

In March 2020, the government announced a new fund and changes to building regulations so that all new buildings must include facilities meeting the Changing Places standard.

Feeling relaxed

One of the strongest themes from our data was the level of stress and anxiety that people experienced in primary care settings.

This arose not only because primary care settings are where one goes when ill or in need of medical care, but also because the environments could intensify people's anxiety or present barriers that they knew they would have to work to overcome.

33% of disabled people said they felt stressed going to the doctor and 43% said they felt worried.

For disabled people who said their primary care building met their needs (65%), only 17% felt stressed and 35% felt worried.

49% of supporters said they felt stressed in primary care settings and 55% said they thought the person they supported felt stressed in primary care settings.

Of those who agreed the primary care building met the needs of the person they support (43%), only 35% felt stressed.

This contrasts with those who disagreed that the building met a person's needs (34%), of whom 70% felt stressed.

Sensory environment

Sensory elements of buildings had a significant role in people feeling comfortable and relaxed in primary care settings. This included the waiting areas, appointment rooms and corridors.

There were a range of views when it came to lighting levels and noise levels. Some people felt that it was important to have lower lighting, whilst others appreciated brightness in their GP practice.

25% of disabled respondents said that there was too much noise or light in their primary care building.

Similarly, some people who have a disability said that background noise, for example music playing or a radio, exacerbated their anxiety and discomfort, whilst others felt that these things could make the space more homely and enjoyable.

Overall, **25%** of disabled respondents said that there was too much noise or light in their primary care building, making it difficult for them to cope and only **32%** of disabled respondents agreed that the noise level in their primary care building was good (e.g. phone ringing, other people talking, music playing).

Participants raised the need for a quiet waiting area that could be used as a space for people who found it difficult to wait in the main waiting room.

Only **20%** of supporters said there was an appropriate quiet space for the person they supported to wait at the practice, though some feedback cited practices using empty appointment rooms as waiting spaces or having a system that enabled people to wait outside or in their car until they were called for an appointment.

Décor

Generally, participants wanted primary care settings to feel friendly and welcoming.

Feedback from workshops highlighted how things like plants, bright colours and comfy seating could help make people feel more at ease during their health appointments.

Contrastingly, poor layout of furniture – so that people had to sit too close together or facing each other across a room – added to people's anxiety.

58% of disabled respondents agreed that the décor in their practice was good and a large majority (**84%**) agreed that their primary care setting was tidy and neat.

> "Feeling anxiety and stress could lead to patients leaving the practice and missing appointments."

People who agreed that the décor was good were more likely to have positive sentiments about being in the environment, with **60%** feeling happy, compared to **48%** overall; and **60%** feeling relaxed, compared to **44%** overall.

This is important when set against participants' feedback that feeling anxiety and stress could lead to them leaving the practice, missing appointments, avoiding seeking medical care and ultimately not receiving the support they need to stay healthy and well.

People who agreed that the décor was good were more likely to have positive sentiments about being in the environment.

3. Patient care and customer service

Whilst this report focuses on primary care buildings and environments, it is important to acknowledge the significant amount of feedback we received relating to the service patients receive when they attend primary care settings.

In workshops and in the survey, respondents said that increased awareness, training, skills and knowledge were needed around a range of disabilities to ensure that primary care staff could effectively meet the needs of patients who have a disability.

Dimensions' work through the '#MyGPandMe: Making Primary Care Fair' campaign has set out some of the major barriers in staff understanding and training. Considerable work is now underway to support primary care professionals to meet the needs of patients who have a disability.

Though a separate area for attention and reform, there is a clear link between the need for primary care staff to be able to meet the needs of patients and the environment in which they work.

Firstly, meeting the needs of patients should not rest solely on individual staff members having the capacity and willingness to overcome significant barriers in the built environment.

Hypothetically, having a member of staff on hand to support a person in a wheelchair in and out of an inaccessible toilet would not be an acceptable solution to a problem with the physical space. Nonetheless, there were examples raised by respondents in which their ability to access the space and negotiate barriers that the environment presented rested almost solely on members of staff being available to support them – such as guiding someone with a visual impairment down a corridor because there were no handrails.

Secondly, where primary care settings are not well suited to meeting disabled people's needs, and also where they are more generally run down or ill-suited to delivering primary care services to an increasing volume of people, it is far more likely that staff will feel under pressure and stressed themselves.

Under these circumstances, there is a higher likelihood that vital interpersonal elements of patient care and customer service will break down.

As with many aspects of this report, such a breakdown is undesirable in and of itself, but is all the more crucial when set against the fact that many disabled people will avoid accessing health care or will end up not getting medical care when they need it on account of the high levels of stress they experience in primary care services.

Primary care settings must be designed to meet the needs of patients who have a disability and eliminate physical and environmental barriers wherever possible, as well as considering how design can facilitate staff members to provide excellent patient care and customer service.

4. Recommendations

Flexibility

Our research found that people value:

- open and approachable spaces
- options for privacy
- ability to change the environment
- balanced sensory aspects.

Involvement

Primary care providers must:

- involve disabled people in design
- proactively engage with them in different ways
- think about how they can reach them
- understand unique perspectives.

Regulation

The Care Quality Commission (CQC) should:

- consider the physical environment in primary care, in relation to inspection domains
- develop Key Lines of Enquiry in relation to the physical environment, accessibility and inclusion
- consider the physical environment in relation to meeting the needs of specific patient groups.

Flexibility

Everyone is different and a person with a disability will experience individual and unique barriers that need to be addressed. For this reason, we believe it is important for buildings to have flexible design so that they are more able to meet a diversity of needs.

One of the clearest examples in our research was around the sensory aspects of a building. The ability to create a quiet, glare-free and low-lighted space for people who need it must be balanced against many people's feedback that a brighter, lively, homely atmosphere helped them to feel relaxed (and distracted from their healthcare concerns) whilst waiting for an appointment.

Similarly, it was clear from our research that people valued spaces that were open and approachable, with enough room to move around.

For example, one participant was calmest when sitting on the floor or moving around the edges of the room to get his bearings. At the same time, people also valued easy access to private space to wait or speak with reception staff, without having to be completely segregated from the practice overall.

Above all, flexibility in spaces – the ability to change sensory elements, to create and remove room partitions and respond to individual needs – makes it more likely that disabled people will be able to access spaces equally.

Too often, the resolution to access needs is to create separate or segregated spaces for people who have a disability, which may overcome immediate barriers, but does not facilitate genuine inclusion – where disabled people are visible and equally valued members of their community.

Flexible spaces that can change quickly to meet patient needs for their short time in a setting will be the ideal way to promote both access and inclusion.

Involvement

People who have a disability must be involved as far as possible in the design of new primary care settings and in renovation and innovation of existing settings.

Primary care providers should be aware that people who have a disability may be less likely to participate in patient forums and feedback groups, often for the same reasons they may find it hard to access actual healthcare settings.

Proactively engaging with disabled people to gather views about building design and environments is vitally important to ensure that primary care settings meet people's needs.

Many people gave feedback that people who have a disability should be brought in to consult on new design – to highlight potential barriers and offer perspective from lived experience.

In particular, people with lived experience will have insight into the reasonable adjustments that can be made to facilitate access and inclusion.

To this end, it is important that primary care services are able to facilitate meaningful participation from a diverse range of people.

This can include contacting Disabled People Organisations (DPOs), self-advocacy groups and members of the local community to involve people. It should also involve the use of best practice approaches to gathering people's views, so that people who have different communication needs are able to participate equally.

A valuable aspect of our research was the use of site visits, where disabled people audited their own practice and highlighted both key barriers and good elements from their personal perspective. This model is one that primary care settings could implement to gain feedback easily and quickly – it is also one that many DPOs can be commissioned to deliver.

Regulation

Primary care services are regulated services. Currently, the Care Quality Commission (CQC) inspect GP surgeries in relation to the service they provide to certain patient groups, including 'People with long-term conditions' and 'People whose circumstances may make them vulnerable' – both of these groups are likely to include patients who have a disability in any given practice.

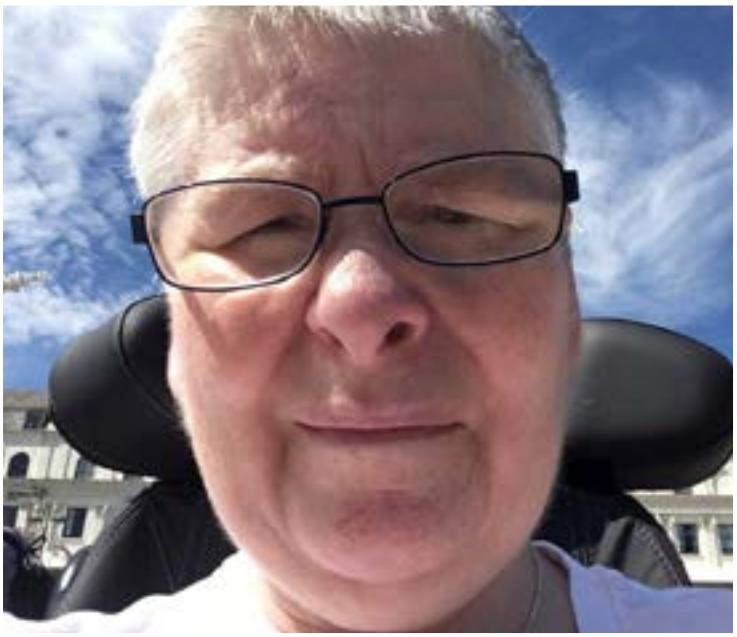
Services are inspected in relation to being Safe, Effective, Caring, Responsive and Well-led.

These inspection areas relate predominantly to the service provided to patients and not the physical environment of the setting itself.

Nonetheless, as this report highlights, the space in which patient care is delivered can have a significant impact on the quality of care. Key Lines of Enquiry should offer the opportunity for inspectors to explore the relationship between the physical environment and patient care.

The CQC are also in a good position to consider access issues within primary care settings, particularly as they relate to legislative frameworks, such as the Equality Act 2010 and to highlight examples of good practice and innovation in inspection reports.

Conclusion by Ann McCallum, self-advocate and Dimensions Quality Consultant



For me, this report has been a long time coming. Feedback from people who have a disability shows that something needs to be done to improve experiences in primary care.

We've got to get it right for people in the future, in new buildings.

At the moment, there are people who need to get to their surgery, but they can't because of reasons that are beyond their control.

I know from personal experience that people can get a fear of doctor's surgeries and hospitals – but I know that if those places could get things right for me, then I might be a bit more forthcoming.

People's health and wellbeing is important. In fact, it's paramount. We need to make healthcare as simple and easy as possible.

There will always be some fear, of not knowing what the tests results will say or how things will go, but it can get blown out of proportion when the whole process is difficult, from making that initial phone call, through to attending an appointment.

I think the relationship between patients and their doctor is really important, but you need time to build it and it's a lot easier when you are more relaxed.

It won't be easy to get it right for everyone, but I hope that this report will make a difference. I think we are already making a difference by asking people for their views.

For me, this report has given the tools to people so that they can change things for the better. It's important that people with disabilities see this report and have the confidence to ask for better in their primary care settings.

'#MyGPandMe: Building Better Together' is starting a conversation. Knowing that people have read this and are discussing what they need with their families, supporters, doctors and others will be a success in my eyes and in the future, I hope people who have a disability expect new buildings that are right for them and have a role in designing them.

"This report has given the tools to people so that they can change things for the better. It's important that people with disabilities see this report and have the confidence to ask for better in their primary care settings."

Observations during COVID-19

In light of COVID-19, we undertook some follow up research to examine the impact of the pandemic on primary care for people who have a disability.

The capacity and resilience of primary care services have been tested during the coronavirus, leading to reflection on what the future of healthcare services might look like. Physical spaces are a key aspect of this.

A clear theme in feedback on the COVID-19 period is that people very much value the opportunity to visit health services and receive healthcare face-to-face.

People prefer face-to-face

Despite the numerous issues that this report highlights in relation to access, stress and anxiety when going to a primary care building, it remains the case that visiting the doctor in person is very important.

Whilst respondents recognised that telephone consults could offer solutions to some health issues, it was clear that this was context specific. Examples included the need to have in person appointments for people who do not use words to communicate and for people who require tests, such as blood pressure checks.

Some noted that, where it was suitable to have an online or phone consultation, it could be beneficial to avoid visiting a primary care building. This was particularly true of people who felt high levels of anxiety in their GP practice or health centre.

However, there was no feedback suggesting that a complete move to virtual delivery of health services would be appropriate.

It is likely that the coronavirus will add to people's sense of anxiety going to primary care settings. People who have a disability also have a higher incidence of underlying health conditions that may mean they have been shielding during COVID-19. Building design for the future will need to accommodate the health needs of people who experience these risks and support people to feel not only relaxed, but also safe in health care settings.

Conclusion

Finally, we believe that a transition to delivering more services online and by phone, where appropriate, offers an opportunity to reduce the number of people accessing primary care buildings overall.

This may prove invaluable in creating the sort of environments that people who have disabilities want in primary care buildings – spaces that are comfortable, flexible, easy to navigate and not overcrowded or overwhelming.

Primary care services should consider how they can use this opportunity to better meet the needs of a patient group that too often struggles to access services effectively and that experiences considerable health inequalities as a result.

"There was no feedback suggesting that a complete move to virtual delivery of health services would be appropriate."

#MyGPandMe

Dimensions provides evidence-based outcomes-focused support for people with learning disabilities, autism and complex needs. We help people to be actively engaged in their communities.

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