

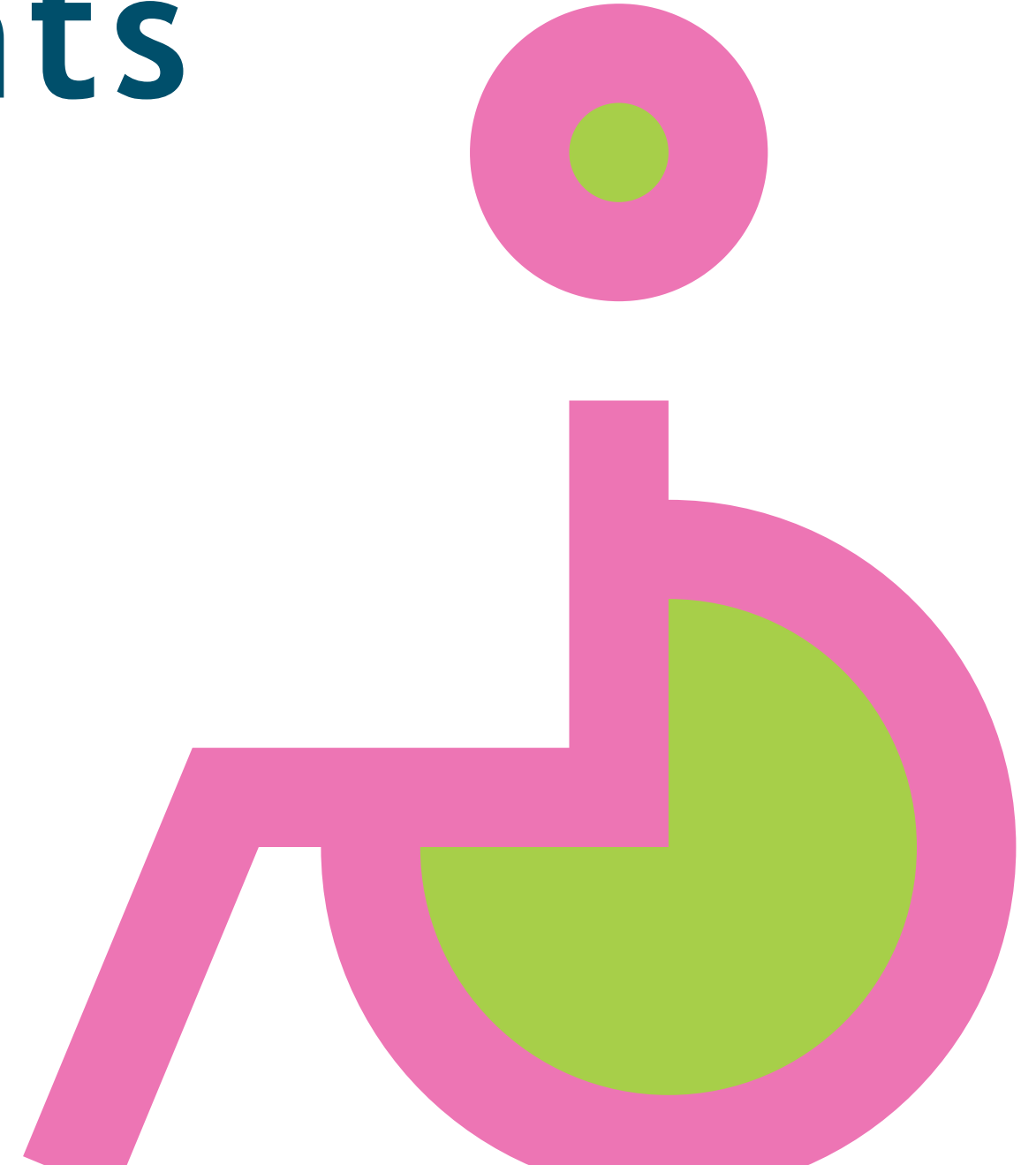


healthwatch
Tower Hamlets

Community Insights

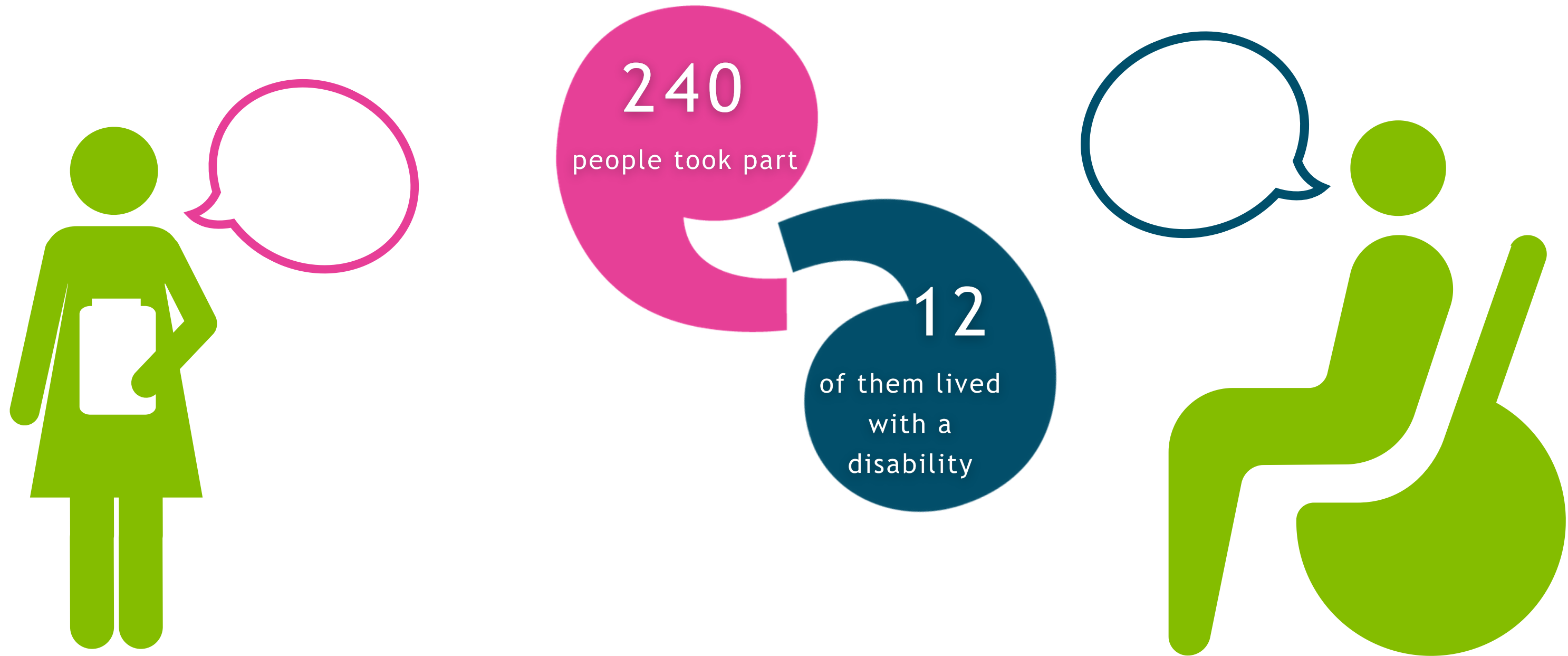
Focus on disabled people

2020



Neighbourhood conversation

In December 2019, we asked local people what makes their neighbourhood a good place to live and how we can support them to live healthier lives. They took part in structured interviews at four locality events in local libraries on the main market days in the area.





In-depth interviews 2020

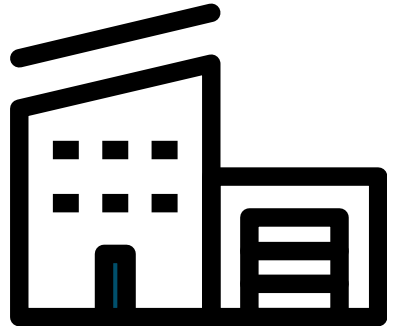
Integrated Domiciliary Care

Between July and September 2020, we carried out in-depth interviews with people who received domiciliary care from professional carers. We talked about their experiences with health and social care services, as well as about the wider impact that living with a disability and/or their care needs had on their well-being.

13
people took part



What we learned



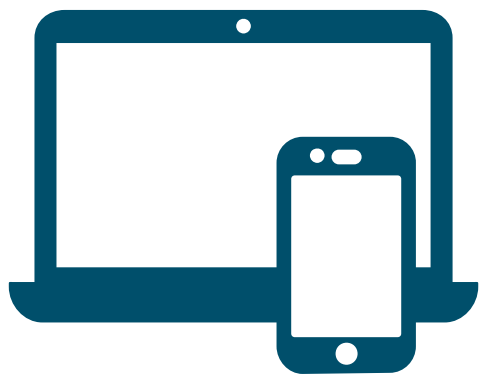
Disabled residents were **less likely** to think their local area was a good place to live, to feel supported to make healthy choices in their local area, to be satisfied with air quality in their neighbourhood, to feel safe in their local area and to be satisfied with their home and where they lived.



Disabled residents reported **lower levels of happiness and well-being**; some of them felt helpless and disempowered in relation to their conditions. A pleasant, warm relationship with carers can significantly contribute positively to disabled people's mental wellbeing.



Supporting disabled patients with **medical treatment** can be a trial and error process and they don't always feel they are receiving the right treatment. Personal care and home adaptations can help disabled people maintain some degree of independence, but the scope of what they can achieve is limited.

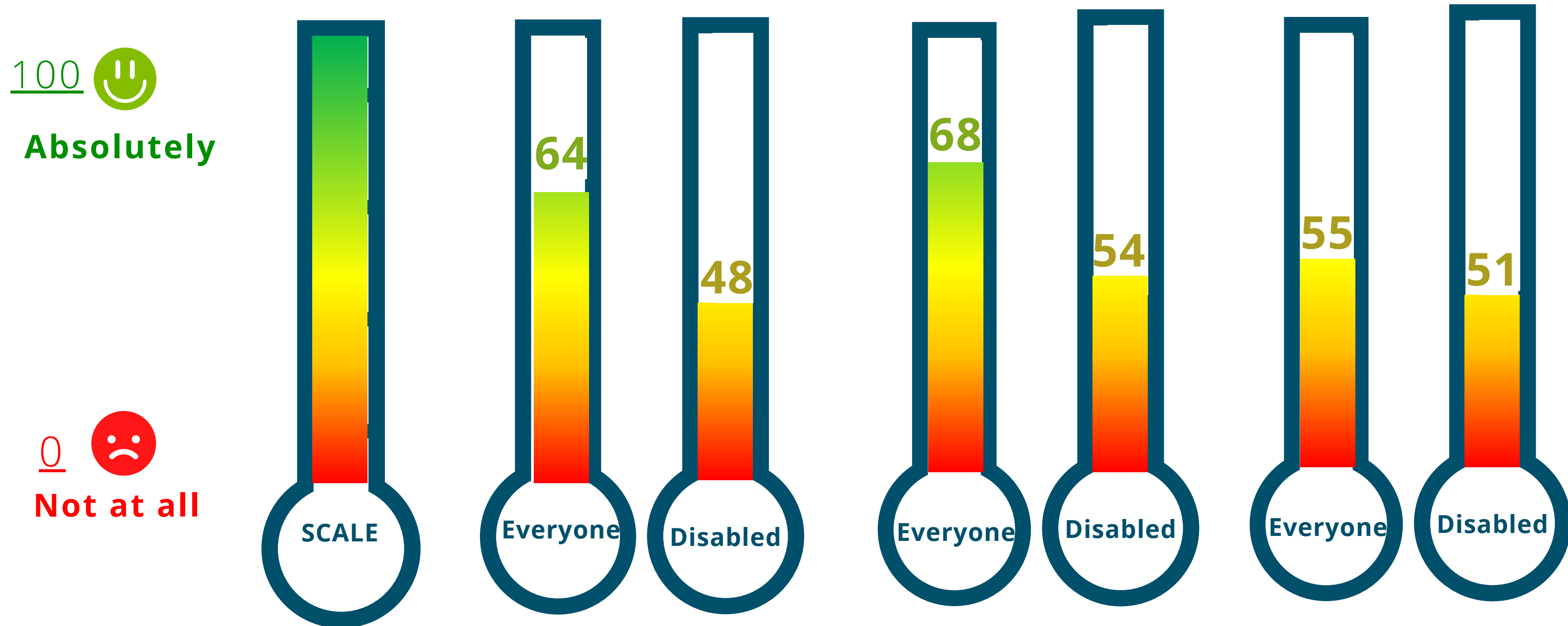


Innovations in access to GP services, which may make them easier and more efficient to use for the general population, can be challenging for disabled residents; particularly those with learning/ sensory/ processing disabilities that impact reading comprehension (such as dyslexia) and those who face further barriers such as a low level of English or digital exclusion



Living in Tower Hamlets

Disabled respondents to the Neighbourhood Conversation had a poorer experience of everyday life and living in their neighbourhood than other respondents.



Do you think your local area is a good place to live?

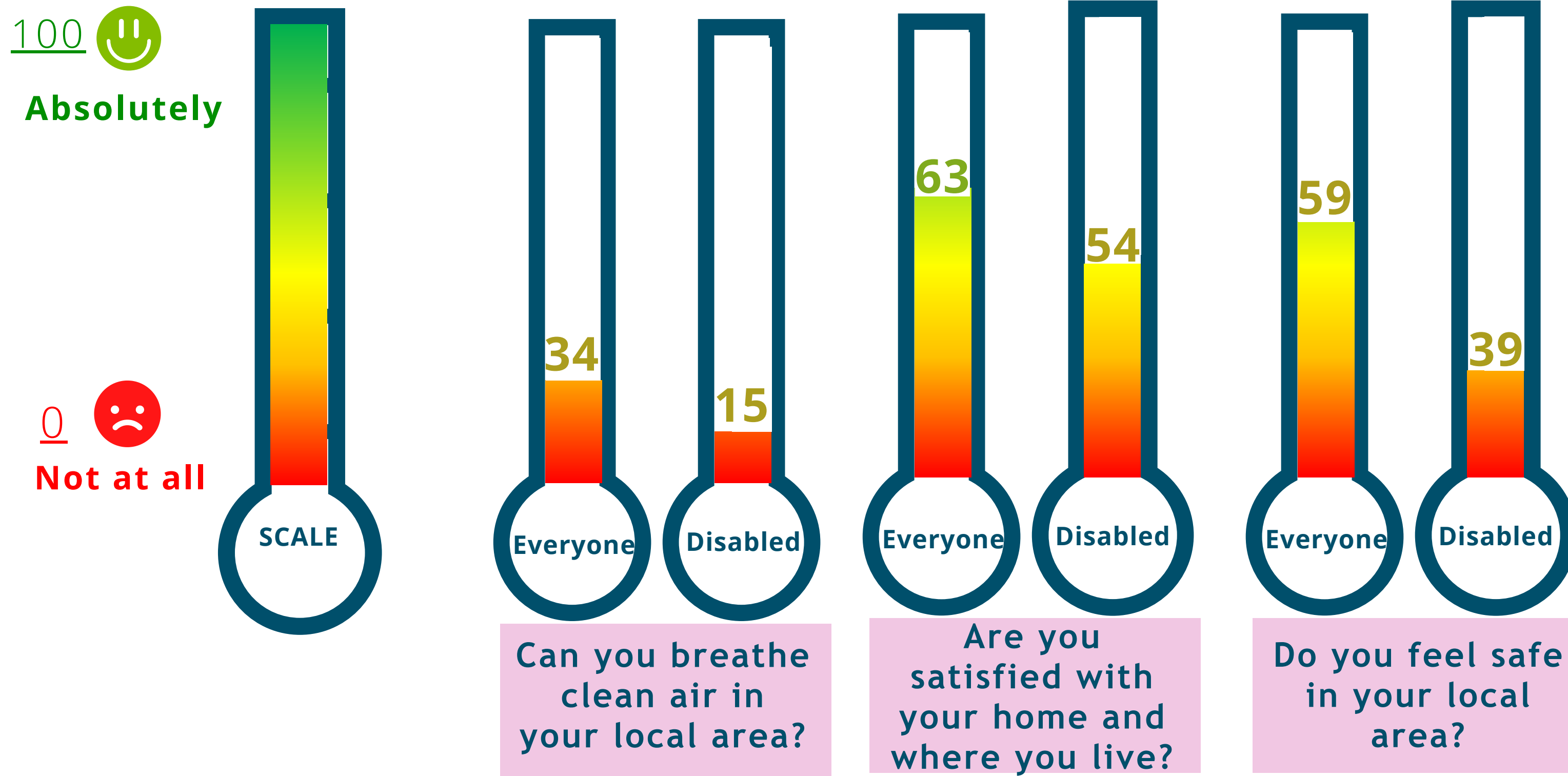
Do you have a good level of happiness and well-being?

Do you feel supported to make healthy choices in your local area?



Living in Tower Hamlets

Disabled respondents to the Neighbourhood Conversation had a poorer experience with everyday life and living in their neighbourhood than able-bodied respondents.





Accessing treatment for managing disability

Patients who took part in our in-depth interviews shed light on the challenges they faced in receiving care and treatment for managing their conditions. Supporting disabled patients can be a trial and error process and they don't always feel they are receiving the right treatment.

Medication

My husband has Parkinsons, and he dribbles. He's had Botox for it, but...It was fine to start off with, but then obviously it was no good, so the Botox stopped, and then they give him drops to go under his tongue, but the drops under his tongue, if they didn't go under the tongue, they hallucinate him, big time. The district nurses done it, but they put it on the tongue, so I come come from work and he was really, really bad, hallucinating, had to come off of them straight away, because that was down to the nurses. He's had the patch on he arm, no good... it might work for a couple of days. He's had the medicine, no good, but now they're going to try another patch, and the Botox again. Th drops and patches are supposed to stop the dribbling, but they only work for a short while.

Physiotherapy

My husband has Parkinsons. We had the physio about two years ago to do exercises with his mouth - couldn't do it. Then, same as his back, where he's like 90% over, and they told him that, gave h imall exercises to do, he wouldn't do them. So if he would have done this, I don't think he would have been bent over, but he's completely bent over. Smashes his head as he's walking.

I have a physiotherapist for my arthritis I can't see them enough (only once a month). It would be good to go more frequently.



Accessing treatment for managing disability

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Independence and mobility

My husband has Parkinsons. The occupational health give him a recliner, because I said that bed is not really any good. He's got a hospital bed, but I said he needs a bed that goes into an armchair or something, so he can get up. They said they don't do them. He tries to go to the toilet at night, and then ends-up not being able to get up from the toilet seat or floor. And when I do try and get him up and push him on the bed, he start screaming because of the pain in his back and all that. But the GP said if it happens anymore, just phone 999 and get an ambulance out. He needs a downstairs toilet, but as you know it's a health and hygiene thing to have the toilet in the kitchen, so you cannot have a toilet in the kitchen, so they put a stair lift in.

Personal care

I fell down, twisted on my back and broke my ankle. My social worker arranged some people- it's not like she was a social worker, she was a human being. She helped me install a landline at home. And she would ring me up every day to check on me.

If I didn't have my carer's help I don't think I would be alive today. She mops every day, she washes up, she won't let me do my own breakfast- she spoils me, she does everything.

It's the small things like the washing up... There are a lot of things that I can't do because of my back injury.



Primary and specialist health services

We asked respondents to the Neighbourhood Conversation and in-depth interviews to give feedback on any health and social care services they have used.

GP surgeries

Getting a GP appointment when I need one is somewhat easy. Very good GP. I'm happy with my Doctor.

Dr [Name] is very good. She's given me her direct number as I'm on the priority list. I can ring her directly re prescriptions etc and they get sent straight to the pharmacy for me to pick up. .'

Accessing GP services used to be all right. But now you can't pick up the phone and talk to them, you have to go through e-consultation and you have to fill in all the things before you can speak to your doctor or get your medicine. It's a bit long-winded to speak to a GP, they sent me a form but I'm dyslexic and I can't read when I have dizziness spells.

No one helps me with getting a GP appointment, so I have to rely on the receptionists speaking Bengali.

Other health services

I'm paying for acupuncture but would like lymph node drainage but I can't afford it.

I go to Glass House Fields (CMHT). They help with everything. Very nice. Help with benefits and everything.

I received treatment for breast cancer at St Barts and stroke care at the Royal London. Never had a problem with any.



Wider determinants of health

Some of the respondents to in-depth interview experienced **poor mental health**, including feelings of helplessness, hopelessness and apathy, or grief in relation to not being able to do certain things anymore.. They felt able to talk about their mental health with the professionals treating them, but felt that the scope of the help they can realistically receive was limited.

I haven't really have any goals, because I just think I got this for the rest of me life... it's only going to get worse, so what can I do. Sometimes I talk to my nurse and sometimes to my psychiatrist and sometimes I just keep hold of things. Cause I think no one can help me.

My husband suffers from Parkinsons. He used to be a painter and builder when he was well. We've let him try, you know what I mean. There was a little thing. He said, 'can I paint?', I say yeah. I give him the paint, the paint brush. It was like a hook. He missed half of it, but it was paint everywhere. And I said, well, you can't do it. We give you a thing to do. You can't do it. So what you want me to say, 'you've done a good job', and you haven't done a good job. So and that was it, now he can't do the painting.





Wider determinants of health

Respondents to in-depth interviews valued being able to have a personal relationship with their carers; the extent to which this happened varied. When carers had a warm and pleasant relationships with the people they were looking after, this had a positive effect on the mental health of disabled people.

There's no real relationship with my carers. They just come, do the job, and leave as quickly as possible. Years ago... I used to have a carer, she was from a different agency. She used to come and she didn't need to do anything, she just sat down and talked to me for an hour.

When my carer sees I'm a bit sad, she gives me a hug. She loves me- I'm like a mother to her. She's such a lovely woman!

My relationship with my carers is good, and they are good to me. I have a friendship with them and I like to chat with them about cooking, life stories and domestic life.

As soon as my carer comes in, she cheers me up. She's fantastic, best friend in the world to me. She was singing this morning as well...



Next steps

We've only spoken to a very small number of disabled people. More work is needed to find out from disabled people what would help tackle what appears to be poorer outcomes.

We would like to work with a range of health and voluntary sector partners to undertake a participatory appraisal based insights gathering project with disabled people.

We would engage with different disability groups including:

- physical,
- sensory,
- mental, and
- learning disability.

Within those groups we may focus on:

- digital access,
- Black, Asian and minority ethnic disabled people,
- carers and
- younger people.

