

Another planet? Disabled and Deaf Londoners and discrimination

The interim results of the Disability Capital 2003 survey

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Greater London Authority
December 2003

Published by
Greater London Authority
City Hall
The Queen's Walk
London SE1 2AA
www.london.gov.uk
enquiries 020 7983 4000
minicom 020 7983 4458

ISBN 1 85261 550 8

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Photographs directed and produced by a small group
of disabled people through Hammersmith and
Fulham Action on Disability.

'The aggressive stuff is more easy to deal with somehow - it is just a shock when somebody crosses the street to spit in your face. When people dismiss you and exclude you and treat you like you are from another planet, that is when the veneer cracks and tears flood inside.'

Foreword by Ken Livingstone, the Mayor of London

The Disability Capital 2003 questionnaire is my first independent survey of disabled Londoners. I asked disabled people to tell me about their experience of living in the capital and said that we would publish interim results at the Disability Capital Conference on 13 December. I would like to thank all of those people who have taken the considerable time and energy to complete what is a long and detailed questionnaire. The information you have given us presents perhaps for the first time a compelling picture of continuing inequality in our capital. This report represents a snapshot of the reality of the discrimination that disabled Londoners face. Through these pages are represented the actual voice of London communities that continue to face exclusion, disadvantage and discrimination on a day-to-day basis. Some of the issues raised, particularly transport, we are very aware of and are acting upon; others may be more surprising and sometimes shocking.

I very much hope that the Disability Capital Conference can be an active and influential forum for change and begin to set an agenda to move forward disability equality beyond European Year of Disabled People.

Ken Livingstone
Mayor of London

Introduction

This report outlines what disabled people have told us so far about the issues that have the greatest impact on their everyday lives. The Disability Capital 2003 questionnaire is a major survey of disabled people and was launched in August 2003. Its purpose was to find out from individual disabled people what their experience was of transport, housing, support services, access to buildings and the local environment, employment, education and leisure and discrimination and access to public life. It aims to establish what the major barriers to equal participation in London are and what could be done to start to remove them.

In 1991 the British Council of Organisations of Disabled People undertook research into the experience of institutionalised discrimination against disabled people in the United Kingdom. 'Disabled people in Britain and discrimination' by Colin Barnes¹ outlined in detail for the first time the level of disadvantage and discrimination disabled people faced. This report set out the case for anti-discrimination legislation and the fact that the experience of discrimination was a fundamental part of disabled people's lives.

'Behind the opposition to anti-discrimination legislation lie the assumptions of... the medical view of disability, which explains the difficulties faced by disabled people in their daily lives as individually based functional limitations. This leads to the assertion that there are few specific examples of discrimination against disabled people. Neither of these arguments corresponds with the experience of disabled people and their organisations, who argue that most problems faced by disabled people are socially created and that discrimination is an everyday occurrence.'

Twelve years on much has changed, particularly in the field of legislation. However, as this report shows, a lot of the experience of disabled people has not. Disabled Londoners routinely face discrimination in all areas of their lives.

The information in this report comes from an analysis of the 500 or so questionnaires that have been completed and returned either by post or through the online version to date. The amount and depth of information and personal experience provided from the questionnaire is considerable. This information will help us complete the GLA Disability Equality Scheme. The personal experiences quoted here are a small sample of what disabled people have told us from an analysis of 400 completed questionnaires from across London.

The survey remains open until the end of February 2004 and we are hoping that many more disabled Londoners will help us compile a comprehensive picture of how far disabled people continue to experience disadvantage, social exclusion and discrimination. A full report including detailed statistical and demographic information and the scheme will be published early next year following the Disability Capital Conference. The questionnaire can be completed on line at

http://www.london.gov.uk/mayor/eydp-2003/disability_capital.jsp

or hard copies can be obtained from the Public Liaison Unit on 020 7983 4100.

Key issues: Transport

Transport unsurprisingly is emerging as the key issue for disabled Londoners.

- 64 per cent of respondents to the questionnaire so far have indicated that transport is the number one priority for change.
- 51 per cent of respondents made a general comment about the inaccessibility of public transport in London.
- However, around 25 per cent of respondents made reference to the fact that public transport had improved.
- Almost 75 per cent of respondents quoted personal experience about the difficulty of travelling on London buses: ramps not working, drivers refusing to use them, buses not close enough to the kerb, wheelchair spaces taken up by buggies, buses pulling away before people were in place, lack of equality training, inaccessible information and experiencing problems with other passengers.
- 36 per cent of respondents quoted experience relating to the lack of access on the Underground.

Disabled people do regularly use public transport:

- 46 per cent of respondents used the buses every week.
- 32 per cent used the tube and 26 per cent the train.
- 33 per cent used a black cab or mini cab every week.
- 79 per cent never use Dial-a-Ride.
- 29 per cent of respondents said that black cabs were very accessible; the most accessible mode of non-specialist transport.
- Fewer than 10 per cent said that buses, trains and the tube were fully accessible.

Transport: what you told us

‘It would be nice to use public transport and not specialist transport: we are not freaks; we just need reasonable adjustments to get about our daily lives and be independent’

‘I would be putting my life and the life of others in danger while using public transport in London’

‘Accessible public transport is ideal, but one still has to get to the station/bus stop from home and do the same on the return journey’

‘I last travelled on a train in 1996 - it was great to be able to observe things through the window and feel 'out there in the public domain' - very rare experience. Using public transport as a disabled person takes enormous energy’

‘In my experience the transport system in London is abysmal for disabled travellers. My scooter is my wheelchair because I travel unaccompanied and must carry an oxygen cylinder. It is impossible to get a small electric scooter onto a bus or onto most Underground stations. The Jubilee line is supposed to have full access, but even when I check if the lifts are working before I set out they are not in service after I have made the

struggle to arrive. The staff are then totally indifferent to my predicament. It does not matter. NO ONE CARES'

'I was quite impressed with my first accessible bus ride a few months ago! I thought it would be really jerky and bumpy but actually it was smoother than most cab rides and certainly less so than some train journeys I've made recently. The ramps - when they work - are good. It means buses are now accessible to me - a powered-wheelchair user - whereas they weren't before'

'I spent a month in central London as a visitor from 11.08.03 to 09.09.03. I used my Taxicard and the buses. A major issue, regarding buses, centred on driver training. The majority of drivers were reluctant to move to the kerb, or drove off rather than extend the ramp, indicating that they did not have a ramp or did not know how it worked. Drivers who were helpful listened to how to extend the ramp and then were astonished when it worked! Worst experience was having to watch drivers stop outside Charing Cross station and deny they had a ramp. I am fully aware of which buses have ramps. One day I waited long enough to get on the sixth bus. I used my Taxicard excessively because of this situation and will now have to eke out the few remaining journeys until April 2004'

'Modern buses have very few seats at floor level and I find that although these are able for use by the elderly and disabled people like myself, they are usually taken by the young and fit who can not be bothered to walk further down the bus. Limit the number of baby buggies on each bus because they make it impossible for people like myself who have limited mobility to get on and off buses'

'I've been shouted at by a bus driver for taking too long to get my change out of my purse - this is a disability related problem for me, and this happened on a so-called 'accessible' bus - it seems the vehicles are accessible, but the drivers' attitudes aren't. I've also fallen over heavily on buses because a driver has pulled away rather than wait two minutes for me to get to my seat'

'It is hard to see bus stop signs on routes, thus unless you know where you are going, it can be difficult knowing where each bus stops. In addition, on request stops it is impossible for me to see what the bus number is until it is right on top of me. Flagging down a bus when you are the only one at a bus stop and then finding out it is the wrong bus can be mentally painful. The other thing is that a lot of drivers of these buses are not very helpful and look at you like you are strange when you ask them where you are because you are on a strange bus route'

'I am visually impaired. My biggest problems are seeing timetables (the print is usually far too small, in difficult and light font styles), seeing the right bus stop or platform number, and knowing the right stop to get off. Train timetables on screens are almost impossible to see and they are rarely announced for commuter trains. Once on board, both train and bus drivers should call out the stops. It is often difficult to see out of dirty windows, when it is dark or platform signs (especially as they are now white writing on blue background and smaller than the old station signs). There are announcements on the tube so why not on buses and trains?'

'Frequent misinformation, or sometimes no information, on display monitors at mainline and tube stations. As a hearing impaired person it can make trips interesting if one ends up on the wrong train or branch of the tube'

'I travel with my two children on two buses every day just to get them to school because there is no direct bus route to their school. My nine-year-old son has a disability but because he has no need to attend a special school, I do not get any help with getting him around. I cannot drive and cannot afford a car. I find the service we have to use appalling. The buses are never on time, are overcrowded and dirty. I have found getting on and off and travelling on the buses difficult and unsafe with young children, particularly one who has a disability. I have found most of the drivers unhelpful and rude, they drive like maniacs and are careless when people are getting on and off the buses'

'I enjoy getting the bus because you can at least attempt an interaction with the driver to ensure that you are able to board safely - even if you do sometimes have to insist on them lowering the step or they pull up miles from the kerb or they move off before you are seated safely. Some drivers are extremely helpful and sensitive, others are diabolical'

'Could a more rigorous effort be introduced to persuade able-bodied to give up their seats to older passengers? I saw a very frail old lady standing on Saturday morning, clearly frightened that she would fall (I was standing). A persuasive advertising campaign might make this a pleasanter capital altogether'

'Only public transport I have used is a London bus. I have mixed feelings. On buses that are accessible and with ramps working adequately, the journey is acceptable. When ramps are not working, the journey can be made longer by having to wait for another bus which is not guaranteed to have a working ramp. Also if another wheelchair is using the bus already, it is not possible for a second wheelchair user to board. Frequently the kneeling buses don't kneel. However, being able to use a bus, however haphazard the experience, is intensely liberating'

'I was going to Islington. I took the Underground from south London, but it was awful, almost a hundred stairs with no lift. The staff suggested lifting me out of my wheelchair, which is not appropriate and difficult for me. Someone who knew how to handle a wheelchair helped me mount the platform area, but still, there were problems with the train doors and the kerbs were too far from each other. I arrived at Victoria which was OK, but where is the accessible bus? I have to wheel about six miles to reach only one accessible bus going to my destination. It was horrible, and I have never tried to travel the Underground and trains again for three years'

'The TfL information line gives incorrect information in three out of four calls regarding steps. Phoning the tube/bus information line asking, 'If I can get a no. 83 bus from Ealing Village, Hanger Lane W5, out of the top of Hanger Lane to transfer to bus 487, will I have to use any steps to transfer from bus 83 to bus 487? What is the distance between the two bus stops?' The tube/bus information staff told me there are no stairs and the distance between the 83 and 487 stops is short. When I got off the 83 bus at the stop specified by TfL, I discovered: I couldn't continue the journey because there were steps down into an underground passage beneath the road to reach the 487 bus stop. I waited an hour in the rain at the 83 bus stop, gave up, called a mini-cab and went home'

'I use the trams in Croydon. I find them disabled friendly and totally suitable for my use'

'One of my main problems is standing for longer than a few minutes so it would really help me if there were seats (and a shelter) at every bus stop'

'I am deaf so I have no physical difficulty in using any form of transport but experience problems in finding out what is happening when a service is disrupted, as I cannot hear any announcements. For example the visual display was out of action at Waterloo main line station today and there were notices up to listen for announcements. Fortunately on the station there is an Info Desk but this is not the solution when you are already on a train and a fault or delay occurs. The same is true on the tube - while displays on the board show the destination of a train it is a pity they aren't used to inform people of delays etc too. In view of the recent power failure business I'm glad I wasn't caught out - that would have been a nightmare as I am totally reliant on lip reading'

'Buses can be a bit of a lottery as the number is not always very legible, even when on the side and therefore lower and more accessible. This is one area which could be addressed easily and without great expense'

'As a powered wheelchair user, I am often told by some drivers that powered wheelchairs are NOT allowed on buses because they have batteries. I have also found out that one particular bus company has a policy of NOT carrying any powered wheelchairs'

'The new buses are a huge improvement but only if the driver pulls in to the kerb. It's worrying when you're getting off out of the driver's sight - I've often had the door closed on me! Having said that - the old Routemasters are completely inaccessible'

'I am a 16 year old with quadriplegic cerebral palsy. I need total care and rely on my parents to do everything for me. I become distressed and can suffer seizures when stuck in slow or non-moving traffic. On the rare occasion that my parents have attempted to use public transport rather than use their car and drive me to wherever I need to go in London, my father quite literally has to carry me over his shoulder as nearly everything and everywhere is inaccessible. The so-called level buses are NOT, and what is the point of being able to use one or two Underground stations but not the rest?'

'Expensive e.g. I spent £80 in cab fares to go to my uni freshers' ball last Saturday. A lot for a student!'

'I went to a bus stop at Euston (near my work). The first bus that came along had a ramp that was not working. The second had a driver who did not know how to operate the ramp. The third had an enthusiastic driver who stopped beside a lamp post and, despite my cries of warning, released the ramp, so that it crashed into the lamp post! And broke it!'

'We went to the Adelphi Theatre by bus and it proved to be a good way to travel into London. I haven't used a bus for about seven years. The ramps seem to have improved since then'

'Hospital Transport - if I could I would walk to John O'Groats and back again instead!'

'As someone with mobility difficulties, the tube system is impossible, largely due to the 'killer' combinations of steps, escalators and crowds'

'Although I own and drive a car, it is rendered useless to me due to the lack of parking spaces'

'Going places where I've never been before on the tube can be an adventure because I never know if I'm going to be able to get out the other end'

'I don't use Dial-a-Ride because it takes too much time to sort out the ride and I prefer to take my chances with a bus'

‘Generally I find the tube a very good means of travel as screens are accessible, the stations are announced on most lines and the maps and staff are all very helpful’

‘Dial-a-Ride has been given a bad name and personally I think they are unreliable. London Taxicard scheme is a lot better. You don't usually as a rule have to book them in advance too much’

‘Dial-a-Ride is useless: they only want to do clubs and short journeys. Will give excuses not to pick up and will travel half empty’

Key Issues: Housing

- 20 per cent of respondents identified housing as a priority for change.
- 44 per cent of respondents live in accommodation which they own.
- 42 per cent live in accommodation which they rent.
- 42 per cent of respondents live in specifically adapted accommodation.
- 60 per cent of respondents were very satisfied or satisfied that their current accommodation met their access needs.
- 19 per cent were dissatisfied or very dissatisfied.
- Of those people who were dissatisfied, 44 per cent cited stairs or lack of lift access as the reason.
- 21 per cent of all respondents mentioned the lack of accessible housing as a major problem for disabled Londoners.

Housing: what you told us

‘I can't visit friends or neighbours because many homes do not have wheelchair access – leads to social exclusion, if I don't try extra hard’

‘More housing is required. It's the major cause of people living in institutions. Right to buy adapted property. More accessible houses for purchase/lifetime homes’

‘Housing in general is inaccessible and built in an inappropriate and ill-conceived way. There is a lack of security and safety for residents due to poor lighting, dark passageways and too many steps. Tenants are stacked on top of each other in small flats which only serves to fuel tension and frustration. There is not enough free space or opportunities to play and enjoy leisure for young people, which subsequently leads them into petty crime and drugs which often escalates into serious crime. There is a lack of parking spaces which leads to social isolation for the older disabled tenants who require outside contact and support’

‘It took seven years wait from when my name and requirements went on the transfer list till we were actually offered a suitable property’

‘We live on the ground floor and applied for a bath/shower conversion, although it took 14 months. We are very limited with storage space, the electric chair has to be stored in the living room’

‘Visiting deaf colleagues and deaf students’ homes (I’m a deaf worker for deaf students). The entry phone system is big ‘NO-NO’. Need for visuals lights to show us deaf visitors instead of sounds’

‘I have had many housing problems but no interpreter has been provided so my needs would not be understood or met. I have had to pay for my interpreter though I live in a local authority property’

‘I bought my flat on a newish private development five years ago. I understand that all new developments must have a certain number of flats/houses that conform to certain access requirements. But, it is important for the people marketing new developments to know which flats/houses are accessible. In my case I happened upon the accessible flat by coincidence through looking at development plans (before they were complete but after they were on the market) and spotted the flats with bigger bathrooms and wider doorways. The people in the marketing suite had no idea that some of the accommodation was accessible!’

‘The local authority will not allow permission to knock down an interior wall to gain access to the bathroom/toilet. Therefore, my washroom area is within my bedroom area and my wheelchair is too wide for the narrow hallway’

‘I like where I live and I don’t want to move. I have my family and friends around me – the local authority make up different excuses why they cannot undertake adaptation/modification:

- It’s a conservation area
- It costs too much
- If we did it for you, we would have to do it for others
- You can do it yourself
- When you leave, what if the next person that moves in doesn’t like/want that change’

‘The housing issue is one of the most important ones for a disabled person. Having your own house is really important because you can plan your daily living better and make plans for the future as well’

‘Occupational therapists must listen to the views of their clients, respect and actually implement them. Too often people are forced to accept the absolute minimum provision because of budget restrictions’

‘The number of accessible flats is very low. The very word ‘accessible’ is also used very often to describe accommodation which is, in reality, inaccessible. The local authorities must be made to understand that they have to provide accommodation which is comfortable to live in. Perhaps they should look at other countries and take the best practices on board. In any case, disabled people and their organisations should always be consulted’

‘More lifetime houses need building and the designs discussed with disabled people. There is a massive shortage of wheelchair accessible homes. I would like to move, but know I will have no choice because it is limited to where the appropriate house is available’

‘My old flat did not provide what they said they would be e.g. flashing lights, mini-com and a fire alerter. It took 8/9 months to move to another location for work purposes, so I did not have access for the whole time. Even though it is costly, I

would really like deaf people to have those video cameras (one out the front and one inside the house) where we can see who the visitor is. It can be very efficient for those who live in flats to provide access for the visitors to get in (unlocking the door electronically). I feel scared to open the door when expecting a visitor'

'I was living in supported hostel accommodation for five years before getting independent accommodation recently, and my experience was quite bad. I was told by staff that the reason I had to wait for so long was a direct result of my disability, and Council/Local Social Landlords have a lack of suitable properties appropriate to my needs. The hostel was declared unfit for human habitation under s.604 of the Housing Act, and 58 of the Landlord and Tenant Act. The substantial disrepair and general poor condition and maintenance of the hostel caused an independent surveyor to be satisfied that it was prejudiced to health, and therefore a statutory nuisance as defined by s.79 of the Environmental Protection Act 1990. Additionally, my landlords and hostel managers, whilst aware of my disability, did nothing about a fire extinguisher that restricted free access space within the hallway to 650mm. On many occasions, I was literally housebound because of this'

'The lifts are frequently out of order, a shower is needed not a bath and need more space to store wheelchair'

'I only know about local authority housing. Money is so lacking in this sector, you have no hope of getting adaptations'

'I can't get in or out. If there were a fire, I would be stuck. I can't reach the street and am wholly dependent on other people's assistance to enter or leave'

'We live in a borough which has a poor housing stock for the general population. For the disabled population opportunities are even more restricted and the council applies barriers, which makes the situation even worse. Only last week a wheelchair user was saved from eviction by bailiffs who felt that he was too vulnerable to evict. The Housing Resource Centre and social services did nothing to help until the very last minute'

'Disabled people are caught between living in inappropriate, inaccessible accommodation that might be in a bad state of disrepair, whilst facing harassment from neighbours or choosing homelessness as a better option'

'When I had to move house in 1999, there was virtually no accessible housing to view. Even all the new developments had not incorporated 'Lifetime' homes accessible criteria. I had to compromise and buy a house that had half my access requirements'

'As a person with mental health issues, I would feel more comfortable living alone. At the end of the day, when I have had to be sociable with work colleagues, and had to face experiences with strangers in shops and on public transport I would like to go home to a space where I can be myself, unchallenged by others. Unfortunately, because of the cost of housing in the capital I am unable to live alone and have to live with strangers which only makes me feel isolated. I have no autonomy to control my own space'

'I feel that mental health problems because they are not visible 'disabilities' are not taken seriously - where housing in a specific area could make a real

difference to my recovery and eventual return to work, I feel I have no chance of ever getting any help'

'There's not enough! That is, there's not enough that allows for flexibility. If you're a PA-User like myself, you always need a second bedroom just for them, let alone friends or family staying over, which can be vital for a disabled person at times. I would like to buy somewhere of my own but there are very few adapted properties that are for sale and because I'm not in permanent employment, it's near impossible to get a mortgage. Even most shared-ownership schemes are not inclusive of disabled people'

'I have always rented ground floor flats, however now I have bought a house with my boyfriend we have had to add grab rails in the bathroom etc. I wish there was a downstairs loo and often hold off on going so that I only have to go upstairs once or twice a day. However, we couldn't find a house with a downstairs loo in our area and price bracket. I made sure there was a room downstairs that I could use e.g. for resting when I don't want to go upstairs to the bedroom. To some extent this limited the choice of house and also meant we had to get a slightly larger one than we planned'

'There should be a register available which tells people where mobility housing is situated. More of this should be available. I live in a terraced house with twelve steps leading to my accommodation'

'There is little housing for disabled people in London and little for the student market, so students who want to live independently in private housing or on work placements are disadvantaged'

'I live with my parents who, although not yet old, are not getting any younger. Dad carries me up and down stairs. One day, my weight and his age will meet in the middle! We need a bungalow but they are too ridiculously expensive compared to houses. So we need to move out of London to afford the dwelling that we need'

'Housing is not accessible. My mobility is currently not too bad, but my condition varies. When I was in a wheelchair I was carried home from hospital by ambulance staff and then literally trapped in my home as it has steps to it and is inaccessible - my one trip out a week (for months and months) was via a weekly ambulance arranged trip for hydrotherapy. When the ambulance turned up, the ambulance staff would carry me down the steps to my home and into the ambulance and take me to the hospital and then bring me home... I was terrified that my condition would not pick up and this would be my life. I am a disabled parent and had to rely on other parents' help taking my child to and from my home to school and taking my child on outings, etc. Social services only offered 'foster care' for my child, which I refused - I was coping fine with the home and helping with homework, etc. and this was not the issue - at the time I just needed some support and adaptations'

'Can't find accessible student accommodation near my uni, so have to live at home'

'I am lucky enough to have a reasonably well-paid job and own my own flat. It is incredibly difficult to find accessible accommodation. I tried and failed to find somewhere to rent when I first came to London and was more or less forced to buy a flat. The choice of accommodation to buy in London, if you are a wheelchair user, is very restricted indeed'

Key issues: Support needs

Responses so far to the questions about disabled Londoners' support needs indicate that there is a high level of unmet need and heavy reliance on unpaid support.

- 52 per cent of people needing support with housework, cleaning or shopping relied on relatives or friends.
- 18 per cent did not have their needs met.
- The equivalent figures for personal assistance were 44 per cent and 16 per cent.
- 45 per cent of people needing advocacy said that their needs were not met.
- 40 per cent of respondents said that their health care needs were not met.
- 29 per cent of respondents said that their communication needs were not met.
- 64 per cent had heard about direct payments, but only 23 per cent of respondents received one.
- 39 per cent would be interested in receiving a direct payment.
- 27 per cent of respondents paid a charge to their local borough for the services they received.

Support needs: what you told us

‘As an advocate for disabled people, I am in contact with disabled people on a daily basis. In general, they lack support on a personal, domestic and social level. This leads to isolation and distress in the home and people are prevented from participating in the normal day-to-day activities of the community’

‘There is very little support available, and what there is, is not what I want’

‘Direct payment for my personal assistance gives me the control I want over my personal/domestic support. It has made an enormous positive difference for me being able to control who provides my personal assistance and when/how it is provided. It definitely makes a difference in the type and quality of care you receive’

‘Due to financial constraints, assistance from social services is only available for those people with extensive care needs. If a person needs only help with shopping or a bath, they will not get it. Also, access to their services is very complex. You have to be fairly assertive and demanding to get past the exclusion barriers such as initial needs assessments done by phone through an untrained person. People have to exaggerate their needs to get an assessment by a Care Manager’

‘When I moved to London last year, despite already having been on direct payments in Birmingham, the local council insisted on re-assessing me. This meant I did not receive direct payments from May (when I left Birmingham) until mid-July. This meant I had to receive Homecare for my personal care, which is very much a ‘take it when convenient to us’ service, instead of the choice one has with staff employed by direct payments recipients. I found the council staff working for Homecare seemed to have a mindset that they were dealing with geriatrics, which I am not. On one occasion they seriously wanted to put me to bed at 6.30pm’

‘As a person with multiple disabilities, my local authority believes I have to be dying or dead to receive services of any description. With my medical condition, I

need preventative support from social services/health to avoid hospital admission (approximately two weeks before and maybe two to three weeks after discharge), this happens two to three times a year. I have, on several occasions asked for help with personal care which neither myself nor my carer can provide. I rely on family and friends. The council has a budget deficit, so if my condition is critical, I end up in hospital. My husband does not get any support or respite even though he is at breaking point. My needs are not statutorily assessed every year. This is statute, but does not happen unless asked, nothing generally happens'

'I had social services' help after my 2 hip operations (1994 and 1998). I felt that the support should have been free. I had to pay for Meals-on-Wheels and for home care. The care was for shopping and taking my washing to the laundrette. Social services refused to help cleaning/household tasks. The charge was far too much for two hours service per week; some of the carers were unreliable/did not turn up/wasted some of the time when shopping'

'Disabled people are asked to pay for services that are over priced and of poor quality. We are forced to accept less than good enough services that are biased towards the carer to the extent that complaints are not properly heard and abuses go unchecked'

'Disabled people needing personal assistance are the only group of local authority residents who have to pay additional charges for services on top of council tax. It is a scandal. If we have to pay then why not charge for rubbish collection, school fees and libraries for everybody else'

'When my wife was alive, she received money from Independent Living Fund. This allowed us to employ a carer of our choice. She worked for us over many years and became a trusted friend. My local authority plans to start direct payment. Hopefully, this will work for people in the way I.L.F. worked for us'

'Support? What support? I suffer from ME and need 15-20 hours a week help to stop me from deteriorating and with this help I might even get better. I am getting an hour from social services, and have had to fight to get that. Social services have no money so are using loopholes to stop us getting the help we need. What is not acknowledged with ME is that help with one activity will give us energy for another. For example, I am offered help with a bath, which I don't want because it's personal and degrading. What I want is help with housework so I have energy to bathe myself. All my personal affairs are in a mess because I don't have the help to enable me to deal with letters, problems etc. I rarely get out and feel ill when I do because of lack of help allowing me to rest. I feel depressed because I am stuck in an unpleasant home and not able to participate in normal life. This can all be helped with a bit of assistance at home'

'I had nine months of being virtually housebound, relying on friends/family for personal care, shopping, cooking, escorting etc and frequently went without meals, hair washing etc. In nine months, 92 different people came over to help cook, shop, feed me, wash my hair, clean the house etc. Again, everything was a battle!'

'Council is considerate in providing support for disabled people in our area. Most of the disabled people in our area are getting full support from the council social services. Depending on the nature of the disability, the council treats and supports people but dealing with them they do sometimes discriminate racially'

Key issues: Access

Access to public buildings and the local environment was the second most popular quoted area for change. 62 per cent of all respondents listed this in their priorities for change.

Not surprisingly, dropped kerbs, lack of parking, cars parking over dropped kerbs, inappropriate street furniture and lack of facilities for Deaf people were top of the list of barriers.

In relation to local facilities, the percentage of buildings judged to be fully accessible was surprisingly low.

- 53 per cent of supermarkets.
- 48 percent of GPs' surgeries.
- 43 per cent of post offices.
- 38 per cent off libraries.
- 36 per cent of health centres were deemed fully accessible.

- 28 percent of local shops.
- 19 per cent of dentists.
- 16 per cent of sports and leisure facilities.
- 15 per cent of schools.
- 14 per cent of police stations were considered not very accessible.
- 12 per cent of dentists were considered to be not at all accessible.

Of those people interested,

- 47 per cent never go to a nightclub.
- 41 per cent to a sporting event.
- 27 per cent to place of worship.
- 26 per cent to a concert.

The most common reasons for this were lack of access, transport and parking.

Only 36 per cent were able to visit friends, 35 per cent a place of worship and 34 per cent go shopping as often as they wanted.

Access: what you told us

'London's streets are like a minefield for wheelchair users. There are deep driveways through footpaths, holes, missing manhole or access covers, gaps in paving and no dropped kerbs on pedestrian crossings etc'

'My experience is of what wheelchair users experience in trying to get around on London transport, getting into work, offices, services, and spontaneously to pubs etc which is horrendous, almost impossible. Every trip has to be researched in order to ascertain whether it is possible or not'

‘All shops/restaurants/public places should be step free/ramped. Local authorities should be responsible for this, refuse licences without it, and monitor it on an on-going basis’

‘Street furniture is all over the place’

‘I have given cinema/theatre partial accessibility as sometimes I need (absent) audio description to help me follow the action’

‘Not enough properly ‘policed’ disabled parking bays, especially in the central London boroughs, where use of the blue badge is restricted. Dropped kerbs are a nightmare in some places. Either they don’t exist at all or they have been designed/built badly and dangerously i.e. with a two or three inch lip. I have tipped out of my wheelchair onto the road on one occasion due to a badly built dropped kerb’

‘I used to be able to visit my local park behind my house - but now the local authority have put a second set of railings within a short distance of all the three exit gates making it impossible for me to negotiate my way in - I haven’t been able to get into the park for years’

‘The built environment is always the mirror of the society in which we live. There are some good examples of accessible buildings in London, but there is a lot more to be done. The parking facilities must really be improved because there are few parking bays in central London. Also, the ‘Blue Badge’ should be used throughout London’

‘I use a motorised wheel chair which is great, but I often have problems getting on or off the pavements because cars are parked in front of the dropped kerbs’

‘There is no lift to the doctor’s first floor surgery and I have to travel to central London to visit a dental hospital’

‘There are hardly any disabled toilets. McDonalds is the only one I know of in Brixton shopping area. Plus, the toilet is up on the third floor!’

‘The street environment causes me numerous complications, due to uneven surfaces, irregular flooring, lack of dropped kerbs etc. There are places that I cannot go because of the difficulty I have negotiating walking, e.g. I love Covent Garden, but the cobbled flooring is a nightmare’

‘It is not easy to attend my GP as there is a steep step at the entrance. In spite of this, they have fitted an automatic door. The staff forget/don’t know that I use a wheelchair and are reluctant to take details for a prescription by telephone. My health centre is much better, with a ramp to the door. The reception is low and allows me to speak face-to-face with the staff. These improvements were made after I started to attend there. They asked what I thought would be helpful’

‘Cinemas, schools, community centres, shopping centres, restaurants etc there are disabled toilets everywhere, but they are poorly designed. You can’t reach the toilet paper; you can’t go from the basin to the drier without propelling, you can’t reverse a battery car to get out of the door. Why don’t architects/builders consult disabled people in and out of wheelchairs?’

‘For people with ME, 150,000 of us, ramps are just as hard as stairs. Please think about this and give us working lifts, or preferably put important staff on the ground floor.’

‘People with ME need seats - this has been a problem for me numerous times; e.g. at post office, police station etc. I have resorted to sitting on the floor behind a

high counter when refused my request for a chair/seat. I sometimes take a portable stool, but it's an effort to carry it which worsens my condition'

'Hammersmith Apollo Theatre is far from wheelchair friendly due to its age, but efforts are made by staff with portable ramps to get you into the auditorium. Once inside you are very restricted, for example, no toilet to use which should be a basic right for every human being on this earth'

'Despite the 'Blue Badge', I am virtually 'banned' from the West End. This form of discrimination is a serious hindrance in my work as an artist. Outside my borough, I regularly get parking penalties and even get clamped for parking in 'restricted areas', places that cause no danger or inconvenience to other drivers or pedestrians. My access and mobility is seriously restricted due to the problem of parking'

'Today I tried to report a crime, and discovered that there are NO wheelchair accessible police stations where I live, so a two-tier system operates: either I can sit outside (if I'm well enough to be taken there) or I can report/fill in forms by post (taking an additional 72- 96 hours). Are the police breaking the law? I'm happy to take them to court if they are. None of the (many) civilians and officers I spoke to knew what to do. I've been trying to enrol on part-time study to broaden my horizons, test my brain and meet new people. I can't find a course at an accessible college and keep meeting the 'but it's a listed building' argument. One college wanted me to enrol before they could tell me whether or not I'd be able to get into the classroom. My friend (who shared my copy of 'Floodlight') could get all the info she needed with one telephone call. I had to make four or five and I still don't know if I can get to do the course I want at an accessible venue which is accessible by public transport (I can't afford any more cabs, and the transport here is very limited, as is my energy)'

'I haven't been to the dentist for four years since mine relocated to a basement premises and I can't find one which is accessible, can deal with nervous patients with disabilities and will take me as an NHS patient'

'The cinema has one screen which is accessible, but the wheelchair space is right at the front which is seriously overwhelming.'

'Few cinemas offer audio descriptions. Apparently this has to be ordered in advance and therefore I cannot go to the cinema/theatre spontaneously like everyone else as I have a visual impairment'

'I have many friends and family who live in apartment blocks with no lifts. I can never visit them. They always have to come and see me'

'Post office - please help to stop local closures already implemented or planned, which inconvenience very many people. The payment keyboards now installed are fixed much too steeply with too little flexibility. I don't need to use them, but in France they are common place for card payments and are at much less of an angle so that what you are typing is not so nearly as visible, and the keyboard is on a flexible cable'

'I was very embarrassed last weekend when I went to the pub with a friend. There was no disabled toilet and the barmaid, whom I did not know, had to help me in the toilet. It was very dangerous, as I had to get out of my wheelchair, and I am not able to walk that well, but there was no other way of getting into the cubicle. Make it better, please!'

'My bank has a ramp, but it is not a permanent one. I have to let staff know that I am waiting outside, and then they put out the ramp for me. When I leave the

bank, they take it back inside. I always have to wait outside, whatever the weather. It's not fair'

'The GP's surgery is not wheelchair accessible. I am housebound without my daughter's help. When I asked the GP if she could come out to me when I was very ill, she said, 'No, we don't do that anymore, you are living in cuckoo land'. After a fight, the District Nurse did come out to give me a flu jab. But, we did have to fight'

'What can I say? - Life is difficult re access on every single level. It ruins friendships, relationships and in the end you give up trying - it's not worth the difficulties'

'How many of your friends have wheelchair accessible houses? Access is a major stopper of many planned activities'

'I go out a lot to cinemas and restaurants that I know are accessible. I would like to go to others but they are either inaccessible or in central London boroughs where parking is too difficult. It infuriates me when new restaurants open and they are not accessible. There is no excuse for such poor planning in 2003!'

Key issues: Discrimination

There is no doubt that disabled Londoners face daily discrimination in their lives. 33 percent of respondents said that they face discrimination on a regular basis and 50 per cent had experienced abuse or bullying. The experiences of disabled Londoners paint a stark picture.

Discrimination: what you told us

'Being told to get off the bus by two mothers with prams and babies'

'People letting their dog bite me because I was in a wheelchair'

'As I am unable to read due to my dyslexia, I am often humiliated in front of colleagues, friends and clients. I've been called: 'dim', 'lazy' and attention seeking'

'In shops and at train stations I have faced verbal abuse. There is a lack of help/support given when asking advice as well as patronising behaviour'

'I've been called a cripple by members of the public. I've also had bricks thrown through my windows by local youths because they know I can't chase them. My children have been bullied because I'm disabled'

'I was told once I had the qualifications for a job, but that I looked 'too blind' so they would not employ me'

'I have always thought that discrimination and inappropriate attitudes can be overcome by confidence, positive attitude and friendly approach to people. In most instances, I have found this successful in helping me to overcome the ignorance, lack of understanding and pure bigotry. Nevertheless, as I get older I find it increasingly disappointing that instead of making progress the attitudes are hardening, sometimes supported by rules and regulations which were intended to limit such attitudes. Nevertheless I have been pleasantly surprised to find that we have progressed in this

country considerably more than in parts of Europe. These days, I would rarely be of any interest to passers-by on the streets of London, however, whilst in Europe recently, every person was staring in disbelief'

'Verbal, emotional, financial and physical. Emotional abuse is the most difficult to erase'

'Being stopped from getting on a bus by two people'

'In previous employment, I fought to stay there for three years and had little support from management. I was told I lacked humour when I found direct abuse from colleagues, i.e. you shouldn't have come back to work, you're not fit/up for it. I was often told not to expect changes 'just for me' as I was the only disabled person and shouldn't make a fuss. I was the only member of a staff of 75 unable to visit the staff room, for example'

'Other car users, parking disputes because I need more space to get my wheelchair in and out of the car. Physically threatened by youths when I complained to police about drug addicts in the area. Some people try to push my wheelchair without asking my permission. Access disputes occur when trying to shop or when a disabled toilet has been misused as a storage room'

'People see that I am disabled and shout at me. Also, in many shops I let them go into my wallet to pay for things, sometimes I get no change or they steal money'

'Discrimination against HIV can be subtle, it can be rumour and innuendo which leads to exclusion. HIV does not cause me to be disabled. It is other people's attitudes towards me because I have HIV which caused the discrimination and is the same as being disabled'

'Making fun of sign language and testing my hearing behind my back'

'I was bullied at school. I left at 16, to escape the abuse. Since then, abuse can range from inappropriate comments or use of language (e.g. spastic, cripple, handicap) to stares or shouts of abuse (particularly from young drunk men!). Attitudes seem particularly resistant to change, I am at a loss to explain why, or how they could be changed'

'When I left school, it happened with attitudes of prospective employers that I was suddenly a fire hazard. The disability rehab officer at the job centre thought that I might be happy at a day centre. This was also the attitude of social workers. My wife was a wheelchair user, so when we were out I sometimes asked passers-by to help get the wheelchairs into the car. The answer was often, 'If you can't manage, stay at home!'

'At work - where I had to fight to have a bar type stool to use when teaching. And when they timetabled me in an outside classroom, miles away from the loo and other facilities. Also, management at work tend to treat me as an 'inferior'!'

'Too much/too often to list here after seven years, often by institutions (council departments, hospitals) as much as (if not more than) by individuals. Mainly, I guess, because they know I don't have the energy to fight back or question decisions. The CAB are fabulous and I look forward to the DRC backing some court cases to get people to take issues around the disempowerment caused by disabling institutions/organisations/businesses/people seriously'

'I accidentally misunderstood a situation. The child minder living in the flat above with her partner went down the road, at 9.30am, unknown to me, and

unusually, when I knew there were children in her flat. I went out into the hall, expecting transport to take me to the day centre. I saw the front door of the house was open for 20 minutes and closed it. When the child minder returned, her partner had to let her back in to her flat. He shrieked at me 'You f***** crippled bitch!' I let his rage wash over me with no response, but talked about it at the day centre'

'When I was young, people used to call me 'Spastic' because I had cerebral palsy. Now, when people see me at a bus stop on the street they look at me as if I am a monster. Nobody says anything; it's just the way they stare at me. When I get on a bus, people get up and move away from me. I say to myself, 'Don't worry, the problem is with them, not with me', and I continue to live my life. The way I look at it, they're not worth it'

'Went to a 'Lets' group; as a qualified teacher (of children and adults). I can offer tutoring among other things. In exchange, I'd only need to trade for an occasional lift. However, it was made clear that my skills were not valued, because as a disabled person, I'd be a liability and therefore I had nothing to exchange/trade. The meeting was the worst I've experienced for discrimination and exclusion. I was the only person not to have details taken, or given the opportunity to receive details'

'Regularly in shops and supermarkets. I hand over my credit card and it is usually given to whoever happens to be with me to sign!'

'Queue jumping, it happens all the time, it's as though I am 'invisible' and not in the queue to pay for my purchases. It happens more frequently when I am shopping about and using my electric wheelchair'

'In hospital, being asked, 'Is that thing really necessary?' Unbelievably a nurse was referring to my calliper!'

'Endless examples. I have been spat at; attempts have been made to push me out of my wheelchair; I have been physically abused; taunted and told I should not be with people in a railway carriage'

'Been hit while out in a wheelchair; been spat at - both for no reason, I had not even looked at them'

'It's largely about attitudes for me. People taking me for a mug, making me feel stupid or laughing at me'

'The abuse came in special school and it increased when I was allowed to mainstream because I was the only disabled person there. Bullying and abuse led to the acquisition of different impairments and the experience of mental distress'

'Often people under-estimate my ability to get around and to cope, a white stick seems to equal complete incompetence in the minds of sighted people. I have been barged to the floor for daring to be in someone's path. I have been harassed on the tube by a bunch of young people when they were alone in the carriage with me, very frightening, I escaped unharmed. I have been told by someone I accidentally bumped into that I should have been killed at birth. The list is endless!'

'Albinism and a visible visual impairment caused a lot of problems at school. As an adult the problems tend to be when you ask for help ('can you tell me when the next train is...') and people either respond by pointing to a screen or timetable or imply that you can't read or are stupid - 'is this the bus to Chingford' 'that's what is says on the front' '

‘As a member of Housing Consultative panel I attended a meeting with my PA and had to leave because they would not allow my PA to be present even after it was pointed out to the Chair that this was against the DDA '95 - this occurred in Feb 03 and again in March 03. Most public meetings do not have a loop system. And the format of information is not always acceptable to me as I am dyslexic and need it in a clear, easy to read format. When I pointed this out to the local authority they had a vote and because they had no problems I was completely disregarded. I also use PAs now and the meetings that I attend for the local authority they refuse to pay for my PA which prevents me from attending meetings and excludes me from tenant participation. My direct payments and ILF that I get does not cover these’

‘My son has been discriminated against by other parents at school. He has been excluded from parties and events. Also sporting activities and clubs and associations we have tried to join. And most importantly childcare facilities’

‘I have been abused when I have not had my scooter with me and have used disabled facilities, ie toilets with radar key. People do not see me as disabled. I do not look disabled. When I have requested to cross the road on my scooter when someone has parked across a dropped kerb, I have been told to f*****g wait. I have been threatened when I object. Builders have threatened my daughter and me for using my blue badge and my carer when she comes to attend me. I have stood on the pavement, in my nightclothes trying to stop someone from damaging her car. This feels like a direct attack on me’

‘I think the phrase I have heard most often from staff of various organisations (housing, council offices etc) is ‘Oh but you don't LOOK as though you have mental health problems’ ‘

‘Ignorance of the able bodied and blame for circumstances beyond my control, eg I was spat on by a member of the public because he could not get on his bus due to the ramp getting stuck’

‘A group of young people took exception to my walking ability before I started using a wheelchair full time - I was threatened with extreme violence but was saved by another small group of youths - weird! Another time before that I was kicked by a person while walking down the road’

‘I wouldn't say I've experienced abuse or bullying in my adult life. I get stared at, pointed at, whispered about etc, sometimes interrogated, but not usually abused. I have suffered discrimination in employment - although I think the bigger employers are beginning to make an effort (or at least paying lip-service - in my experience lip-service is all it is as yet), smaller businesses can have very bad attitudes. The most traumatic experience I've had in the past few years was when the landlord of a local pub - a very popular and trendy place - made it very clear that I was not welcome in his bar. And let me add that my disability is by most standards minor, and often is unnoticed!’

‘Discrimination by the job centre and by the sports clubs nearly all the time, very very disappointing’

‘At schools was beaten every day, but in those years no support from school or family’

‘Physically abused on a daily basis at sixth form college. Many of the bullies are now in the BNP’

'Began from childhood - at school. I had a terrible, terrible time. I am 43 years old now but still am affected by what happened to me in my childhood. I am not able to have proper relationships, with men in particular. It affected me both emotionally and mentally. I now do not believe that I am good enough for anything. I am in a dead end job with absolutely no prospects even though I am quite bright. I have given up. I now only live for my son and my cats. I just hope my son won't be affected by my odd way of life - I don't mix with other people for fear of having to endure verbal abuse because I do not walk the same as able-bodied people. I am very bitter'

'Job interview - was asked indiscreet questions as to my physical ability and competence, such as could I eat without assistance, totally unrelated to the job description'

'Trying to get employment. I have a lot of problems getting employment because of epilepsy'

'When walking in the street alone and in shop queues from both shop assistants and other customers. This occurs more in London than elsewhere in the UK'

'Constantly. Ignorance of Deaf issues, what it means to be deaf, communication issues, patronising attitudes'

'I was mugged by 3 youths'

'I was sworn at once on a bus for 'ignoring' someone who spoke to me. That's the most direct instance. People regularly don't bother to repeat things for me if I ask them to. I would say about ten per cent of the population will bother to include someone Deaf in their conversations, while for the other 90 per cent it's too much trouble. Bad attitudes like this are endemic. Much of it is not direct, one is aware of it but it is difficult to pin down, or challenge'

'I get abuse and insults on a regular basis from local youths and children where I live. I get shouted at, spat at and have objects thrown at me at least three times a week. I have had break-ins of my home when I have been out and on one occasion, whilst I was indoors by these same youths and children - seven times in less than five years'

'Work: I have many experiences of people questioning my CV and experience once they see that I am disabled. I look good on paper but in reality 'not what they are looking for'. I have been denied support because I don't look disabled enough by service providers, not to mention disability organisations, but as I said I am also black, so there is the double whammy feature in these events'

'I have experienced general discrimination as a disabled parent, from my council social services in particular - it has been very much implied I was a bad parent and could not be a good parent because I was physically disabled, without any actual facts or grounds for this attitude'

'The children at my school are caring and try to help. Some teachers feel I should not be there, as I can't keep up with the work. Eg they say they don't know how to differentiate the work, and give me the same as everyone else, which I can't do. The local sports club said I could join a group, after my first visit they said I couldn't come back unless I brought my own support'

'Stopped from applying for jobs. Quizzed at job interview about use of PA/space needed. Told I had to dress in a way which was physically painful to keep a job'

'I got on a bus which was fairly crowded. A young boy got up from the disabled person's seat for me only to be pulled back by his father who shouted that he'd had to pay for his son's fare but I was travelling for free. No one said anything in my defence and I was left standing. I frequently get derogatory comments when I'm on public transport because I hold up the flow of people. Meetings at work are often scheduled in rooms only accessible by stairs - I can manage a limited number of stairs but am very slow. Trying to get up/down the stairs in front of colleagues is shaming'

'I have always found that the discrimination disabled people face is far more subtle than that facing other 'minority groups'. It is often institutional, and rarely aggressive. This makes it very difficult to prove, as people are often not openly abusive. Instead by pitying a disabled person, passing them over for job opportunities, assuming they don't understand or don't want a social life, boyfriends/girlfriends/education... basically all the things able-bodied young people expect'

'I cannot access my children's school very well. The DDA gives no rights to disabled parents and I have taken this up with the Chair of Education with my local authority - no luck, even though my school was spending nearly £2m on a rebuilding programme. I contacted the DRC about this but realised there would be too many complications involved in trying to put pressure on the school where my children attended every day. I worry about discrimination at work because if I lose my job I will be unemployed longer than anyone else!'

'I know that in the past I have been turned down for both jobs and training because I am disabled. But I don't think this has happened in the last 15 years or more. My experience now is much more of being patronised and not taken seriously by people whose intentions are often not at all malicious. I have a PhD but I don't usually call myself 'doctor' unless I get into a situation where I feel that someone is simply dismissing me and my views, in which case I manage to draw attention to my title in not-so-subtle ways. The other maddening thing is people assuming that I don't have a paid job and that therefore I am free to do whatever it might be (participate in community activities, wait for NHS appointments etc) because I don't have anything to do with my time. When people do realise that I have a job, even though I tell them what it is, they always assume that it is something to do with disability and also that I am an expert on disability issues and on other forms of disability'

'The bleak walls of my childhood institutions hid abuse which provides a constant backdrop to my life as a disabled person. The aggressive stuff is more easy to deal with somehow - it is just a shock when somebody crosses the street to spit in your face. When people dismiss you and exclude you and treat you like you are from another planet, that is when the veneer cracks and tears flood inside'