

Barriers to Independent Living. Report by the Independent Living Group for the European Independent Living Day – 5th May 2018.

Action Disability Kensington and Chelsea is a user-led disabled people's organisation that has been operating in the Royal Borough of Kensington and Chelsea, a local authority region in the west of London, for 37 years.

Known for its diversity of culture and its wealth in terms of the amount of Local Authority monies and cost of properties, the Royal Borough of Kensington and Chelsea is home to some of the richest and poorest people in the country. It is also the borough in which Grenfell Tower was situated.

As part of our Independent Lives Kensington and Chelsea project, local disabled people who attend our monthly independent living surgery looked at the “12 basic rights” for disabled people, and at what barriers they have experienced around independent living.

The 12 basic rights for disabled people are listed as being:

1. Appropriate and Accessible Information
2. An adequate income
3. Appropriate and accessible health and social care provisions
4. A fully-accessible transport system

5. Full access to the environment
6. Adequate provision of technical aids and equipment
7. Availability of accessible and adapted housing
8. Adequate provision of personal assistance
9. Availability of inclusive education and training
10. Equal opportunities for employment
11. Availability of independent advocacy and self- advocacy
12. Availability of peer counselling

Group members chose a few of these rights to look at in more detail.

Appropriate and accessible information:

- Appropriate information:

It can be difficult to get to the right bit of information... it can seem like there has not been any thought about how to present information in a clear and accessible way. It can be easy to find out general information, but not necessarily the specific thing you need.

- Online access:

There is a lot of reliance on online information provision as standard – many disabled people do not have access to a computer or have the skills to be able to get the information needed.

- Accessibility:

It is rare to find “accessible formats” already available - you have to request and then wait.

Even when it is already known that you need information in an accessible format, for example for getting a copy of a report from social services, it tends only to be provided in standard format. People are told about the expense of providing accessible formats

Many people who need support to access and understand information have to get informal support around this. This can include asking strangers to read out personal letters for information.

- **Gate keeping:**

There are many organisations able to provide advice and information, however resources are limited and are often not conducive to disabled people's needs. Long queues, unanswered phones, lack of interpretation services and inaccessible buildings make some advice centres inaccessible. Additionally some services, such as home visits are only available if requested and/or a referral is made by a professional. People who are not in touch with services already, can miss out on these adjustments.

An adequate income:

- **Benefits:**

The benefits system is not supportive of disabled people. There is a dread of having to go through the assessments in the first place ... and then, as the system is broken, there are

months of mandatory reconsideration and appeals to get the support you are legally entitled to.

The categories used for determining eligibility for Personal Independence Payment does not take into account the difficulties experienced by many disabled people with invisible and fluctuating impairments... if you can wash and dress yourself you are probably not eligible!

The new Universal Credit system is causing hardship - people have to wait 5 weeks to get money through... and the disability premiums have been removed, meaning having less money for basic living needs.

- Paying for care and support:

The government has allowed local authorities to charge for care services even for the most basic of support, such as washing, dressing, using the toilet and eating. The financial assessment doesn't take into account any debts.

Additionally, guidance provided by the government around the "Minimum Income Guarantee", which recognised the amounts needed for a basic quality of life means that "working-age" disabled adults are allowed to keep significantly less than a person of pension age is allowed to keep, before starting to pay for care. This impacts on the amount of money people have to meet basic needs, hence this is a barrier to being able to live an independent life.

A fully accessible transport system:

The public transport system is vital in supporting disabled people to live independent lives and although the transport system in London has many good points, there are many issues that disabled people identify as barriers to independent living.

- **Access:**

The underground system is still only partly accessible. Even when a station is accessible, sometimes a station is only accessible from one direction, or for interchange only. Upgrades to stations don't necessarily include improving access!

- **Staffing:**

Many of the accessibility features rely on staff action. There can sometimes be reluctance – for example the cab driver not wanting to take someone with an assistance dog, no staff available on the platform to help a wheelchair user board a train, a bus driver being reluctant to put out a message to vacate a priority seat / wheelchair space. This leaves some disabled people nervous about using public transport without support. There is a general feeling that more training is needed for staff on how to support disabled people, and more information available for disabled people to know the support that they should be able to rely on.

- **Initiatives:**

Unless prompted, passengers take no notice of the “please offer me a seat” badge and card for people with hidden impairments, meaning people often feel they have to explain why they need the seat. It is felt that this is not widely

advertised enough / there are not regular announced reminders.

The “turn up and go” initiative, which was to overcome the annoyance of disabled people having to book assistance at a train station, does not always work due to lack of (or untrained) staff.

Availability of accessible and adapted housing:

- Social housing

The lack of sufficient affordable and social housing is a particular issue in inner city areas such as Kensington and Chelsea.

The system of applying for social housing can be seen as a barrier to some disabled people, as forms can be quite complex and “bidding” for social housing done on-line. Allocation of accessible / adaptable social housing is also assessment based – recommendations can sometimes mean that a person remains stuck in a very inaccessible property, rather than being moved to a more accessible, though not ideal, property.

It is still acceptable for a person with a mobility impairment to be housed above ground floor in tower blocks, resulting in isolations /dependence on others and/ or worry if the lift is known to break down regularly. The size of the accommodation can prevent manoeuvring with, and storage of, vital mobility aids.

- **Adaptations to properties**

Policies and procedures can also hinder.. “new build” properties tend to have a “12 month no faults warranty”, meaning that no adaptations can be made during those 12 months. Likewise, private landlord can be reluctant to allow adaptations to be made.

- **Dealing with emergencies / disasters:**

The lack of accessible temporary and permanent accommodation has had a huge impact on the local authority’s ability to rehouse people who lived in and around Grenfell Tower, following the terrible fire in June 2017.

Inappropriate temporary accommodation has severely impacted on some disabled ex-residents ability to maintain an independent and active lifestyle and on that of the people who have become impaired as a result of the tragedy.

More widely, disabled people, who were at the “top of the list” for rehousing have had offers of more appropriate housing withdrawn, or have not been able to progress their rehousing due to a closure of the “bidding” site, which has, in turn had a negative impact on quality of life.

Adequate provision of Personal Assistance:

The Care Act 2014 was supposed to increase wellbeing and promote disabled people’s ability to lead an independent and fulfilling life... however, due to insufficient funding for “social care”, the powers in the Act are being under-utilised.

- **Impact of austerity:**

“Feed and clean” support is not enhancing the ability to lead an independent life. Although the Act says that “wellbeing” should be promoted, there is no “hierarchy of need” and that a package should be “sufficient”, the reality is that people who have to rely on “care and support services” report that they do not have a life that is comparable to their non-disabled peers. Unfortunately Kensington and Chelsea recently scored the lowest of all Local Authorities with regard to the impact of social care services on a person’s ability to live a good life.

- **Limited options:**

People have the option of “commissioned care” (traditional paternalistic care as opposed to Personal Assistance in the true sense), or a Direct Payment, with which to employ their own Personal Assistants.

There is currently no intermediate option locally - either a person becomes an employer, accepting all the additional responsibility that a person choosing to go into business has, or else they put up with “fitting in” to a system that cannot possibly support independent living goals and aspirations.

- **Support Services:**

Locally, there is no official Direct Payment support service for local residents. Social workers are responsible for “selling” the benefits of Direct Payments to disabled people, however there seems to be no confidence in setting these up, resulting in long delays and confusion.

A lack of ongoing support for Personal Assistant employers results in confusion about rights and responsibilities, changes in legislation (such as minimum wage for sleep-overs, pension responsibilities etc).

-Recruitment and retention of good quality support:

Recently, recruitment and retention of Personal Assistants (and care workers) has become more difficult. Time and task based assessments result in packages of support where short visits, to meet only basic support needs, are spaced out throughout the day. This is not conducive to attracting and keeping Personal Assistants.

“Universal services” and “advice and information”, while a good solution for some people, do not support people with higher support needs to live a life that is comparable to their non-disabled peers.

Finally, there is agreement that Independent Living means having control over your life, to be able to have a life that is similar to non-disabled peers, even if that means having appropriate support if required. It is not about being able to live without support.

Report compiled by Jenny Hurst, Independent Living / Personal Budget Coordinator. With thank to the attendees at the ADKC Independent Living Surgery of 2nd May 2018 -JC, YS, PD, MW, MS, NW, MP, HT, GJ and DS.

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