

Thurrock Coalition



Submission of evidence to the Extra Costs Commission

About Thurrock Coalition

Thurrock Coalition is the User-Led Organisation for Thurrock. We are a company that has been set up to ensure that people who live in Thurrock have access to all the information they may require to get the support and care that they need.

Thurrock Coalition is an 'umbrella' company that consists of 4 organisations, all of which follow the Social Model of Disability and aim to improve the lives of disabled and older people living in Thurrock by seeking to remove environmental, attitudinal and physical barriers that exist in society. We connect to over 1500 individuals and organisations with an interest in disability issues. Thus, we have a direct interest in the work of the Extra Costs Commission and welcome the opportunity to provide input and evidence of individual lived experiences.

Summary

A meeting of our Consultation and Campaigning Partner Organisation – Thurrock Diversity Network, a registered Co-operative, was called, and our members consulted and views were gathered around the key themes relating to the added costs of living with impairments. The feedback appears under the headings suggested by the Extra Costs Commission, namely:

- **How the market is working for disabled people**
- **The quality, choice, price and availability of products and services**
- **Suggestions for how markets could better drive down extra costs.**
- **Changing infrastructure – How this affects disabled people**
- **Suggestions on changing infrastructure to improve access, meet needs and drive down extra costs.**

Headline feedback and lived experiences gathered from Thurrock Diversity Network

Assistive Technology

TDN members took the view that sensory devices are a costly luxury, for example specific technology such as a “type phone” can cost £900 upwards.

In addition, specialist I.T. equipment, screen readers, computers and assistive technologies are expensive and not always suitable to use given the often inflated retail price. By comparison a generic Smartphone with “open source” accessible applications offers greater customization and better value for money, but not everyone is aware that this is a possibility.

Minor Adaptations & Equipment

Our members found the overall mark-up on equipment is unacceptable, especially for items such as bath boards, toilet seats, hand rails and chair raisers whereby if an individual does not have access to the internet and online retail sites, then the alternative on the high street can in some cases cost 150% more. One TDN member was charged £25 for an electronic tin opener from a high street specialist retailer. The same item is available online for £8.99.

Transport

TDN members discussed the use of Taxis in Thurrock, with members who use Access to Work experiencing Contract Taxi hire being more costly than the normal journey would cost. For example, £12 per journey (contract) versus £5 per journey (if paying by cash).

Household Costs

TDN members have found it expensive to dispose of rubbish, old domestic equipment, in particular bulky items of equipment and specialist furniture.

One TDN member had been asked to take out a separate insurance policy for their wheelchair. The issue of costs around taking out public liability insurance for Personal Assistants was discussed; one member had been quoted £120 per Personal Assistant.

Members also shared experiences of the additional running costs of specialised equipment, for example an electrically operated bed, which needs to be switched on 24 hours a day, leads to higher energy bills than would otherwise be the case.

The issue of energy costs for vulnerable people was raised along with the point that people who have to pay for their energy (gas, electric) using key-cards appear to pay hugely inflated costs per unit / kw/h compared to those paying via Direct Debit.

Experiences were also shared around paying for small household tasks to be carried out, particularly if the individual is not able to carry out the task themselves due to mobility difficulties or other impairment. For example, changing a light bulb.

Holidays & Leisure

The overall experience of TDN members was having to pay a premium for accessible holidays, for example a canal boat with an electronic lift and hoist cost around £1500 for a week.

In relation to holiday insurance, TDN members felt that staff at insurance companies often have a lack of knowledge regarding individual specific medical condition(s). This was of particular concern given that different impairments affect different people in different ways. Offering and providing disability equality & awareness training to such organisations could therefore be a solution.

The issue of the need for clarity as to how insurance companies share the information relating to various conditions was discussed. One TDN member had been quoted £300 for travel insurance from the Post Office, but after discussing the issue with a Third Sector organisation who signposted her to the British Heart Foundation, she was quoted £45 for the same level of cover.

Verbatim Feedback & Evidence gathered through Thurrock Diversity Network for submission to the Extra Costs Commission

1. Rebalancing markets

The Commission:

- **Wants to know how the market is working for disabled people**

People who do not or cannot use Internet shopping to acquire goods at lower prices need assistance to buy goods and/or services online.

Therefore there is a need for advocacy services to support people to meet the extra costs of living with impairment in a disabling society.

There is also a need for greater awareness of the availability of online retail options as well as reliable financial advice and support.

Sensory devices are very much a costly luxury, which should be an essential part of our everyday living. For example: Magnifying glasses can cost from £300-£2,000. A type phone can cost from £900-£3,000. A pair of glasses can cost £160 upwards.

Safety devices are often completely out of reach, due to cost.

Local authorities may or may not supply equipment, but most councils charge.

Holiday insurance; lack of knowledge by some companies drives insurance costs up e.g. post office will charge £300+ for annual insurance for a person with dextrocardia and situs inversus. The British heart foundation signposts to an insurance company with much lower premiums because they have an understanding of the condition(s) People who have mental health conditions have been quoted holiday insurance at a higher cost than the holiday itself.

TDN members reported higher fuel and energy costs are higher due to managing mental health conditions and physical impairments, this is likely to affect everyone over time, given the ageing population.

Experiences of using taxis were also noted, specifically that when Taxis stop in the street (as opposed to Private Hire firms) - they cost more money as people have been charged time on the meter including the time it takes to lower ramps, position ramps and assist wheelchair users into and out of the taxis..

Equipment stores are expensive e.g. toilet raising seats are really expensive with a wholesale of around £3 and retail at around £20. Delivery charges are high.

TDN members discussed the use of Taxis in Thurrock, with members who use Access to Work experiencing Contract Taxi hire being more costly than the normal journey would cost. For example £12 per journey (contract) versus £5 per journey (cash).

- **Wants to know about the quality, choice, price and availability of products and services**

Choice, quality, availability of products and services is limited for Disabled people, particularly for individuals for whom access to the Internet is not available and therefore may need help and support in order to access it.

Someone with a sensory impairment, without access to assistive technology and/or a computer with access to the internet is less able to access cheaper equipment, therefore the choice and control of disabled people is limited.

Usually, people with sensory impairments tend to rely on trusted suppliers, mainly because we don't have a problem, but as almost all disabled people will say, other people, e.g. people without impairments do! Therefore, we use suppliers that have an understanding or knowledge of our impairments.

The Digital Divide is real and this poses an issue for people in areas where Local Authorities are providing services with a "Digital by Default" approach to access to information advice and guidance.

Many disabled people need specific clothes e.g. shoes, trousers, dresses etc. due to

their impairments, this is specialist, the market is “cornered” and therefore Disabled peoples’ choices are limited.

TDN members were concerned by experiences of salespeople not explaining all available choices; “they focus on your disability not what you need.”

Disposing of large household waste is very expensive, and recycling is very hard.

Adaptations are often cost prohibitive.

Extra cost of waterproof clothing, extra heating cost, lighting cost.

Changing light bulbs and other small household jobs - have to pay a P.A to assist.

The high cost of pressure relieving mattress for an electric bed (and cost of keeping the electricity supply to it turned on 24 hours a day).

Have to pay for public liability insurance every year because people employ P.A’s.

Have to pay separate insurance premium for wheelchairs.

For holidays, I have to pay a P.A. to go with me.

Feeding costs of staff if you need help i.e. needing a P.A to help with feeding when out, have to pay for own meal and the PA’s, this can be costly.

- **Welcomes suggestions for how markets could better drive down extra costs.**

We are concerned as to why providers of goods and services are allowed to inflate the price of items. There needs to be some kind of national financial management of provider organisations offering equipment and small items etc. Perhaps some kind of Code or Kite Mark that could provide an indication of ethical trading to and for Disabled people.

Introduce assistive equipment into shops of all kinds, rather than sole suppliers.

Holiday insurance companies should receive training, delivered by Disabled people, to share knowledge and experience to understand a wide range of conditions and the effects/impacts.

The spending power of the Local Authority should be used to drive prices down.

There is a massive problem with the costs key-card energy, these are expensive and so are taxes on poverty/disability. Ideally there needs to be a government backed supplier of cheap energy, the cost could be taken directly from people’s benefits.

2. Changing infrastructure

Inaccessible housing, town-planning, transport, energy and services can make life cost more. For example there is a strong correlation between suitability of housing and disability-related spending.

The Commission:

- **Wants to know how this affects disabled people.**

A house can have the effect of imprisoning disabled people who cannot get in or out of their homes.

There is a very poor selection of shopping opportunities, establishments and outlets if people do not have access to transport. The need to travel to towns or shopping outlets is a must, especially for socialising, well-being and access to the community. Yet, there is a large population of people with impairments living in the borough, far from shopping areas, thus increasing isolation.

- **Welcomes suggestions on changing infrastructure to improve access, meet needs and drive down extra costs.**

Homes built to “Lifetime Homes” Standard would empower people and reduce costs for adaptations.

The added costs benefits system (especially Personal Independence Payment [PIP]) needs to better acknowledge and reflect the specific needs of each individual to achieve Personal Independence.

The possibility of Disabled People starting micro-enterprises, pooling their resources (e.g. their Direct Payments) to bulk buy items to drive down costs.

Improve standards for access to all new buildings (both internal and external). The legislation exists in this area, but needs to be better enforced.

Introduce reduced energy rates (electricity) for wheelchair users, mobility scooters and stairlifts that have to be regularly and continuously charged.

People who use keycards to buy their energy because of their impairment should not have to pay higher rates.

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