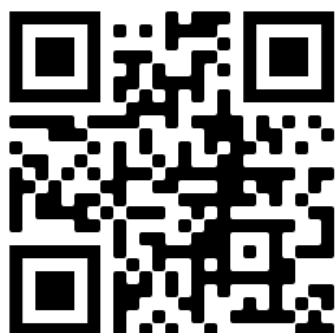

A new online resource to help firms better know, understand, and support disabled consumers.

WhatWeNeed.Support



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Authorship

Dr Christopher Fitch is Vulnerability Lead at the Money Advice Trust and a Research Fellow at the Personal Finance Research Centre, University of Bristol.

Dan Holloway is a disability activist, Co-convenor the Futures Thinking Network at The Oxford Research Centre for the Humanities, CEO and founder of Rogue Interrobang, a spin-out of the University of Oxford.

Relationship to Experian

The authors have both contributed to an ongoing Experian programme on disability, consumer vulnerability, and data (described at the end of this paper).

This paper and the Support List it describes are a product of this programme.

The list and other related materials have been placed in the public domain and can be freely accessed, used, and copied for any purpose, product, or service that improves the lives of disabled people or people in vulnerable situations.

The authors have not been paid to write this paper, but have received payment for their contribution to Experian's ongoing work in this area.

Disclaimer

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The views in this paper should not be interpreted as reflecting the views of Experian. They are solely the responsibility of the authors. All errors or omissions are the authors' own.

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What is WhatWeNeed.Support?

WhatWeNeed.Support is a website for disabled consumers, vulnerable consumers, and the firms providing everyday services to them.

- It contains a ‘Support List’ of changes, reasonable adjustments, and support needs that disabled and vulnerable consumers want firms to meet.
- It allows disabled and vulnerable consumers to add new support needs that are missing from the list.
- It is free and open-source. Anyone can suggest a support need to add to the list. And any firm can use the list to improve the way they do business (including designing new products or services).

WhatWeNeed.Support is run by a team who either live with a disability, have experience of vulnerable situations, or specialise in this area.

- The team work to ensure that people can describe, share, and discuss new support needs.
- The team work to encourage firms in financial services, energy, water, and ultimately every sector that engages with consumers, to review and listen to consumers’ identified needs.
- And the team organise our virtual WhatWeNeed.Support conference. This brings consumers, firms, researchers, policy-makers, and specialists together to understand how to meet consumers’ support needs.

WhatWeNeed.Support is a practical, independent, and transparent project.

- It’s practical aim is to ensure that more firms understand and meet consumers’ support needs.
- It is independently run by a team with lived and professional experience of disability and vulnerability, with an Oversight Group of consumers, firms, and specialists governing its activities.
- It is currently seed-funded by Experian, but will secure other forms of funding to support its activity.

1. Everyday grind

The grind

Being a disabled consumer can be draining, difficult, and downright demoralising.

This is because everyday services and companies – like our bank, energy supplier, mobile provider, or local authority – do not always know how to meet disabled consumers' needs.

And this can mean getting what you need from such a service can be harder for disabled people.

The knock-on

But there's more.

Everyday services do not always understand and meet disabled consumers' needs first-time. Disabled people therefore often spend precious energy, effort, and time trying to remedy this.

And this is time they could have spent living life, rather than being ground down by it.

The change needed

Disabled consumers want firms to end this misery-go-round. Firms want this too. But for this to happen, firms need to understand the full range of disabled consumers' needs.

And they need to also be shown how to meet these needs.

Making this change together

This White Paper aims to help make this happen.

First: it introduces a list of support needs/reasonable adjustments firms can make. Identified by disabled people, this provides a starting point on which to build.

Second: it places this list in the public domain on an open-source platform. It does this so anyone with lived experience or insight can improve the list.

Third: it encourages firms to engage with (and learn from) this open-source platform.

The list and platform is for everyone who wants to learn about, understand, and meet disabled customers' needs.

This paper covers each of these areas. However, it begins with the case for taking this action. This spells-out the legal, regulatory, and commercial reasons why more firms must understand and meet disabled customers' needs.

Box A: lost opportunities



I'm Dan Holloway. I'm a researcher, disability activist, and a member of the team that has built the Support List in this guide. I'm the only person to win both the Creative Thinking and Intelligence World Championships. I also have bipolar disorder and ADHD.

My experience of being a 'disabled consumer' is one of frustration, but also of lost time, and lost opportunity.

Companies don't understand how mental health issues just stop me from doing things – like making a phone call to sort out an issue (like many neurodivergent people I struggle to process spoken information in real time) that other people would do without thinking.

Or worse, companies say they do understand my difficulties, but then ask me to 'just give them a ring' to talk to them about my needs.

For example, two days after I won the gold medal in the Creative Thinking World Championships, I tried to sort out a problem with a company. I had explained that I needed to communicate via email, but they told me the only way to resolve it was via the telephone.

It took me 10 hours to complete a task that others would take ten minutes over. And to get what I needed, I had to repeatedly tell many people the intimate details of my medical history.

And it didn't take just 10 hours of my life on the day to resolve the situation – it also took me days trying to anticipate problems, panicking about the potential outcomes, and days after recovering.

Critically, this was time I was unable to spend doing anything fulfilling or meaningful, the things that other people take for granted. All of this would have been avoidable if firms truly understood needs such as mine, and had listened to me. And also if there was a way that I could easily let them know, and trust they would do what I needed.

And that's why I became part of the Support List team – using my experience of disability, and being a consumer to try and bring about change.

2. Case for change

Lives lived

Our first rationale for change is clear from Dan's experience (Box A).

Firms that know about disabled consumers' needs and meet these, change lives for the better.

Here, rather than disabled people pouring their precious time and energy into getting services to work as they should, they can get what they need first-time, and get on with living.

Services delivered

Our second driver is business.

No firm wants to deliver a service that is inaccessible to disabled consumers.

No firm wants its disabled consumers to have poorer experiences than its other consumers.

And no firm wants disabled people to routinely have poorer product or service outcomes.

This is happening – but it doesn't have to if firms can learn about disabled customers' needs, and how to meet these in commercially realistic ways.

Legal duties

Our third driver is the law.

Firms are legally required to make reasonable adjustments to the provision of goods or services so disabled people can access, use, and benefit from these like any non-disabled person.

Firms are also required to anticipate and know the support needs disabled people might have. And they are required to put reasonable adjustments into place without waiting to be asked.

In England, Scotland, and Wales, this is overseen by The Equality Act (2010).

In Northern Ireland, the Disability Discrimination Act (1995) covers this.

Regulators' expectations

Our last driver is regulatory expectations.

Every essential service regulator expects firms to comply with disability legislation, and – under vulnerable customer regulation – to identify, understand, and support such consumers.

And acting to understand and meet disabled customer needs can help other customers as well. This includes vulnerable customers who are not disabled, but face similar support challenges.

Box B: the difference it could make



My name is Ziad Khan, a husband and father to young children.

My condition is Glaucoma which suddenly left me with 5% blurred vision in my right eye only.

I work as a website analyst with the aid of assisted software. I'm also an Ambassador for Digital Inclusion and assistive technology.

My experience as a consumer with sight loss has been mixed.

Recently, I needed to talk with a company about a product I had purchased. However, the only option on offer was webchat, which was not designed to be visually or audibly accessible. And when I tried to find contact details for the retailer, these just pointed back to webchat as the only channel.

At times like these, I question why retailers don't design basic shopping environments that are accessible for consumers such as myself.

This is a common experience for me. And the emotional stress and anxiety of not being able to complete a simple task often leave me physically deflated and morally defeated.

If companies understood my support needs and frustrations, they could remove these barriers.

And this is the reason why I am supporting the Support List project.

Box C: disability in the UK

Sight loss

Two million people living with sight loss, 350,000 registered blind or partially sighted¹.

Hearing loss

Twelve million people have hearing loss or are D/deaf, and 151,000 people use British Sign Language².

Mental health

One in four people will experience mental health problems each year³.

Dementia

There are 944,000 people living with dementia in the UK⁴.

3. The Support List

List for life

The list is not complex – it just contains support needs.

However, if you searched online for a single list of the support needs that people living with disability want firms to meet, there isn't one.

And there certainly isn't such a list that is live, continues to grow, and is directly informed by people living with disability or those working with them.

It's not that simple

We're often told that it is not possible to create such a list.

After all, every individual has different needs, every disability is different, and what might help one person, may not help another.

This is all true. However, what if firms had access to a resource that set-out the support needs that many people with different disabilities had? And what if that provided a foundation for firms to better engage with their own disabled consumers to provide the individual service they need?

The disabilities

A 'birds-eye' view of such a list is in Box D. The current disabilities covered are:

- sight loss
- hearing loss
- mental health and dementia.

However, over time, further disabilities, situations, and adjustments will be added to the Support List by people with lived experience of these.

The support needs

The list of support needs and adjustments firms can make is simple. It is built around common interactions with firms relating to:

- telephone communications
- written communications and in-person meetings
- communication preferences (how an individual wants to communicate with firms)
- other types of interactions.

Critically, this Support List aims to communicate the common and everyday needs that disabled and vulnerable consumers want firms to meet. And in doing this, it builds on the desire of most firms to understand, learn about, and meet these needs.

Box D: current list

The disabilities/situations:

My sight
My hearing
My mental health or dementia

For each of the above, we have the following support needs and adjustments:

- Calling me
- Writing to me
- Meeting me in person
- How I prefer to communicate (e.g. phone, letter, email SMS, webchat)
- Interacting with me (e.g. taking time, helping with memory)

Future development

In the future we will expand the range of disabilities and vulnerable situations covered.

This will include (but also go beyond) the following:

- My speech
- My languages
- My movement and dexterity
- My physical health
- My decision making
- My social interaction
- My personal situation
- My spending controls
- People who help me
- Other things about me

For each of the disabilities and situations, over time, we hope to include other types of adjustments and support needs such as how best to:

- Deliver goods to me
- Put spending controls in place
- And other needs identified by people with lived experience of disability and vulnerability.

4. Built on experience

Who has built this?

The initial Support List was developed by:

- reviewing research about disabled consumers' experience of essential service provision
- surveying 1400 people about their personal experience of disability or vulnerability
- interviewing 20 people about lived experience of disability or vulnerability
- engaging closely with over 20 firms that provide essential or everyday services to understand what information they needed to better support disabled and vulnerable consumers.

The development work was led by Dan Holloway (a specialist on disability, data, and essential service), and Chris Fitch (a specialist in consumer vulnerability, data, and essential services).

A team at Experian led by Paul Lamont, Jon Roughley, Jez Fawcett, and Dipesh Sanghrajka provided technical guidance and support on the list and its structure, while Becky Rowe and Joe Cryer of Revealing Reality surveyed and interviewed the 1420 research participants.

Why was it built?

The Support List is an output or 'spin-off' from a programme of work funded by Experian. This is exploring with disabled and vulnerable consumers whether a tool to share their support needs with multiple organisations would be useful to them. It also is listening to views on the controls that consumers want over how these support needs are shared with firms.

While this programme continues, it was decided to make the Support List publicly and freely available to everyone as a standalone resource for four reasons:

- to help the greatest number of disabled people get the support they need from firms, and to help the greatest number of firms understand and meet these needs
- to allow people with lived experience to take control and improve the List, identify new support needs, and make their voices collectively heard
- to stimulate innovation – in making it publicly and freely available, anyone can use the Support List without charge in any way that improves the lives of disabled people
- to create a dialogue between disabled people and firms that – over time – builds a freely accessible set of support needs that cover more disabilities and vulnerable situations.

What underpins this approach?

Selected research findings (page 15) indicate that disabled and vulnerable consumers need firms to improve their understanding of disability support needs, and to meet these.

Box E: avoiding assumptions



My name is Tim Scannell. I'm a Business Development Consultant.

I'm a Trainer and Tutor for Deaf Awareness Training and British Sign Language. And I'm profoundly Deaf.

In my job, I help organisations provide better services to people like me. However, as a Deaf consumer, I regularly experience poor service. Let me give you an example.

When I tell organisations I am Deaf, they make assumptions. They assume that written communications will work for me. And they assume this is all I need.

But, this is not right. Like many Deaf people, my first native language is British Sign Language. And BSL uses a different grammar, syntax, and structure to written English.

Therefore like many Deaf people, while I can read written information, it has to be simple. Otherwise, I do not understand it. But organisations often don't know this. And even when I tell them, many keep giving me written information I can't understand. That helps no-one.

What would really help me are two things.

First, more organisations not just assuming 'Deaf customer = written information'. And second, more organisations allowing me to use BSL to communicate with them.

This is why I'm supporting Support List. It will help firms to better understand and meet consumers' needs. And doing that would help Deaf people across the UK.

5. How the Support List works

Public, open, and practical

The defining features of the Support List are that it is:

- publicly shared for anyone to access
- openly available for anyone to use and improve
- practically focused on informing better services for disabled or vulnerable consumers.

To achieve this, the Support List can be used in four distinct ways.

Read or review

Anyone can access, read, or download the Support List at **WhatWeNeed.Support**.

Discuss and improve

Anyone can propose changes they believe would improve the Support List.

Anyone can participate in (or organise) discussion groups on the site about such changes.

Through such discussion, improvements to the Support List will be made - these might include new support needs for a disability already in the List. Or the inclusion of a new disability or vulnerable situation that is not currently considered.

Collaborate and innovate

Anyone using the Support List site can use it as the foundation or 'engine' for a project of value to them, their community, or organisation.

Here, the aim is to encourage innovation and new thinking that builds on the Support List.

Shaping essential services

Each year, an Oversight Group – made-up of people with lived experience, and specialists from research, policy and industry – will convene an annual conference to shape (and issue) a public recommendation report.

Initially led by the WhatWeNeed.Support team, this group will draw on suggested improvements and insights to make recommendations on how firms and organisations can better meet disabled and vulnerable consumers' needs, and to issue a new version of the Support List.

Box F: evidence from experience

Research indicates the need for a better understanding of support needs among firms.

MMHPI – 18% of the adult population (9.5 million people) have a mental health problem that entitles them to protection under the Equality Act (2010) – despite this only three in ten (29%) people with mental health problems surveyed say that essential service providers usually anticipate and meet their needs, as required under the Act⁵.

RNIB – in surveys with people with sight loss, up to one-third do not receive information from their bank in their preferred accessible format⁶.

Alzheimers – nearly two-thirds of people with dementia surveyed said that due to their condition they needed extra assistance when using a bank, while 70% reported needing help in paying bills⁷.

RNID – essential services are not routinely meeting need, and more than 70% of surveyed hearing aid users said that deaf awareness among firms would encourage them to choose one business or service over another⁸.

Box G: the vision

Anyone can access, read or download the Support List.

Anyone can discuss, debate, or propose improvements.

Anyone can take the Support List and freely use it as the engine for their own projects.

Anyone can participate in the free annual conference (held online). Here a new version of the Support List will be debated, agreed upon, and issued.

Support List
WhatWeNeed.Support

6. Becoming involved

People with lived experience

The Support List website is for people with lived experience of disability or vulnerability.

It aims to allow them to define and share the types of support that would help them to access, use, and get full benefit from the everyday essential services that feature in our lives.

To get involved, visit **WhatWeNeed.Support**, review the current Support List, and start to consider what support needs need to be added or refined to make a difference.

Essential service firms

The Support List offers insight for essential service firms into the needs they could meet.

While the website is for people with lived experience or specialist insight, 'sounding boards' will be organised to allow discussion to take place with firms about identified support needs.

Disability and vulnerability

The Support List has an opening and enduring focus on disabled consumers' needs. But, over time the support needs of non-disabled people in vulnerable situations will be incorporated.

7. Getting on with life

Breaking the grind

Being a disabled consumer should not be draining, difficult, or downright demoralising.

To avoid this, everyday essential services – like our bank, energy supplier, or mobile provider – need to know and understand what disabled consumers' needs are, and how to meet these.

The Support List described in this paper makes a small contribution towards this.

And in doing this, it aims to contribute to disabled and vulnerable consumers living their life, rather than being ground down by the everyday services that are supposed to make life easier.

8. Further information

What is the Support List?

The list is simply a statement of support needs that disabled people, or people in vulnerable situations, might have. Firms that understand and meet these support needs should be able to provide better products and services to consumers.

Anyone visiting the site can review the List, make suggestions to improve it, and review the suggestions made by others (and contributors can do this anonymously if they wish).

How will the Support List work in the first year?

In the first year, discussions and identified improvements will be reviewed by an Oversight Group (see below) at least twice, and changes to the core Support List will be made.

Taking this approach will allow people to freely discuss and identify improvements to the Support List (and others to act upon these), but will avoid multiple versions of the Support List existing which could cause confusion.

Who owns the Support List?

No-one owns the Support List. It has been placed in the public domain so people can learn about the support needs that disabled and vulnerable consumers have, can contribute to improving this list, and can use this information to improve their own work.

Who oversees the Support List?

WhatWeNeed.Support is run by a team who either live with a disability, have experience of vulnerable situations, or specialise in this area.

Led by Dan Holloway and Chris Fitch, you can find the team's biographies on the website.

Who funds the work?

The Support List will initially be funded by charitable and other sources of funding.

An Oversight Group (see below) will help establish how to use and secure this funding.

What is the Oversight Group?

Each year, an Oversight Group – made-up of users of the Support List website, practitioners with lived experience of disability, and vulnerability specialists from research, policy, data analytics, and essential services – will agree a public recommendation report.

Initially facilitated by Dan Holloway and Chris Fitch, this group will draw on suggested improvements and insights to make recommendations on how essential services can best meet disabled consumers' needs, and to issue a new version of the Support List.

Where did the Support List come from?

The list is a 'spin-off' from a work programme that Chris Fitch and Dan Holloway have collaborated with Experian on.

This work programme is focused on understanding whether disabled and vulnerable consumers want to share information about their situation and needs with organisations to get better services from them, how they might want to share this information, and how to ensure any personal or security concerns about sharing such information are met (including the controls necessary to do this based on an explicit consent approach).

The Support List was developed as a part of this exploratory work. Experian agreed to place the list in the public domain so anyone could use and benefit from this, as well as improve it.

If I want to use the Support List in my own work, who should I approach?

There is no need to approach anyone for permission. If you want to let us know about the work you are doing, we are always interested to hear your news and use of this.

How do I suggest a support need? Or discuss the Support List with?

Visit the website and get involved. You can discuss the Support List with fellow visitors to the website. It is there for discussion, collaboration, and innovation.

How do I contribute if I do not use email or the internet?

At this point in its development, Support List is a digital-only project.

However, we are reviewing options for future contributions to be made via other channels.

What is coming next?

Every 12 months, we will round up some of the most interesting uses of the Support List that we've become aware of in the last year as part of our annual report and recommendations.

References

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