

The Lilac Review

Interim Report





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Thank you to all the organisations, stakeholders and entrepreneurs involved in the making of this report.

A Word About Language

There is a diverse range of perspectives on how to discuss disability, given its broad spectrum of conditions and lived experiences.

Despite this, it's essential to establish a consistent language for this report.

A Global Guide To The Language of Disability by The Business Disability Forum says,

"Getting the language of disability "right" can seem scary – but global organisations should not let this stop them talking about disability. It is more harmful to say nothing about disability than to try in good faith to use the right language. You may make mistakes along the way (and certainly you won't be able to please everyone), but it is always better to talk about disability than to avoid it."

We draw insights from disabled entrepreneurs' experiences without prescribing a specific language.
Respecting each individual's preference is vital, reflecting the report's core principle of dignity and respect. We also acknowledge that, following feedback, some entrepreneurs, such as Deaf and Neurodiverse entrepreneurs, do not define themselves as disabled.

In our report, we primarily use "entrepreneur" or "founder," occasionally specifying "disabled founder" or "disabled entrepreneur" for clarity.

This is done in the knowledge that some people may not feel this is the right language for them, and for that we can only ask your forgiveness and understanding.



Foreword

Minister Hollinrake

Minister of State for Enterprise, Markets and Small Business

Minister Davies

Minister of State for Disabled People, Health and Work

The UK's small businesses are the lifeblood of our economy. Disabled entrepreneurs account for 25% of small businesses but only 8.6% of total small business turnover. They are some of our most innovative businesses, making a significant contribution through the products and services we use every day - yet 84% of disabled founders feel they do not have equal access to the same opportunities as non-disabled founders.

Convening the Lilac Review and publishing this Interim Report is both timely and of great importance to the success of the small business ecosystem. Whilst entrepreneurship is not for everyone, and brings its own challenges, it should be available to anyone.

Government delivers a range of support schemes to help businesses start and grow. By engaging directly with disabled entrepreneurs, we are improving the accessibility of our business support offerings to make them as inclusive as possible.

Our <u>Business Support Service</u> has been adapted to ensure all contacts can access it, offering a text service, British Sign Language interpreters, web chat, and adapted forms of written communications.

The Help to Grow Management programme offers mentoring and aims to match entrepreneurs to mentors based on their individual needs, including where an understanding of managing a disability as an entrepreneur is required.

Additional work is also underway to enhance the visibility of mentors that understand disabled entrepreneurs' life experience. We have also recently launched Help to Grow Management: Essentials, an online training course filled with practical advice for small business leaders. Content is divided into three modules and each module contains bitesized resources for entrepreneurs to work through at their own pace.

We appreciate the time pressures entrepreneurs face, felt more acutely by disabled entrepreneurs. As part of the *Health and Disability: Transforming* <u>Support White Paper</u> reforms, we will legislate to remove the Work Capability Assessment so that in future there is only one health and disability assessment - the Personal Independence Payment (PIP). This will mean that there will be no need to be found to have limited capability for work to get additional income-related support for a disability or health condition.

The <u>Health Transformation Programme</u> is modernising health and disability benefit services to create a more effective service, reducing the time it takes to go through the process. We aim to vastly improve the claimant experience including trust and transparency in our services.

It is clear from the research to date that significant barriers continue to hold back disabled entrepreneurs and that needs to change. We are committed to working with the private sector, financial services and the wider community to ensure that entrepreneurship is a positive and productive career choice for all.

We look forward to the further good work of the Review and working together to deliver more for disabled entrepreneurs.





Foreword

Victoria Jenkins

Founder of Unhidden Clothing. Co-chair of the Lilac Review

As an entrepreneur passionate about finding solutions for the unique challenges faced by disabled founders, I am delighted to introduce the Lilac Review Interim Report.

In a journey to further understand these challenges, thorough research has been conducted to delve deep into the lived experiences of disabled entrepreneurs. Through this process, we've uncovered not only the barriers but also heard stories of the resilience, creativity and passion that defines our community.

One thing that resonates strongly with me is the overwhelming nature of entrepreneurship for many disabled individuals. From navigating inaccessible systems to fighting against financial constraints, the path to success is an uphill battle. I've personally experienced the tough realities of securing financing and accessing vital support, which only underscores the importance of the work of the Lilac Review.

Looking ahead, I am filled with hope and determination. The Lilac Review will continue its vital work, amplifying the voices of thousands of disabled entrepreneurs and advocating for meaningful change. With each recommendation highlighted in this report, we are one step closer to creating a world where entrepreneurship is truly accessible to all.

I firmly believe that our community has invaluable insights and contributions to offer. By championing diversity, equity, and inclusion, we not only empower disabled entrepreneurs but also enrich the entrepreneurial landscape as a whole.



Foreword

Elyn Corfield

CEO, Business & Commercial Banking, Lloyds Bank

In the landscape of entrepreneurship, diversity is not just an option - it's an imperative for the UK to realise its economic potential and a core part of our purpose at Lloyds Bank, helping Britain prosper.

I have had the privilege of meeting many Disabled entrepreneurs over the last year since we launched our Disability & Entrepreneurship report with Small Business Britain, and it has been incredible to see how government, corporates and the broader Disabled entrepreneurial ecosystem have united in response through the formation of the Lilac Review.

Disabled entrepreneurs are a critical yet often overlooked segment of society, with varied needs, and it's long overdue that we challenge preconceptions and embrace the wealth of talent, innovation, and resilience within this community. The report sheds light on the overwhelming barriers faced by Disabled entrepreneurs when starting and growing their businesses – barriers that just shouldn't be a part of navigating entrepreneurship.

The Lilac Review Interim Report and its recommendations are an important milestone in guiding us all to take meaningful action to make entrepreneurship equitable for Disabled entrepreneurs. We remain committed and proud to be part of this review to help enable systemic change.

Recommendations for Government



Continue to streamline and simplify access to Government programmes and support: radical simplification of processes and requirements.



Up to the point of (and excluding) eligibility for benefits, a move across Government to **a trust-based approach to assessing disability** rather than a proof-based approach.



For life-long conditions, a **re-evaluation of annual assessments for benefits** to reduce the administration cost to Department for Work and Pensions and the pressure and stress on entrepreneurs.



Inclusion of Disabled entrepreneurs in the development and review of Government programmes to ensure that all access and support needs are considered.



Targeted support for Disabled founders, specifically created as part of Government programmes and a central place in Government that brings all programmes together, including from business departments and from Department for Work and Pensions.



Departments to work together on programmes and information to create a more joined-up approach to entrepreneurship across Government.



Create and implement mentoring initiatives focused on the unique needs of Disabled entrepreneurs, offering flexible, relevant support.

Recommendations for Financial Services



Continue to streamline and simplify access to financial services products and services: radical simplification of processes and requirements for programmes.



A move across financial services to **a trust-based approach to assessing disability** rather than a proof-based approach.



Inclusion of Disabled entrepreneurs in the development and review of financial products and services.



Create and implement mentoring initiatives focused on the unique needs of Disabled entrepreneurs, offering flexible, relevant support.

Recommendations for Business Support



Streamline and simplify access to business support: radical simplification of processes, forms, websites and requirements for programmes.



A move across all business support to a trust-based approach to assessing disability rather than a proof-based approach, and a reassessment of assumptions about entrepreneurs suitability for programmes based on their disability.



Inclusion of Disabled entrepreneurs in the development and review of business support programmes to ensure that they are considering all access and support needs.



Targeted, specific support for Disabled founders, including training designed for Disabled entrepreneurs specifically, marketed specifically at Disabled entrepreneurs and including mentoring designed with flexibility and founder needs in mind.

Overview

The Lilac Review launched on the 1st of February this year to understand the key changes required to make the world of entrepreneurship more equitable to Disabled entrepreneurs.

The first phase of this work included a wide range of focus groups with Disabled founders as well as a literature review of the extensive insight into Disabled entrepreneurship that already exists.

This has led to some specific recommendations for Government, financial services and business support organisations that are laid out in this The Lilac Review Interim Report.

This will be followed up in 2025 with the next phase of the Review reporting which will include insight from thousands of Disabled entrepreneurs as well as input from a wide range of organisations working in disability and entrepreneurship. Submissions of evidence for this phase are open now on the Lilac Review website www.lilacreview.com.

A key theme that has emerged from the first phase of this work and review of existing research is that of the extreme overwhelm faced by Disabled founders. As well as the challenges involved in starting and running and growing a business, Disabled founders face additional challenges on a daily basis.

Some of these are related to disability, but some of these are related to the way that the world of entrepreneurship is structured that creates barriers and boundaries, creating an almost overwhelming experience for Disabled entrepreneurs.

Gateways to support that are fundamental to starting a business are inaccessible

This may include the challenges of accessing benefits. It may include the challenges of accessing business support and it may include the challenges of accessing financial services across a broad spectrum of different financial products and services.

A common theme is the "gateways" to support that are fundamental to starting a business, such as HMRC, Companies House or even getting a website, are inaccessible. In many cases existing services are not accessible for entrepreneurs with limitations. When developing these services, the needs of those that face limitations must be considered from the outset.

This it is not just the case for Disabled entrepreneurs: these gateways may also assume a level of education and a level of digital skills. These assumptions may be baked into the structure for applications, which needs to change.

A key factor in services being accessible is working with Disabled entrepreneurs when developing these products and services. Including Disabled founders in the creation process, and starting with accessibility early, will ensure more appropriate solutions are developed, which will save time and money trying to retrofit them later. Disabled entrepreneurs should, of course, be properly compensated for their time on this.



"I've just been through the grant application process and came out successfully at the end but after months of going backwards and forwards with a huge lack of clarity. I consider myself neurotypical, so I don't have some of the challenges that others might, and I found the process tricky to navigate. There was a lot of mis-matched information between the forms and what I was being told by the people that I was speaking to. It felt a bit like a dark art that I was trying to unlock but nobody could quite tell me how to do that."

Carly Cannings, Founder, The Happy Business School

One of the responses reported by Disabled entrepreneurs on requests for accessible gateways is that they ARE accesible because they are WCAG compliant. However, founders share that this is not sufficient for accessibility. It is whether Disabled entrepreneurs can reasonably be expected to complete a lengthy or complex application.

Accessibility issues are not simply whether something is readable. Chronic fatigue, visual impairment, fatigue from long term illness or medication, neurodiversity and many more factors may make these gateways to support impossible to overcome.



"A support network would be great, and I think there would be a big uptake on that from all corners of disability, both physical and invisible. Regardless of what condition you have, you are going to understand some of the tolls it takes with trying to run a business and having to deal with taking medication or taking the appropriate time to recharge batteries and those ambitions for your business where it's not all about profit, it's getting by, and not having to be seen as one of those people that's just sitting at home on benefits."

Jimmy Gregory, Owner, Retrograde Arcade

A bigger question also needs to be asked: why do long and complex gateways need to be created? There appears (to the entrepreneurs) to be a rationalising of these gateways as necessary for safeguards, necessary for risk management, necessary for quality assurance and even necessary for maintaining the prestige of the product or service.

The gateways putting off Disabled founders are acknowledged in the Innovate UK funded research by the Innovation Caucus that acknowledges the low level of Disabled founders applying for grants. There are profound changes required.



"The findings suggest that Innovate UK is not well known or accessed by many Disabled innovators. There is considerable scope to increase visibility and awareness of Innovate UK among these groups."

Summary Briefing, Road To Wonder, Innovation Caucus



"A collective focus on redesigning the entrepreneurial experience to be more accessible and equal at each stage of the journey from start-up to scaling and growth is required. Removed hurdles to business support by maximising accessible design - across all stages from the promotion of support, to information gathering, sign up processes and programme delivery and design"

Disability and Entrepreneurship Report - Small Business Britain, Lloyds Bank

Bringing in Disabled entrepreneurs early in any process will help understand better where these gateways are being put up, and what needs to be done to make them more accessible.

A cross-section of entrepreneurs agree that bringing down the barriers to entry requires a rethink to the gateways for business support and finance at the fundamental level. What needs to be delivered is a simplified and pared back gateway to any product or service for entrepreneurs: what is the least you can ask, what is the least information that you need and what is the least complexity you can put in place.

This benefits everyone: anyone who does not have a further education or digital skills training; anyone who doesn't have a role model or a mentor, or someone to guide them through the process of entrepreneurship; in fact, any entrepreneur who is overwhelmed by the many challenges of starting and growing a business, particularly as a micro business.



"The Access To Work application forms are too complicated they are not suitable for the Deaf community. For hearing people, maybe the forms are ok and they can fill it out themselves but for us, we need a simple way or a way which is fair comparably to a hearing person's experience of the process. We are never on an equal footing. We (everyone in the UK) should also be able to access information in BSL; there should be a step-by-step guide in an accessible language so that things are easy and clear."

Joel Burgess, Owner, Sweet Soaps

Another factor in the burden on Disabled entrepreneurs is the requirement to repeatedly prove that they are Disabled or "Disabled enough" to get support. Taking away that burden of proof, as is done for other marginalised communities, will significantly reduce the pressure on Disabled entrepreneurs, and reduce the indignity of this process.

Examples of this change to a trust-based approach exist in society and have been shown to have significant positive results. GlaxoSmithKline has implemented such a trust based approach for employee workplace adjustments and have seen it reap rewards for both staff and the business.



"I almost wish there was a central register confirming my condition. I have a disability, it's not going away and it's only going to get worse, I shouldn't need to justify it every time I go to an appointment. Not being able to walk again, unaided, should be enough, right?"

Amelia Peckham, Co-founder, Cool Crutches

There are opportunities to apply a trust based approach up to (but excluding) the benefits system. Business support programmes and Government-backed financial services can look at this as a positive move towards improved engagement with Disabled entrepreneurs. This can certainly be applied to business support services, and potentially for financial services from the British Business Bank.

This constant process of proof includes benefits assessment on an annual basis, which for founders with a lifelong condition is felt to create unnecessary stress on the individual. Feedback from Disabled founders in focus groups included "I am not going to grow my leg back" and "I'm not going to lose a chromosome" really articulate the frustration felt by Disabled founders.

The burden of this annual process of proof is placing huge pressure on Disabled founders and is also creating cost and workload for the Government. Implementing a process whereby lifelong conditions could be marked on the entrepreneur's file would significantly reduce this burden.

With broader business support, not only is it about gateway access and reducing the burden of proof, but also having relevant content and support specifically for Disabled entrepreneurs.

A clear point of reference

Specifically, a clear single reference location for Disabled entrepreneurs is required. This should include information about business support, Disabled entrepreneur specific programmes and links to other support across Government such as Access To Work.



"The main barriers identified were: funding and investment, lack of support system, skills, social prejudices, network and connection, health, and physical access."

Exploring essential entrepreneurial competencies for entrepreneurs with disability - Dr Ning Baines, Te Klangboonkrong and Paul Baines in collaboration with Dr Mark Esho MBE, Ability Connect

A strong theme to come out of the research is a need for mentoring, specifically designed for Disabled entrepreneurs. Mentors with lived experience of disability or experience working with Disabled entrepreneurs are required for targeted, tailored advice. This should be reflected in the process, such as how mentoring sessions are scheduled, time required, and the flexibility of the mentoring. It should also include an understanding of the barriers faced by Disabled entrepreneurs, such as limitations on time, managing hospital visits, healthcare or fatigue.

Over time, bringing together business support and disability support should lead to a better and more nuanced process for supporting Disabled entrepreneurs. One example outcome should be bringing together the business and health needs which allows for a more holistic view of the entrepreneur, and can help to create better solutions as a result.



"I don't tell anyone about my disability because I think they'll have a preconceived notion about it and that I won't be up to the job. There is still so much stigma attached to disability and a sense that we have to prove that we're like an athlete or super successful, there's no middle ground"

Vie Portland, Founder, VieNess Discover You Love You CIC

Disabled entrepreneurs are not asking to be given special treatment. In fact, many said they don't like the idea of being seen as "other" or to be seen as inspiration just because they are Disabled.

What they are looking for is to be given equal access to opportunities and to be given the freedom to start and run and grow their business to the best of their ambition and abilities.

Equal access to opportunities

By bringing down barriers, by taking away inaccessible gateways, by taking away the burden of constant proof and by starting to create products and services with specific needs in mind, we can create a more equitable world for Disabled entrepreneurs.

Overview of Focus Group Research

ARU Peterborough & Small Business Britain Dr Cheryl Greyson, Dr Tom Williamson, Karen Campbell

In Q1 of 2024, The Lilac Review conducted 18 Focus Groups talking directly to more than 120 Disabled entrepreneurs about their lived experience of running a business and what they felt needed to change to overcome the challenges they faced.

One of the key messages to come from these sessions was a strong acknowledgement of being asked to share their experiences and contribute to solutions in a positive way. **Entrepreneurs felt that they need to be part of developing solutions for business**, and for many this is the first time they had felt their voice had been heard.

The lived reality for many entrepreneurs, shared in the focus groups, is very stressful and emotional. Entrepreneurs shared stories of ongoing struggles, isolation, loneliness and **a sense of not being heard**.

Many entrepreneurs also shared how the hurdles they had faced drove in them a sense of determination, resilience, and strength that has contributed to their determination to run their businesses well.

Many participants stressed how much they were moved into entrepreneurship by default having found that **a** 'typical' working structure didn't accommodate their needs. Despite this, there is a strong sense of pride about being an entrepreneur and the social value that goes with it and there was a real desire for this to be better recognised.

A daily balancing act

All the Disabled entrepreneurs talked about the balancing act of managing their ongoing health alongside their daily energy, and for some, their chronic pain, especially for those dealing with a range of comorbidities.

This was highlighted when discussing the form filling processes that accompany funding applications or business support, with many sacrificing time working in their business to try and complete these, resulting in their pool of energy being severely depleted. Many said they were **unable to complete the necessary forms in the timeframe without assistance**, which led to a sense of frustration and low self-worth.

Energy and general health were very much inhibitors of business growth, with the two directly linked by the entrepreneurs. Participants discussed time when they couldn't work or having to make operational decisions about the business or incurring additional costs for travel due to balancing the business benefit with the physical consequences and recovery period required to get back on track.

There was a strong call for a better and simpler way to access what is needed, when it is needed, and for a better understanding by all of society of their needs as an entrepreneur and Disabled person.

Areas of business support were discussed at length in the focus groups. **Mentoring came up repeatedly as a need**, specifically designed for Disabled entrepreneurs. Entrepreneurs want opportunities to network, but without barriers such as travel, balancing energy for the day, too much standing up, name tags that are hard to read for the visually impaired, and challenges experienced by those who struggle in group situations.

Support to write business plans and to stimulate sustained growth is a key need. This needs to be driven by an understanding of how a Disabled entrepreneurs' capacity to work may fluctuate. Businesses feel this would lead to more confidence in applying for finance and ultimately reduce their dependency on welfare support.

An exception to this is the need to **maintain Access to Work**, which is invaluable particularly for Deaf entrepreneurs and those using Virtual Assistants. However, many entrepreneurs were not aware of Access to Work and were concerned about further reliance on the state.

The participants shared stories of inconsistencies and delays experienced with welfare. **Demonstration of lifelong conditions on an annual basis has led to a sense of mistrust** and at times alienation from the "system".

For a number of participants, this unease has created a perception of needing to **preserve mental and physical health over applying for benefits and support**. For these entrepreneurs, there are clear examples of where this is leading them to miss out on opportunities for support available to others.

Entrepreneurs were clear that they wanted better access to finance, but the broader business support landscape was overall more of a priority. **The Deaf entrepreneurs in particular discussed making financial services more accessible**, and the accessibility of communication channels was a reoccurring theme.

During all these sessions, there was **a need to be heard**, and for Disabled entrepreneurs to have a community to be part of with empathy, education and understanding at its core.

Disabled entrepreneurs want to be part of the processes, the building of the systems and to have a voice on the areas that impact them.

Methodology

The aim of this initial schedule of research was to identify and explore the key themes relating to the challenges faced by Disabled entrepreneurs and generate rich insight around their lived experiences, feelings, access to finance and support, and differences based on types of disability.

An interpretivist qualitative approach was taken with 17 focus groups with 4-12 participants in each. Disabled sole traders or small business owners were selected as participants using purposive sampling via the Small Business Britain customer database, the British Deaf Institute, and through snowball sampling to identify harder to reach Disabled entrepreneurs, to ensure that a broad representation of disability was included.

Significant efforts were taken to include, rather than exclude, different voices in the way that the focus groups were designed and took place, for example, taking place online, providing the option to contribute by email, phone or via the online chat,

giving participants the option to turn their camera on and off during the discussions, and using a BSL interpreter in a face-to-face session for hearing impaired or Deaf participants.

The groups covered the spectrum of disabilities and included those with chronic pain, neurodiversity, physical disabilities, and the visually and hearing impaired. The BSL group was recorded by video cameras and dual signed and interpreted with later transcription by the interpreter to account for the rich narrative of British Sign Language.

The discussion guide was developed by the Lilac Review team in consultation with Disabled entrepreneurs to ensure that the language and approach was appropriate. The discussions took place during March 2024 with a small incentive offered to participants to cover business expenses. Participants were asked for their informed consent to participate and reassured that their comments would be anonymised. Groups were kept to 45-60 minutes to avoid fatigue.

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