

1 in 5

**An exploration of life with a
visible difference**

Isabella Matthews
2024 Churchill Fellow

**Where community and representation overcome public perception
across the UK, US and the Czech Republic.**

**the
CHURCHILL
fellowship**

**The purpose of this report is to enlighten those outside
of the visible difference community about the issues
individuals face and to create change to benefit the UK.**

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Acknowledgments

Without the help of a number of individuals this work would not have been possible. First and foremost, I am incredibly grateful for the opportunity provided by the Churchill Fellowship to open so many doors and the support to allow this type of deep immersive research. Thank you also to Roger Warnock, my mentor at the start of this process, for his words of wisdom as I embarked on my travels.

I would also like to thank the countless individuals and organisations who had a personal connection to my exploration and connected me with those mentioned in this report. Namely, Changing Faces, MyFace, Zebedee Management and the EADV.

To the ‘extraordinarily ordinary’ people mentioned in this report, thank you. I will be forever appreciative of your time, your stories and your friendship shared.

Finally, I would like to thank my loved ones for their encouragement and support throughout this life-changing experience.

"Every now and then, in life we need someone to walk along beside us, put their hand on our shoulder and say I believe in you"

- Tony Wright CF 2011, Connect and Inspire Churchill Fellowship Event, London 2024.

About the Author

Isabella Matthews is an activist based in Kent. Isabella developed a severe form of cystic acne aged nine and began sharing her story online under the alias @spottylittlething during the COVID-19 pandemic. Through her time engaging online, Isabella became aware of the global impact of dealing with a visible difference. She was a campaigner for the charity Changing Faces for two years and shared her story through various media outlets including BBC Southeast (television), BBC Radio Kent (radio), Channel 4 (online), Metro (article and interview) and Pinterest (panel discussion).

Previously, Isabella has presented the Wednesday Breakfast, Friday Drive Time and Sunday Lunch shows for West Kent Radio, featured on Made in Kent Radio and BBC South East Upload and has written for magazines across the world.

As a result of her Fellowship, Isabella now works full time in television (for broadcast including Channel 4, ITV2 etc.) and established her own production company, IM Entertainment Productions CIC to share her findings through documentary form in educational settings and beyond. In 2025, she was nominated for BAFTA Breakthrough and shortlisted by Production Futures as Best Breakthrough Talent of the Year. In the long term, Isabella hopes her work will impact policy and social reform.

About The Churchill Fellowship

The Churchill Fellowship funds the travel and learning of over 100 individuals each year to learn from countries across the world and develop new approaches to current challenges. The Fellowship was created as a lasting living legacy of Sir Winston Churchill in 1965 to honour his memory and spirit in a unique community of changemakers across the UK.

I am grateful to the Fellowship and its community of changemakers who have supported and inspired me to create change in society. Already, towards the end of 2025, my life is unrecognisable by comparison to the life I had throughout the application process in 2024 – all due to the opportunities and impact following the Churchill Fellowship.

"What is the use of living, if it not be to strive for noble causes and to make this muddled world a better place for those who will live in it after we are gone?"

– Sir Winston Churchill, 1908, Kinnaird Hall, Dundee, Scotland

Executive Summary

When I first began this journey, I understood I had the potential to change the lives of others but I hadn't realised how much it would also be able to change my own. I set out to discover how communities with visible differences were being built, how individuals seemed to thrive in their industries, what more needed to be done and to see what we in the UK were doing right.

I decided to focus my Fellowship primarily on three countries, the US (New York and Los Angeles), the Czech Republic (Prague) and, virtually, India. My travels led me in directions I hadn't expected, and therefore, less work was done virtually in India but more in the US, which I believe has had a great positive impact on my findings. In the US, I spoke largely to individuals within the visible difference community about their wildly varied experiences. It was fascinating to discover how lives and experiences varied across different states and I'm incredibly grateful for the weeks spent in New York and Los Angeles. These individuals welcomed me into their lives (and homes) as we explored everything from their creativity and passion to work. It was incredibly important to showcase individual stories through this process because a key aspect of change, in my eyes, is building human connection. As this effort was so fruitful, it meant that time was more meaningfully spent with those individuals and comparing to the UK experience rather than exploring what I had aimed to in India virtually.

In terms of my Fellowship in India, I had aimed to speak to individuals and medical experts. However, through these conversations I became aware that the individual experience in India often echoed that in the UK. Additionally, the medical aspect I sought was happily encompassed within my time in Prague and by the doctors, who had travelled from across the world, shared there. Therefore, I have not included this experience as comprehensively in this report.

Contrary to the focus on individuals in the US, in Prague I sought insight on the medical perspective from the professionals.. It was an honour to attend the European Academy of Dermatology and Venereology conference in Prague, hearing about the

psychological impact of visible differences doctors are supporting patients with, challenging their ideas and also hearing about progressive upcoming treatments.

As a result of my findings, I believe there are three main themes to exploring the impact of visible differences: community, representation and public perception. I believe this can be influenced through education around acceptance, asking questions and advocating for ourselves. We should aim to educate in three primary ways: by humanising individuals outside of media portrayals, examining the language we use and raising awareness of the needs of those with visible differences, particularly for doctors and teachers. We need to instil confidence in those with visible differences and give them the platforms they need to thrive. The confidence to do this is built through community and it is key to bridging the gap between those with visible differences and those without.



The Report

London - New York - Los Angeles - Prague
Virtual conversations in India

Introduction

The reason for this report is simple: 1 in 5 people have a visible difference. 49% of people experienced hostile behaviour because of their visible difference in 2023. A 15% increase from 2019 (Savanta, Changing Faces, 2023). And frankly that terrifies me.

I grew up with a severe form of cystic acne. Acne is a normal condition, affecting more than 80% of the population at some point in their life (Purdy and Berker, 2006). Mine has existed for as long as I can remember, and strangely, seemed to totally clear up whilst on my travels researching this report.

An average morning routine for someone battling acne is this – wake up, check skin in mirror. Begin medical-grade skincare routine. Feel every bump and lump covering the surface of your skin. Stare back at the reflection in front of you. Take a breath. Begin the day. Walk down the street. Notice the glances, people scanning the areas of your face, recoil. Whilst this may sound dramatic, it is an insight into the daily battle of dealing with a visible condition in a more and more visually focused world.

Menial tasks become laden with repercussions and, for me, a moment that sticks in my mind will always be attempting to get colour-matched for lipstick. At the time, I was about 15, sat in Boots on what I thought was a ‘clear skin day’. I’d been on *another* medication which made me sick but my spots were getting smaller so it felt like a great success. I remember feeling positive about my skin that day, until I sat in the make-up chair. In the heights of the Kylie Jenner lip kit trend, colourful lipstick was in, and like any other teenager, all I ever had was a desperate need to fit in and be accepted by my peers. The beautician began testing corals, reds and mauves against my skin tone. Then randomly, she asks if I’ve ever tried niacinamide or tea tree oil, both well known ingredients for treating acne-prone skin. The worst aspect of this all too frequent scenario is the shock I receive when I have to inform anyone who offers unsolicited skincare advice that I’ve tried it all and I know a lot about skincare, often much more than the average person.

Simply existing with a visible condition becomes ‘*a thing*’ in every action from routine shopping tasks to accomplishing career goals and being taken seriously in interviews. Acne is a common skin condition that, at times, can be hidden from the

outside world. Yet there are many visible differences, like port-wine stains, alopecia and burns scars that you can't always hide. And nor should you have to.

Through my work as a campaigner for the charity Changing Faces, I became acutely aware of the various types of 'visible differences', a term coined by the charity and defined as 'a scar, a mark or condition that affects the appearance of the face or body' (Changing Faces, 2025). It was incredibly empowering to be in a room surrounded by individuals who each had their own story, their own condition and their own need to create change. In those rooms, I felt like an imposter – I *'just had acne'* – yet, regardless of the scale or the severity of the visible difference, each of us bonded through a terrifyingly large amount of shared experiences.

I believe that creating an inclusive society where an individual can be anyone and achieve anything begins simply with education. Our world is increasingly more focused on appearance, particularly considering the rise of Ozempic and *'heroin chic'* (Saner, 2025). Depictions of those with visible difference are often exclusively shown as villains in the media. In the James Bond franchise (EON Productions, 1962-present), most villains have some form of visible difference, with *No Time To Die* (2021) showcasing two villains both with visible differences. The message that looking visibly different is bad is a narrative pushed to us from an early age, for example 'Scar' as the villain in Disney's *Lion King* (1994). My belief is that by showing the UK, and the world, that people with visible differences aren't anything different (they aren't extraordinary or brave, they are just people) allows us to humanise those with visible differences. It's my aim that the startling statistic that sparked this piece will begin to decrease.

Social media can be a place where negativity and hate are harboured. But it can also be a place for connection and creativity to thrive. I began posting under the alias 'spottylittlething' during the summer in the midst of the COVID-19 pandemic. I remember it fondly as the first time I saw bodies and faces that looked like mine and naturally I discovered ways to connect and become inspired. It was through social media that I discovered many of the incredibly kind, passionate individuals who fill this report.

In my eyes, the US was doing something that we weren't in the UK. There are hundreds of individuals across the US championing their success and visible differences

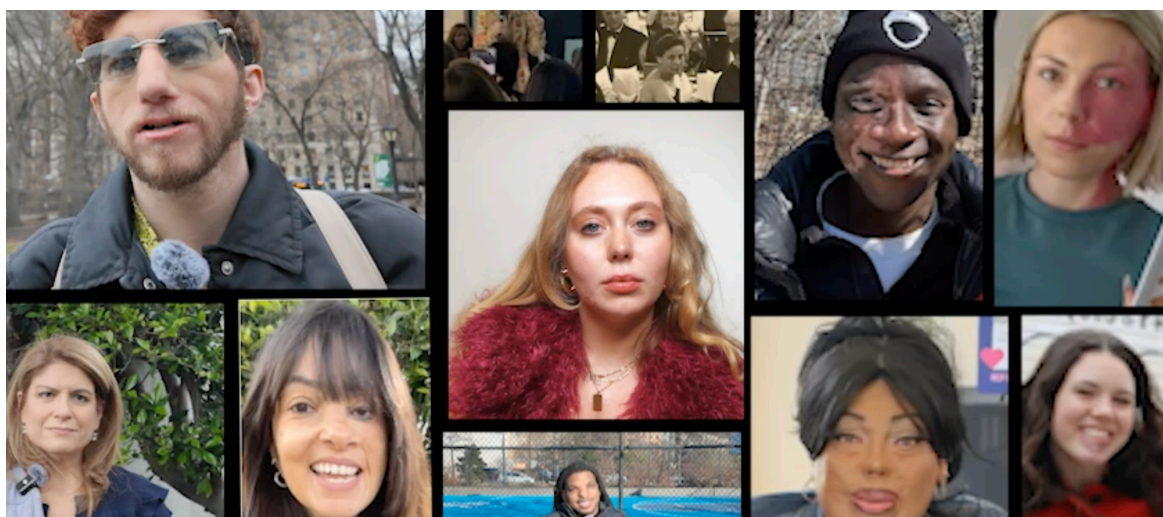
who are building connections in a grass roots style format. These individuals are building connections and challenging individuals on a much larger scale than those in the UK.

It is my belief that in the UK, often due to funding and resources, charities focus on large organisations and supporting individuals with visible differences rather than harbouring connections between those with visible differences and those without. I hope this report helps to bridge the gap that I feel exists in the UK. I hope those with visible differences feel seen but with less of an ‘us vs them’ mentality and instead a relatable story.

By showing the psychological impact of having a visible difference, I hope teachers will gain a deeper understanding of the struggles children with visible differences face and that generally children will act with more empathy and compassion towards each other. The world I travelled in during 2025 looks quite different to the world now and my hope is that when we have our next ‘shift’, this work can help to impact the 1 in 5 with a visible difference.

Alongside this report, I have also created a documentary both for festivals and for schools (<https://www.imentertainmentproductions.com/>). I don’t believe what is currently on the PSHE curriculum is adequate or aimed at connecting with children in the way it should. In our digital world, children are used to consuming quick, fast media. A teacher reading resources in front of a classroom is, frankly, not enough to target the ingrained sociological ideas that come from visible differences combined with the messages we receive from the media.

The term ‘visible difference’ is often used in the UK, whereas in the US, the term ‘facial difference’ is more commonly used (MyFace, 2025). They are interchangeable terms and are used as such in this report. My findings can be broken down into three key themes: **community**, **representation** and **public perception**.



Community

“One of my superpowers is making people around me feel able to be who they are around me.” - Austin Halls

My Fellowship journey began in New York City, where the importance of building community was clear. From individual friendships with Austin Halls, Aaliyah Booker and Naomi Hadar to organisations like MyFace, the US provided a community completely unmatched by the UK. My first interview was with Austin Halls, a Grammy nominated artist who has facial paralysis due to Moebius syndrome. He brought his friend, Aaliyah Booker, a presenter with a craniofacial condition, along to our interview.

Immediately, from my very first interaction with anyone in the visible difference community in the US, there were key differences from those in the UK. Firstly, both individuals are loud, proud and a total celebration of who they are. My perception is that their visible difference is an aside to their identity. Whereas in the UK, I’ve noticed through my interviews that often people with a visible difference introduce themselves noting their difference first and, after prompting, proceed to tell me more about who they are. A moment in Aaliyah and Austin’s company fills you with joy; they’re fiercely determined to make changes and also to bring everyone and anyone along for the ride.

Coincidentally, later we were headed to the same event, an adaptive runway show hosted within the Mount Sinai Hospital building overlooking Central Park, created by Runway of Dreams to ‘celebrate inclusion, highlight change in the fashion industry and empower people... with opportunity, confidence, independence and style.’ (Runway of Dreams, 2025.) Not only was I witness to an empowering event but I also met more individuals who I’d lined up for interviews back in the UK, and who already knew each other. This wonderful group of friends each have a different visible difference but celebrate each other’s milestones and rarely, if ever, talk about their visible difference.

A highlight of my trip to New York was sitting down within the MyFace headquarters, hub-cum-home for people with visible differences who work with individuals across the US to provide them with support, medical assistance and connection. As I entered their building, a young girl had just arrived with her father, having recently had an operation. Already in the hub were several of their ambassadors

(including Austin and Aaliyah) to chat about her experience with her whilst her father spoke to the incredible staff about next steps and logistics. Five minutes after they left, the reception had a call from a family who had recently been in a car crash and a member of the family had acquired a visible difference. Immediately, the team put them in touch with another family who had a similar experience.

I was struck by not only the immediacy of their work but also, how this was just an average day in the life at MyFace. Their ambassadors were relaxing and chatting, the staff working hard in a well-oiled, harmonious machine. I was invited to join them for lunch but also to chat about their work, the change they want, and interestingly, to hear where they felt were behind the UK. Over the course of 4 hours I interviewed everyone at the table including their Executive Director Bill Villafranco. Whilst Bill does not have a visible difference, he has a personal connection to the charity. He describes it as ‘electrifying’ seeing his seven-year-old grabbing his wife’s phone to record Austin Halls performing at one of the yearly MyFace galas ‘with no preconceived notion of Austin’s conditions’. MyFace fosters fun and is simply a place for ‘empowerment’ (Bill, 2025). It’s clear that having a hub in such a big city, and hosting large-scale events does provide that home-from-home base to allow community to thrive.

Community can be found in many ways, whether it’s through friendship, physical hubs or family, and the concept of finding people who support and love you unconditionally became a repeated theme throughout my conversations. Familial bonds were key for individuals like Justin Stewart, James McLeod and burn survivor Cindy Rutter. Their families were key to their healing and path to self-discovery to the extent that now they’re able to facilitate help and support to others without familial love.

Cindy, who survived a house fire aged 6, became a burns centre nurse manager and is part of the team at SOAR (Survivors Offering Assistance in Recovery) who provide recovery and peer support programmes across Canada and the US including summer camps (Phoenix Society, 2025). Her work aims not only to support families but also to encourage those who no longer have families to come together and find strength. In our time together, Cindy spoke warmly, yet modestly, of the changes she sees in support groups and, particularly, her passion for helping people still feel beautiful and encouraging intimacy in relationships with their new exterior appearance.

In the sunny state of California, resides a base for Face Forward International, who support ‘survivors of crimes, sex trafficking and slavery medically across the world’ (Face Forward, 2025). I was invited to their ‘home’ to meet Tonya Renee Meisenbach, a content creator who was set alight by her husband resulting in burns over 35% of her body (Longman, 2023). I met her in the midst of further facial surgeries alongside Mandy from Face Forward International. Tonya, like Austin and Aaliyah, is a larger than life personality and incredibly happy in her own identity. We spent a long time together discussing everything from her almost half a million social media followers, her story and surgeries to the Hollywood premiere she had attended the night before.

Face Forward are not just an organisation that supports medical treatments and surgeries. Through their fundraising efforts, they have secured a home where those going through surgery in LA could stay. They fly international survivors who need surgery to LA. Face Forward support their individuals, who often face scars and burns as newly acquired facial differences, to create a new life.

Mandy had spent Thanksgiving with Tonya in the house with the other residents and they spoke fondly of those who had passed through its doors. In particular, Mandy highlighted the importance of the home, considering that often individuals are ostracised by their own families or communities for being different or struggle to relate through the trauma. The physical home provides a familial base for individuals to recuperate, receive treatment and plan for their life beyond. The results are clear: Face Forward’s first acid attack survivor, Hanifa Nakiryowa, was able to attend Pittsburgh University then establish her own non profit in Uganda (CERESAV, 2026). Mandy and Tonya discussed the ‘healing’ that takes place by having a home where people from similar backgrounds can come to recuperate. As I left, Mandy even invited me to stay next time I was in LA.

Meanwhile, in the UK, there is no physical hub for people with visible differences to go to. Changing Faces are a wonderful yet relatively small charity with most active work available online or as sessions for parents or children in person. There are wonderful residential for young burns survivors (CBT Trust, 2026) but as far as my research has found, nothing wider for anyone else with visible differences exists in the UK. The only comparison from my research, would be Alopecia UK, who host a yearly trip to Alton

Towers (Alopecia UK, 2025). Whilst these are admirable efforts, there isn't anything regular or reliable to foster community in the wider facial difference community, and most events are online. Considering this, social isolation is a concern. On the contrary, in a moment's interaction with anyone at MyFace or their ambassadors you're struck by the confidence they portray to the outside world. You can't help but want to become part of their gang who encourage conversations to bridge the gap between those with visible differences and those without. I believe it's this gap that the UK is failing to bridge and it can only be healed by empowering these communities. But the community can only be built with confidence, a base and funding.



Representation

“There is no rulebook. I wish there was... Just know in your heart, that that’s who you are. And go do it.” - Nicole Cyrille

When was the last time you saw an individual with a visible difference on screen? The fact is, people with visible differences are rarely depicted in the media. On the rare occasion they are, it is often in a pitying or negative light. Only 1.8% of the 500 major characters in the highest grossing animated films between 1994 and 2023 had visible differences (Sullivan, L., Alter, N., Lear, G., Hiller, A., Pontell, D., Golinko, M., Galdyn, I., & Pontell, M, 2025). The importance of representation is well-established, not only as a means of encouraging those in that minority but as a method of acceptance outside of it. The media plays an ever increasingly important role in this as we become more and more digital.

Social media plays a pivotal role. In my own personal experience, social media allowed me to access incredible opportunities and to connect with those in this report, albeit alongside trolling. Globally, but in the US particularly, there has been a rise of social media influencers with visible differences, like Tonya, whose platform @BurnedBeauty showcases make-up tips and her surgery journey. Her account is not only aimed at individuals who have burn scars but also those outside of that community, and she is able to educate them. On the other hand, we have individuals like Austin showcasing their music on platforms like Spotify celebrating their differences.

One individual I was slightly starstruck to meet was Paige Lauren Billot. Paige was the first person I saw who celebrated their difference in a positive light on social media. She doesn’t hide her port wine stain, instead she creates make-up looks framed around it or even making it the canvas itself. Outside of showcasing her creativity and advocacy to her followers, she is an actress, model and producer. Recently named as the face of IT cosmetics, Paige could be seen in Ulta and Sephora stores across the US (@flawless_affect, 2025). I was saddened yet not totally surprised when Paige shared that she receives fewer acting roles when she shows her visible difference in auditions. She spoke to me about working in Hollywood and how social media not only gives her a voice but helps her to give her voice to others. Paige’s face is instantly recognisable and we

discussed how those with visible differences are being showcased in the modelling industry.

Winnie Harlow was the first model to walk the iconic Victoria Secret runway with vitiligo in 2018 (Valenti, 2018) and through my conversations with Paige and New York based model, Justin Stewart, it's clear there's vast differences between representation in the US and the UK. In separate conversations, both Paige and Justin's comments agreed that plus-size representation is minimal in the US. In 2025's New York Fashion week, Vogue reported that 'size inclusivity declined overall. Mid-size looks dropped from 2.8 per cent last season to 1.5 per cent, and plus-size looks increased from 0.5 per cent to 1 per cent this season. Straight-size looks increased from 96.7 per cent last season to 97.5 per cent this season' (Shoaib, 2025). Whereas in the UK, approximately 28% of UK adverts spotlight women with diverse body types, which is significantly above the global average (Kantar, 2025). Justin also believed there would be more opportunities for people with visible differences to model in the UK. Whilst it's impossible to say for certain, I struggle to think of a specific instance where someone with a visible difference has been the face of a nationwide campaign to the same scale as Paige's IT Cosmetics campaign. As far as my research would allow, the same IT Cosmetics product launched in the UK without a 'face' attached.

As previously asserted, confidence comes from community. With this confidence, individuals can become the representation they want to see. Tonya, Justin and Paige didn't see anyone who looked like them in the media so they harnessed their confidence to be that representation, which then in turn inspires others (including myself). By existing and celebrating themselves across social media, all of the individuals I spoke to become the representation they didn't see and as a result inspire the next generation. In addition to this, they provide a place for people to ask questions and through regularly seeing their faces on social media feeds, individuals become familiar with seeing someone who looks different. In Rosemarie Garland-Thomson's paper, she explores how anything other than 'normal' is treated as a curiosity – 'we stare when ordinary seeing fails, when we want to know more' (Garland-Thomson, 2009). Staring is considered a micro-aggression by many within the visible difference community. In order to stop this, we need to show more diversity in all media we consume.

LA seemed like a key place for me to visit considering this, to see what it's truly like behind closed doors. Prior to my trip, I'd been fortunate to attend the UK premiere of 'A Different Man' (2024) starring Sebastian Stan and Adam Pearson, who has neurofibromatosis. As part of the film, Sebastian Stan transforms through prosthetics to look like Adam Pearson. I was able to get in touch with Mike Merino, the award-winning make-up artist who created the prosthetics. He spoke at length about the empowering nature of working with someone like Adam, and the skill and process it took to do his appearance justice. He ended our call describing it as an 'honour' to work with Adam and hoped there would be many more stories like his to tell in Hollywood (Merino, 2025). It was great to hear such positivity from an Oscar nominated make-up artist (IMDB, 2025). It felt as if there could be a turning point in Hollywood.

However, when I then spoke to Nicole Cyrille, the Screen Actors Guild American Federation of Television and Radio Artists (SAG AFTRA) Disability Chair, the positivity from Mike felt more complicated. As a representative for the disabled community and a renowned actress in Hollywood, Nicole was able to provide key insight into the conversations, negotiations and reality behind this representation. She asserted that those with visible differences would be classed under the disability umbrella because 'if they're going to be marginalised, which they are, for having a visible difference, then we need to take them into our community' (Cyrille, 2025). She believes that disabled actors are still marginalised and that the key to creating change is to 'bring us into the room'. She called for writers to bring disabled people into the writer's room, and for actors to bring disabled actors in too. If a character is written as disabled, controversy remains over whether this role should exclusively be played by a disabled person or whether any actor could. She argued that roles that are just 'normal' roles should be open to disabled actors too. Whilst Nicole couldn't play a 'marathon runner', she could play any other role like a mother or nurse. We celebrated the impact of Shondaland, Shonda Rime's production company which is universally celebrated for representation in its shows (Spooner, 2024), including Bridgerton and Grey's Anatomy (for which Nicole provides audio description) and our conversation felt impassioned but hopeful that change was on the way.

For an alternative perspective, I met with James McLeod, a motivational speaker, DJ and teacher with vitiligo who penned the book *The Boy Behind The Face*. He takes this

book around schools in the US, reading to the children, encouraging conversations and for children to ask questions.

James separated the visible difference community into ‘generations’. His take was that the new generation saw their difference as art and an object of beauty, something to celebrate. Whereas James sees it as an acceptance and a struggle to heal. His passion is more than just visible differences, it’s simply to empower people to love themselves. James uses his ‘facial difference to make a difference’ (McLeod, 2025). James provided a fascinating perspective, different to the others in New York. Clearly, he had been on an in-depth healing journey and was now using his power to change the world for good. I saw moments of his outwardly confident and positive demeanour change off-camera but his passion to change the world is what connects him to the others I spoke to across the US. James highlighted the impact of figures like Michael Jackson, who is rumoured to have had Vitiligo, (Brooks and Kindon, 2026) and how without his mum, he may have struggled significantly more. I believe this proves that community is even more key to providing representation. James is supporting children across his state with their own self-discovery, providing representation and facilitating key conversations. However, again, this wouldn’t have been possible without his family community.

In the UK, representation is starting to improve. Notably, through the efforts of charities like Changing Faces and individuals like Adam Pearson. The Welsh Government have committed to the Changing Faces ‘Pledge To Be Seen’ campaign, which commits them to representing more people with a visible difference and agreeing to to ‘raise awareness... and identifying how we can improve representation’ (Morgan, 2021). In the CBBC show, *Malory Towers* (2020-2025), actress Beth Bradfield, who plays series regular Jean, has facial scarring following surgery to remove hemangioma. This is a significant step towards representation as Beth’s character’s appearance is never commented on. It doesn’t play a central storyline; I struggle to find any other examples of similar occasions. There is clearly much still to be done in terms of representation. However, following conversations with Mike and Nicole in particular, I felt optimistic that change is still on the way.

Considering the current political climate in the US, Nicole felt that their access to representation was now threatened. My fear, given the rise of far-right politics in the UK

(Labica, 2025), is that this could be repeated in the UK and we appear to already be behind the US in terms of media representation. I believe the way to fix this is to have individuals, like myself, creating easily consumable media with people who have visible differences and encouraging those with visible differences to engage in the wider community. This would ensure governmental rulings and ‘trends’ have little to no impact on the grass roots displays of representation. And, in turn, this impacts public perception.



Public Perception

“Have you ever seen someone with a fully burned face? 'Cause I hadn't.” - Tonya

Renee Meisenbach

Individuals with visible differences are regularly prejudged and become treated as a spectacle rather than just a person existing. Whilst not everyone means harm, when faced with someone with a visible difference, people feel pity, consider it brave or see them as villains (Shakespeare, 2014; Norden, 1994). Aside from extensive medical implications, a life can be completely altered due to social stigma. The impact of achieving acceptance through realistic media portrayals and conversations is insurmountable to even consider. Rather than viewing individuals as a marvel or a symbol of pity or fear, we should be viewing those with visible differences as ordinary – as friends, parents, doctors, teachers, actors etc. When this acceptance is achieved, we bridge the ‘us vs them’ gap.

Even with my experience, I fell victim to this trope, initially framing questions to those I interviewed around viewing a visible difference as a ‘superpower’. However, my mind was quickly changed when I realised how little our conversations needed to revolve around the intricacies of the visible difference. There is much, much more interesting conversation to be had around the music that inspires Austin, what encourages artists like Celina Leroy to paint, how doctors like Ayberk Aktaran see the medical landscape changing with AI.

In order to see and encourage this view of visible differences, it's key to challenge public perception by spotlighting those who make those efforts. For example, Runway of Dreams adaptive runway proves to both able-bodied and disabled bodies that anything can be achieved with the right support.

I was inspired to go to New York particularly due to the work of one individual, Celina Leroy. Celina is a talented artist who facilitates art displays and community gatherings to celebrate individuals' uniqueness (Positive Exposure, 2023). Many of her portraits are of people in the visible difference community but Celina incorporates their personality and likes into her work. She's created over 100 pieces and when we met, she was preparing for her next exhibition hosted in Williamsburg. Celina shared her personal story with me exploring everything from finding her confidence, her struggles with

medical professionals and family perceptions as well as her passion for art. It was an honour to attend her exhibition, see the scale of her pieces, meeting those who were featured (including 2 people from the UK!) and hearing how her work has established its own community. So much so, that two individuals had embarked on a long-distance relationship between the US and Brazil!

It's hard to put into words the feeling of being in a room with friends, family, those with visible differences and random members of the public. Each one seeing such beauty in Celina's work. What sets Celina's work apart that it's not simply a celebration of the visible difference but a celebration of the individual. For example, showcasing the individual as a marathon runner, adding in their favourite guitar or even using their favourite colours.

Alongside MyFace, Celina has also orchestrated her exhibitions to become a highlight and special event for the visible difference community to feel welcomed and accepted and, yet again, the visible difference was the least interesting topic of conversation. I was fascinated to speak with Celina's father. Celina had touched upon how she'd struggled with the ideas of perfection growing up and, heartwarming, her father whilst bursting with pride noted 'You have to stick by your kid. You just have to stick by them' (Leroy, W., 2025). I felt this completely encapsulated my research. Celina's father had been challenged by his child looking different, but through her own confidence building and sheer talent, Celina has carved herself an entire body of work to celebrate with simply the hope that people 'make friends' (Leroy, C., 2025) at her events. When we 'stick by' individuals who may be dealing with different life challenges, we provide them with the confidence and necessary encouragement for them to create the change they want to see.

Furthermore, I had the pleasure of meeting Lorena Bryant who has had regular surgeries to treat a birthmark covering the right-hand side of her face. When we met, she had just moved to New York and already connected with much of the visible difference community due to Celina. She spoke of the importance of finding your tribe in the face of self-discovery and her struggles in overcoming her medical traumas. She spoke of the freedom of living in New York, where no one cares about your difference. The people and culture in New York innately celebrate your individuality or, on the other hand,

simply don't care! There are so many different things happening in New York in a day that seeing someone who looks slightly different is not a point of interest (Bryant, L. 2025).

This sentiment was echoed by Aaliyah Booker and Poonam Patel. I connected with Poonam, who has vitiligo, online and we discussed the cultural differences between the US, UK and India. She spoke of how India is focused on beauty and perfection; in her experience she was either idolised because of her vitiligo or ostracised. In order to overcome this, she conducted a 15-day 'body neutrality' experiment to help her not feel 'positive' or 'negative' about her skin condition (Patel, 2020). Poonam explained how her interactions with others had made her feel and how her vitiligo had been fetishised in India. She had spent a significant amount of time in the US and felt that there, her face was considered an object of beauty rather than something shameful. Poonam felt that in the US, she could explore her individuality in ways she couldn't in India, due to their cultural differences. Her views inspired me to consider that the focus of public is to place someone with a visible difference into a box. They are either beautiful because of their visible difference and must be celebrated, or it's a terrible thing. This concept was reiterated by James McLeod who spoke at length of the differences between the 'new and old' generations of those with vitiligo.

There was a moment in Los Angeles that has stayed with me ever since. As a TV fanatic, I sat in the audience of a live taping and was called upon by a household comedian. After explaining my reason for being in LA he proceeded to ask 'What do we call people with alopecia? Alopecians?' I replied 'People, people with alopecia.' Whilst some audience members laughed, those next to me gave an awkward smile. I wonder why we feel the need to box people, why we need to make an 'us vs them' mentality with regard to visible differences. This may also be part of the generational gap that James highlighted, given the age difference between myself and this host, but it's an experience that has certainly stayed with me.

Many would consider a place like Los Angeles to be the epicentre of beauty ideals given its Hollywood past and plastic surgery boom (Wilson, 2022). However, from my conversations with Paige, Tonya and Nicole, it didn't appear that they were affected as much by daily interactions as they were in specific situations, for example, the audition

room. Combining this with Mike's optimism, I left LA overall with the view that visible differences don't have as much daily impact as they do in the UK.

Complex medical treatments often go hand in hand with visible differences. Whether it's repetitive surgeries or countless medications (as it was in my case), it reiterates the idea that there is something that must be fixed. I began taking tablets for my skin from age 10, and many of those at Celina's event had been through surgeries regularly as babies through to young adulthood. I was informed by multiple people that often, treatment only stops when the patient decides and works to accept their difference. I found discussing our medical past was a great bonding tool between myself and the contributors regardless of the visible difference. Unfortunately, each of us had a horror story.

Therefore, I wanted to connect with more doctors to establish the thought process behind treatments. Were they necessary? Is the doctor's mentality to 'fix' a person's face? Are they seeking perfection? I had made a lifelong friend in film producer Katy Haber whilst in LA and her father, Henry Haber, was a renowned doctor of venereology and dermatology (after whom Haber syndrome is named) from Prague. His passion and lifelong dedication to helping his patients, instilling hope and humour into his work (as shown through glowing obituaries and papers after his tragic death in 1962; see A.H.H. Obituary, 1963) challenged my perception of doctors. In my experience, it had been fuelled by negativity and my discussions with contributors had only added to the idea that doctors are trying to reach a perfection that doesn't exist at the detriment to overall health, mental health and comfort. The articles about Dr Haber talk of his care and support helping to provide his patients with clarity and lessening their pain. His care argues against the above theory and also that of a 'generational gap', given that he practised during the early 1900s.

My next stop on my Fellowship was to Dr Haber's birthplace, Prague, to attend the European Academy of Dermatology and Venereology Symposium (the EADV, 2025) to speak with current medical practitioners about their work and treatments, to try to gain more clarity on their approach. It was fascinating to hear so many talks and conversations from doctors across the world sharing their expertise on a range of visible differences from tumours to skin conditions. It struck me how matter-of-factly these doctors discussed deeply personal stories accompanied by intimate pictures of their patients.

However, particularly when speaking to Dr Brett King, who became emotional discussing the impact of helping someone improve their life, as a doctor, something switched for me. Ultimately, doctors want to help individuals live a pain-free, easier life. Dr Brett King is using cutting-edge, experimental technology to encourage hair growth in alopecia patients and skin cell development for those with vitiligo using JAK-inhibitors. This isn't the mechanism behind Marty McFly's ability to travel 'Back to the Future' with Doc (1985) but instead a mechanism to create a new, easier future for Brett King's patients one where they aren't dealing with the views and opinions from the public that vitiligo and alopecia can bring. Furthermore, Dr Ayberk Aktaran is keen to start using AI models to help people gain earlier diagnosis for rare conditions thereby preventing mental trauma for misdiagnosed patients and repeated tests to quickly begin helping them process and lead a fulfilled life (Aktaran, 2025).

The reality is, no one wants a visible difference and the world makes it tougher on those who do. Whilst it's motivating to see individuals like Austin and Celina utilise their talent inspired by their visible differences to make change, their talents would exist regardless. On one hand, it could be questioned whether individuals with visible differences feel the need to prove they are not entities to be pitied or villainised and see it as a duty to confidently present themselves to the public. Particularly as the individuals I spoke to are doing such incredibly impressive things, far from the realm of 'normality'. However, I believe this pessimistic view diminishes the impact of their work. The individuals I spoke to are just a small segment of the hundreds of individuals working each day to change the public's perspective on those who have visible differences. Without them, there is no change and statistics will rise above 49% of people with visible differences experiencing hostile behaviour (Savanta, Changing Faces, 2023).

In the UK, public perception is impacted largely through staring. However, unfortunately in the UK there are so many troubling stories like those of Oliver and Kaylin. After a hospital visit, Oliver went into a nearby restaurant and was asked by staff to "please leave", because in their words I was "scaring the customers", and there had been complaints about me' (Bromley, BBC News, 2024). This isn't an isolated incident, Kaylin also shared her experience of being heckled whilst waiting for the bus, where she was told "you're the ugliest f***ing human I've ever seen in my life" (McLaughlin,

Changing Faces, 2023). Whilst shocking, it puts into perspective the abuse those with visible differences face everyday.

When comparing the US's pride and activism, alongside the daily positive interactions felt by many of my contributors with my personal experience (which is echoed by many of those with visible differences in the UK) it's clear to see that public perception has less of an impact in the US. It could be that there, people aren't afraid to ask questions compared to the stoicism and stiff upper lip trope exhibited typically in the UK (Social Science History, 2024). Following the whirlwind trip, it is, in my view, clear to see that there is a direct link between community, representation and altering public perception. Quite simply, more needs to be done to help the lives of the 1 in 5 with a facial difference and to alter the public perception and reception of those who have facial differences. We need to change the mentality from pitying, celebration or villainy to just simply accept people as they are.



Final Reflections

It's hard to know how much our personalities are impacted by our visible differences, but I know from my perspective I felt a loss of identity once mine was no longer a part of my daily life. My visible difference brought me an immense amount of motivation to make change in the world and I'm grateful for the experience and how it shaped me. I wonder how that would have been impacted had I not been battling low self-esteem and the views of others for most of my life.

Creating this report changed my life in ways I did not expect. It's shaped me entirely into who I am today. I sit now, exactly a year on from the start of my trip in a brand new city, with a new career, a new purpose and, I believe, a new identity. Identity is a key factor in shaping our interactions with the world, and having a visible difference can greatly impact this. However, I hope this paper has shown the true human side to the 1 in 5 with visible differences and motivates those who feel restricted by any circumstance, whether it is a visible difference or any other socio-economic barrier, that they truly possess the power and ability to alter their lives in whatever direction inspires them.

We cannot underestimate just how much we are shaped by those we surround ourselves with. Having spent a moment in the joyous company of those who have helped immensely with my report, I knew I was coming back to an entirely different life post-Fellowship. It seemed the road ahead was clear and I hope to do those I spoke to proud in my steps going forward.

Adam Pearson is set to star in a new adaptation of Bernard Pomerance's play, *The Elephant Man*. With filming only just beginning as I finalise this report (Tangcay, 2025), I'm intrigued to see the impact of his portrayal. Adam possesses immense talent as an actor and a speaker garnering a loyal audience. Following the positivity generally from the film industry, I can't wait to see the final output of the film and, more significantly, the impact it has worldwide.

As a result of this Fellowship, I've become aware of how crucial small incremental movements are and particularly how key community is to changing the world. It was something I had attempted to start by facilitating events for people with acne; however, there is a much wider yet more local need for connection to be established first. With community, comes representation, and with that comes altering public perception. Each

one is necessary to influence the other and I hope that with my next steps, I'll be able to play a significant part in this.



Next Steps and Recommendations

Following my Fellowship, I have established a Community Interest Company (CIC), **IM ENTERTAINMENT PRODUCTIONS**, to begin distributing the accompanying documentary and shorts to schools, universities and local communities across the UK. We intend to facilitate open discussions around visible differences, providing those without visible differences a safe platform to ask questions and understand, and to help teachers and leaders facilitate healthy conversations.

The aim of the CIC does not end with this project; we aim to continue making social impact content to engage our audiences in various mediums and also to provide entry level opportunities to those passionate about film-making, media and our social causes.

The eventual goal will be to establish a physical hub to provide the community that is so desperately needed where people can learn and share their talents with each other. I am also keen to enact policy change where necessary. To keep updated with our progress, please explore <https://www.imentertainmentproductions.com/> or get in touch with me via the Churchill Fellowship or via email: isabellachurchill25@gmail.com

My key recommendations:

- Facilitate physical hubs and a central connection point to connect individuals across the country
- Encourage neutral media representation
- Boost individuals' confidence through shared connection and support
- Support those confident individuals to create their own change
- Communicate openly and honestly with the general public to prevent and stop an 'us vs them' mentality
- More individuals like myself need opportunities like this to change their lives.

I believe IM Entertainment Productions will be this key organisation for the UK.

Further Acknowledgements

With immense thanks to every individual who contributed to this report and made my travels such a wonderful experience.

Particularly,

Ayberk Aktaran	Eleanor Hardie	Cindy Rutter
Paige Lauren Billot	Naomi Heather	Mandy Schier
Aaliyah Booker	Brett King	Mount Sinai
Lorena Bryant	Stasha Leith	Justin Stewart
Mandi Budd	William Leroy	Zebedee Talent
Nicole Cyrille	Celina Leroy	Craig Taylor
Gary Dartnall	James McLeod	Paige Taylor
Face Forward LA	Laura Mathias	Julia Verdin
Natalia Freitas	Tonya Renee Meisenbach	Bill Villafranco
Henry Haber	Mike Merino	Alicia Wakeling
Katy Haber	MyFace	Roger Warnock
Austin Halls	Poonam Patel	

And my wonderful friends and family for their endless support and motivation.

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