



**Colour Between
the Lines**





Acknowledgements

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Changing Our Lives is a rights-based organisation. We work in partnership with disabled people and people with lived experience of mental health difficulties to find solutions to social injustice and health inequalities.

All of our work is rooted in the belief that no one is too disabled and that no one's mental health is too complex to lead an 'ordinary life'.

Our approach rests firmly on the social model of disability. As such, we don't believe people's lives should be limited or defined by labels or diagnoses, and we are committed to reframing how society views mental health and disability.

Our vision is of a society in which disabled people and people with lived experience of mental health difficulties of all ages are afforded universal human rights, resulting in them being in control of their own lives as equal citizens.

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Introduction

Across disability movements and society in general, the lives and experiences of disabled people from minority ethnic communities are often overlooked and obscured from view. Oral histories of disabled people rarely mention the lives of individuals from minority ethnic communities; likewise, oral histories from minority ethnic communities rarely mention the lives of minority ethnic disabled people.

To combat these gaps in the narrative, Changing Our Lives is committed to preserving these invisible histories, on both an individual and collective level. Taking both an anti-racist and human rights based approach, we believe it is essential that the history of disabled people from minority ethnic communities is recorded and celebrated, so that individuals are acknowledged for their contributions to society. Colour Between the Lines emerged from that belief.

Drawing on oral history approaches, and funded by the Heritage Lottery, Colour Between the Lines charts the individual development and successes of 7 individuals who, in spite of societal prejudices and discrimination towards race and disability, have established successful and thriving lives. These individuals are Siraaj Nadat who has worked within the self-advocacy movement made up of people with learning disabilities and also outside of the movement since 2007, as well as Caprice Haughton, Monique Meehra, Andrew Faure, Kashmire Hawker, Samee Ahmed and Gina Patel, all of whom were part of the Rights For All leadership programme which worked with young disabled people from minority ethnic communities from 2014-2015. We gathered people's experiences and reflections via individual meetings, as well as reminiscence workshops. We also facilitated photoshoots as we were keen to capture good quality portraits both for the book and subsequent exhibitions.

Walking through the experiences and perspectives of these 7 individuals, we wanted to find out what - if any - impact the wider disability movements had on their experiences. Chapter 2 gives an overview of these movements and individual's responses to them, chapter 3 examines people's experiences of disability discrimination and racism and chapter 4 features the histories of the 7 individuals.

We have chosen to use 'minority ethnic community' as this is the phrase we use when we describe our work on a large scale. However, our preference and the preference of people we work with is to recognise the local community we are working with, for example the British Pakistani community. We recognise that no language is ideal and seldom reflects the communities we work with, for example, many communities we work with are not minority in their local area and any label naturally papers over the diversity of experiences and cultures within groups of people.



**In or out: what people felt about being
part of a wider disability movement**

The disability movement

From the late 1960s disabled people began to politically mobilise. Although influenced by the women's rights and civil rights movements, disabled people came together in their own right, challenging the fundamentals of why they were not included in society. In 1960s Britain it was common for disabled people to live in residential institutions or large hospitals and to be educated separately, if at all. Most disabled people did not work and most communities were inaccessible. Disabled people were excluded from mainstream society and lived a segregated, restricted life that was far from ordinary.

Disabled activists questioned the way society was organised and the way disabled people were segregated and excluded from everyday life. As Jane Campbell (1997) documents in 'Growing Pains: Disability politics - The journey explained and described', a catalyst for the disability movement was a letter written by Paul Hunt in 1972 to the Guardian, 'encouraging disabled people to join forces and vocalise their dissatisfaction with their lot in life, particularly if they were institutionalised.'

It was in this environment that the Social Model of Disability was developed. Mike Oliver (2004) in 'The Social Model in action: If I had a hammer' charts the development of the Social Model back to 1976 when the Union of the Physically Impaired Against Segregation (UPIAS) published The Fundamental Principles of Disability. They wrote:

'In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. It follows from this analysis that having low incomes, for example, is only one aspect of our oppression. It is a consequence of our isolation and segregation, in every area of life, such as education, work, mobility, housing, etc.'

UPIAS was a hugely important disability rights organisation. It was radical in its thinking, rejecting traditional perspectives and reframing the concept of disability in terms of a socially constructed phenomenon and as a civil rights and equality issue, rather than a medical or charitable issue. UPIAS redefined the experience of disabled people as a form of social oppression, arguing that disabled people are excluded because of the way society is organised and responds to disabled people.

The continued campaigning and protests that took place in the years that followed, particularly during the 1990s, took the social model of disability as the starting point and focussed on eliminating barriers in society that exclude disabled people. The activism of groups such as Direct Action Network (DAN) and Campaign for Accessible Transport (CAT) put the civil rights of disabled people in the spotlight and moved the agenda firmly away from pity and sympathy. The rights of disabled people in the UK were finally underpinned by law and the passing of the Disability Discrimination Act (1995) which made it illegal to treat disabled people differently to non-disabled people and introduced a requirement for employers to provide reasonable adjustments and remove barriers to access for disabled people. Subsequent reforms introduced specific requirements around accessible public transport and an equality duty on public bodies. The Disability Discrimination Act has subsequently been subsumed into the Equality Act 2010 which replaced previous anti-discrimination laws with a single Act.

In recent years there has been criticism of the Social Model of Disability, with academics and disabled people arguing that it ignores the intersecting factors of race, gender, sexuality and other considerations (Marks, 1999). There is much debate around this and Mike Oliver who came up with the term the Social Model of Disability argues that just because the social model has not adequately incorporated these

The self-advocacy movement

factors does not mean the model cannot do so or cannot cope with these factors, arguing that 'In the broadest sense, the social model of disability is about nothing more complicated than a clear focus on the economic, environmental and cultural barriers encountered by people who are viewed by others as having some form of impairment – whether physical, sensory or intellectual' (Oliver, 2004).

Dan Goodley (2000) describes self-advocacy as 'a counter movement to state paternalism, wherein people with the label of learning difficulties conspicuously support one another to speak out against some of the most appalling examples of discrimination in contemporary British culture.'

The self-advocacy movement is said to have started in the UK in 1984 with the founding of People First in London after a group of people with learning disabilities were inspired by a visit to an international self-advocacy conference in the USA. Its earlier roots lie in the 1970s when professionals and academic advocates supported the development of self-advocacy through conferences and events (Buchan and Walmsley, 2006). From the 1980s onwards self-advocacy organisations began to spring up around England but it was the government white paper, Valuing People published in 2001, with its four key principles of civil rights, independence, choice and inclusion, that bolstered existing self-advocacy organisations and led to new ones forming. Self-advocacy organisations in the main tended to hold self-advocacy group meetings where people learnt about and spoke about their rights, trained professional staff in learning disability awareness and the production of easy read documents, commented on services for commissioners, carried out consultations with their peers by asking their opinions, and campaigned around specific issues.

In order to monitor progress on the commitments made in Valuing People around England, the Department of Health commissioned the National Forum of People with Learning Difficulties and Regional Forums of People with Learning Difficulties around England. People from local self-advocacy groups attended the Regional Forum, and it was at each of these forums that 2 people were elected to represent the region on the National Forum. The National Forum aimed to speak to Government about big issues, as well as monitor progress on civil rights, independence, choice and inclusion. The National Forum lost its government funding in 2017, however by 2019 there were still over 100 self-advocacy organisations still running, the majority of which were independent from provider organisations (Walmsley, 2009).



Siraaj's thoughts on the self-advocacy movement

Siraaj Nadat had been part of the self-advocacy movement for 5 years (2007-2012), initially being part of what was called Ethnic Advocacy from 2007-2010, then the West Midlands Regional Forum from 2008-2011 and the National Forum from 2009-2011.

Siraaj acknowledges that there have been positive strides made by the self-advocacy movement. These include improved awareness of and access to easy read communication, more people having access to Communication Passports which are a portable way of showing people how a person with a learning disability communicates, more people living in their own homes, rather than residential settings, greater awareness of health inequalities and Hospital Passports which are a way of giving health professionals a quick overview of the person so they can receive improved healthcare. However, he feels that the movement has become mired in talk, rather than action. Siraaj questions the purpose of having self-advocacy meetings where people simply talk about experiences and feelings and there is no positive action and outcomes that result:

'There is too much talking and no doing. There are rarely any positive outcomes from all of this talking.'

This view is echoed by Simone Aspis (2001):

'Self-advocacy should not just be about saying how one feels about a situation. It should be about action, i.e how to achieve real and long lasting change.'

Aspis argues that in meetings, self-advocates would be asked to give their opinions and talk about how they felt about situations, but because of the power imbalance 'self-advocacy has come to legitimate what service providers and commissioners want, rather than what people with learning disabilities wish to have.' Self-advocacy seen in this context serves a legitimating function for those in power

and whatever rights the self-advocate is told they have, have to be negotiated from an unequal position, rather than demanded. This is reflected in Siraaaj's experiences:

'Self-advocates hold a range of knowledge about what's happening around them but professionals want people who mainly agree with them. I have spoken out against professionals in the past and they don't like it. They say they are giving people a voice but professionals are doing this to make themselves look better.'

Siraaaj also talks about people in the movement becoming trapped by the label 'self-advocate'. Individuals with learning disabilities had fought for years for discriminatory and limiting labels to be removed, and yet Siraaaj argues that the self-advocacy label itself can be used in a way which is restrictive. People are invited to meetings and introduce themselves and are introduced by others as self-advocates, not seen as professionals with a skill set, but seen as an expert only in their personal experience.

'The word self-advocate is a label. I am not a self-advocate, I'm a professional. People used to limit me and ask me questions such as, "How did you get to the meeting today?" I used to say, "Same way you did." Some people may need support to travel but the problem is they make the assumption that everyone needs that support. Then self-advocacy limits you.'

For Siraaaj, this move away from self-advocacy also had a racial element as he was invariably the only brown face in the room. To have the label 'self-advocate' and the additional label 'minority ethnic' in Siraaaj's words, means he 'ticked both boxes'. These labels meant he was expected to represent everyone in the learning disability world and the world of minority ethnic communities.

'Working at a national level as a disabled man from an Asian background I stood out. There were no other brown faces. I thought this is not right. There are so many communities out there. I'm not here to tick your ethnicity box. Just because I'm Asian and disabled, doesn't mean I hold all the knowledge. I don't know everything about being Asian and disabled.'

This frustration built up in Siraaj until one day in 2011 he stepped away from the self-advocacy movement in the middle of a National Forum meeting. Hit by a wave of frustration after endless meetings over several months with no actions or outcomes achieved, Siraaj stood up, banged the table mid meeting, and expressed that he had had enough and couldn't continue the work he was engaged in as it was not making things better for anyone. Siraaj reflects on this time and his move away from self-advocacy:

'I wanted more responsibility and I wanted more to be expected of me. I didn't want to have the label self-advocate and have people say that was all I was. I wanted to blur out the disability and not been seen as a self-advocate.'

Siraaj's views were echoed by and influenced the team in Changing Our Lives and in 2013, after being borne out of the self-advocacy movement in 2002, the organisation made the decision to no longer describe itself as a self-advocacy organisation. This decision had been several years in the making but following on from a strategic review, asking disabled people and stakeholders their views on the work and what they saw the role of the organisation being, people overwhelming said that they did not consider Changing Our Lives to be a self-advocacy group, nor did disabled people consider themselves 'self-advocates'. They preferred the language of a 'rights-based organisation', characterised by coproduced initiatives and an outcome driven approach.

The background to Rights for All

Siraaj would go on to be awarded the British Empire Medal in January 2017 in the Queen's New Year's Honours list in recognition for his years of rights-based work.

Taking a dual approach of both equality and equity, Changing Our Lives from our very beginnings made a commitment to ensuring our work included a broad demographic reflective of local ethnic minority communities and at the same time developed targeted projects, coproduced by people from minority ethnic communities and aimed at issues important to people from these varied communities.

Equality involves ensuring that individuals and communities have an equal opportunity to make the most of their lives and talents. Equity is about giving people what they need in order to make things fairer and plays a key role in achieving equality.

For us, this means targeting our resources to the benefit of communities that are more likely to experience social injustice and health inequalities on multiple levels throughout their lifetimes. In many cases, ethnicity has historically and continues to be a key contributing factor.

Borne out of this drive, Rights for All, delivered between 2014 - 2015, was a bespoke leadership development programme specifically designed to enable young disabled people from ethnic minority communities across the Black Country and Birmingham to become actively involved in leadership opportunities. We knew through our national work that disabled people from minority ethnic communities were seldom offered leadership opportunities to develop the knowledge, skills and attributes they needed to thrive as individuals and members of society, and therefore decided it was imperative that we tackle this head on.

Set within a human rights context, the programme gave individuals an understanding of how universal human rights can unlock opportunities, widen their knowledge and help them to manage many of the most critical opportunities, challenges and responsibilities they will face throughout life. It also explored the concept of race, and how racism, the product of this social construct, impacts leaders, both present day and historically.

Alongside leadership development workshops, every young person was offered mentoring opportunities with highly skilled professionals from across England, who held leadership positions in a range of fields. Enabling the young people to have leadership experiences before the project began, each potential mentor was required to sell themselves to the young people and young people chose a mentor that they felt would be the most benefit on their leadership journey.

9 young people progressed through this programme and all 9 have achieved significant goals in their lives, including:



5 of the young people went on to paid work with Changing Our Lives in a range of paid roles including Quality of Life facilitators, co-leading Quality of Life reviews, coproducing a range of rights based projects and speaking at events.



4 of the young people went on to university, and the youngest individual is still at university.



7 progressed into paid employment.

Rights for All alumni's views of the wider disability movement

Talking to the young people who were part of Rights for All, we asked them if they felt they were part of a disability movement and if they thought they needed to be in order to make an impact. Two clear themes emerged: no one felt the need to attend meetings, go on marches and say they were part of a movement in order to make a positive impact on disability rights and disabled people's lives, and everyone wanted to be free of disability labels, free to live their lives unencumbered by negative assumptions that accompany diagnoses and labels which set them apart, as 'special'.

'I don't think I was conscious of being part of a movement at the time. It felt that when I was doing this work that it was very collaborative. Then when we did an event and one of the young people's moms spoke to my mom, and I really saw the affect we were having on other families and other young disabled people. I realised that what I was doing was important. I was making a difference and a change but when I was in the middle of the work I didn't think, I'm part of a movement.'

Caprice

'This work gave me a real perspective and understanding about everyone being different but everyone being on an equal footing and this is what stayed in my mind as I've been in various roles throughout my career. It's about making everyone realise that society should be one team ultimately. I didn't really see myself as being part of a disability movement.'

Kashmire

Caprice described bringing about change by 'occupying spaces'; by overcoming barriers in her own life and pushing herself to succeed which acts to promote all disabled people:

'Having disabled people occupying spaces, for example when we go to uni and succeed at uni or myself now working within the field of law, that helps all disabled people to move forward. Having disabled people exist in those spaces is action in its own right.'

The Rights for All alumni felt that traditional self advocacy and disability movements, although they had a valuable and powerful place in the history of disability rights, placed pressure on individuals to be part of a formal structure made up of regular meetings, events or forums. They felt this approach was not for everyone but that contributions made by individual disabled people in many walks of life was equally improving disability rights. As they are all prolific users of social media, they felt meetings were somewhat outdated and old fashioned.

Their refusal to align with a movement and their celebration of occupying mainstream spaces does not mean they are not politicised in relation to inequality and discrimination experienced by disabled people, but rather they advocate for a life where they are seen as human before disabled. There has been debate within the disability movement and within academic circles about the need to identify as disabled first in order to speak out against oppression. Identifying as disabled first has given disabled people a powerful voice to bring about social change, however as Shakespeare and Watson (2002) argue 'identity politics can be a prison, as well as a haven.' Needing to always identify as disabled, in the minds of Sirraaj and the Rights for All alumni is to oversimplify their experience. As they argue, they are also all from minority ethnic communities so which experience should take precedence when they are lived simultaneously? Equally, being so wedded to what they see as a label, can be limiting in and of itself.

What is, and was back in 2014, striking about these individuals, is that they are all fiercely outspoken about their rights and expect no less of life than their non-disabled peers. They were not asking for a seat at the table, they knew one would be waiting for them. And if they got there and there was no seat, they would bring their own. These individuals are all unashamedly on the front line of activism in their own lives.

'I wasn't really aware of the disability right's movement because I always sought to get what I wanted and nothing ever stopped me.'

Caprice

'When people tell me I can't do something, that makes me more determined!'

Samee

Equally, they felt that being called 'inspirational' for arguing for basic rights that their non-disabled peers take for granted was something they were often greeted with and was something that must always be challenged:

'I expect equality. It's patronising to call me inspirational. You wouldn't say this to someone who is not disabled, so don't say it to me. When I went to uni I was told I was an 'inspiration'. Let's face it, puking on the street after drinking is not inspirational!'

Caprice

'It's not inspirational. It's just what we do. We don't do anything different from anyone else.'

Siraaj

'I want to be judged on results and what I have done, not patronised.'

Kashmire

Several of the alumni reflected on what is often the segregated nature of certain disability movements. Caprice recalls being invited to national self-advocacy events and being shocked seeing only people with learning disabilities present:

'I don't think it's always useful to hang around with other disabled people. People need to learn from people different to themselves. You can't expect me to be best mates with someone just because they are disabled. In fact, I wouldn't actively go out of my way to make friends with disabled people.'

However, although people did not feel being part of a movement was necessary to bring about change, a core aspect of coming together on the Rights for All leadership programme for all of the participants was the friendships and contacts that were developed. Some individuals said that being disabled and living with these labels meant that through their lives they had struggled to make friends and connections largely due to the perceptions of others.

'Before Rights For All I didn't have a lot of people I could connect with so making friends with other disabled people was really important to me. But it was more than that, these people were like-minded.'

Andrew





'Being autistic can sometimes make you feel like curling up in a ball and so meeting new people was really good for me. To know that I have contact with these individuals who are now my friends still and this is very important to me.'

Kashmire

**Experiencing disability
discrimination and racism**

Walking through the histories of Sirraaj, Caprice, Monique, Andrew, Kashmire, Samee and Gina, the intersection of race and disability featured in everyone's narratives. Indeed, the disadvantages that arose in young people's lives because of the intersecting factors of race and disability was a key motivating factor in the development of the Rights for All leadership programme.

Intersectionality

Intersectionality describes the ways in which inequality, whether it be based on race, ethnicity, disability, gender, class, sexual orientation, or other forms of discrimination, cut across each other and are experienced simultaneously by people. The origins of intersectionality as an approach to understanding oppression are said to originate in the Black feminist movement of the 1970s and 1980s. Black feminists were critiquing the feminist movement, saying that it was largely white women writing and campaigning about white women's issues. During these years, several prominent Black feminists wrote about the intersections of race, gender and class. However, if you go back as far as Sojourner Truth, a powerful anti-slavery and women's rights campaigner born into slavery in 1797, she spoke about intersectionality in her 1851 speech, *Ain't I a Woman?*

'That man over there says that women need to be helped into carriages, and lifted over ditches, and to have the best place everywhere. Nobody ever helps me into carriages, or over mud-puddles, or gives me any best place! And ain't I a woman?'

By 1991 intersectionality had become a popular approach, especially after Kimberlé Crenshaw wrote an article entitled, 'Mapping the Margins: Intersectionality, Identity Politics and Violence Against Women of Color'. In this article she focused on the intersections of race and gender to highlight, 'the need to account for multiple grounds of identity when considering how the social world is constructed.'

Speaking with the group about intersectionality, everyone said they had experienced prejudice and discrimination in relation to race and disability, and yet all refused to be defined or limited by this. Whilst it's difficult to separate out disability and race because they are lived simultaneously, people did speak about experiencing these differently at times. Those individuals whose disability was visible had less experiences of racism and more experiences of disability discrimination.

'I've seen more discrimination because of my disability than the colour of my skin because people just see the chair and they assume I can't speak or they're afraid to speak to me. When this happens people aren't horrible, it's the silence that hurts the most. I'm very proud of my culture and its traditions. They assume I'm paralysed, that I can't move my legs but I can. They need to turn it around and focus on my abilities and not my disability.'

Monique

'I haven't experienced much racism. People tend to look at me and see the chair first and think he won't be able to do things and he won't be able to communicate. When they hear me speak and see me do things, they are shocked. They can see how passionate I am.'

Samee

Caprice spoke about the complexity of intersectionality, reflecting that assumptions can be made between different groups of people, where one group who have experienced oppression might assume they know the experiences of another group of people.

'Disabled people always bring it back to disability and think you can understand racism because of the discrimination you have experienced as a disabled person, but it's a whole different experience being disabled and also experiencing racism. In a way being disabled and experiencing racism can make it harder sometimes. There are lots of myths out there like Black people don't experience pain in the same way. Things like this can make a Black disabled person's experience a real struggle at times.'





Disability myths

Monique and Sirraaj spoke about myths in their cultures surrounding disability, which although mainly restricted to older individuals, can be hurtful and need to be resisted:

'Its most likely to be the elderly aunties and uncles where they have said to me, 'Oh, what's wrong with you and why don't you go to the Golden Temple in India and go into the waters to get healed? I know myself and know what I can and can't do. I enjoy the waters but they will not bring about a cure. Telling people God will heal them gives them false hope. Before I stepped into the disability world I didn't know much about the politics of it. Now I see what a positive impact disability has on people's lives.'

Monique

'I've been told you will get better but disability is for life. You can't let disability restrict you; it's part of you.'

Sirraaj

Caprice had similar experiences in her everyday life:

'I used to be stopped by preachers on the street saying God would heal me and I would say, 'So is there a way to reverse brain damage?' That always shut them up.'

Tackling racism

Experiencing life as disabled people from minority ethnic communities, everyone talked about the daily need to tackle not just disability discrimination but actively challenge racism in the drip, drip of everyday interactions and the impact this had and still has on their lives.

'When I am working with professionals, I have people make assumptions about me. People see both my disability and ethnicity. In terms of disability, they look at me and don't appreciate what I can do and don't see me as an equal professional. In terms of ethnicity, they often try to use me to tick boxes, assuming I know everything about Asian cultures, when I don't! Being in my local community, being part of the mosque, walking my local streets and having people seeing me as just Siraaj, and not a label, is a blessing to me. It brings me strength when I have to deal with rubbish in my professional life.'

Siraaj

'I grew up and I always thought I looked different and ugly but then I realised I just went to school with white girls. I am not seen as Black enough to be part of the Black community and I am not white enough to be white in some people's eyes, so I'm somewhere in the middle - in limbo. It's important to tackle racism. Those people who say they are not racist but then do nothing about it - what use are they?'

Caprice

'I feel like some people speak down to me. They see I'm Black and maybe make assumptions that I am a gangster from the hood. They use slang words because I'm Black or maybe because they don't know my name, but this feels racist to me. This is not right.'

Andrew

For everyone who contributed to this book, experiences of race and disability are intertwined. These experiences shape their everyday lives, add to their lives and drive them forward to achieve independence and success.

Individual histories

Siraaj Nadat

British Empire
Medal holder



Siraaj Nadat is known nationally as a leader in relation to his work championing the rights of people with learning disabilities. Both within Changing Our Lives and further afield, Siraaj is a role model, encouraging leadership and advocating for an 'ordinary life' where universal human rights are a reality in the lives of disabled people. This relentless drive was rewarded in January 2017 when Siraaj was awarded the British Empire Medal in the Queen's New Year's Honours list.

2003 - 2010

Siraaj's experiences in early life were like many of his peers. In 2003, after attending a special school he moved to Walsall College and remained there for 3 years. However, with no other opportunities after college, he joined a group called Ethnic Advocacy from 2007 to 2010.

2008 - 2011

Siraaj attended the West Midlands Regional Forum of People with Learning Difficulties. The forum fed into the National Forum of People with Learning Difficulties which brought people with learning disabilities together from around the country to monitor progress the government was making to ensure people had equal rights and equal opportunities under the new White Paper called Valuing People. This white paper promoted people's access to employment, good quality housing options, community inclusion and equal opportunities.

2009 - 2011

Siraaj was voted onto the National Forum of People with Learning Difficulties to represent the West Midlands. During this time Siraaj was the health champion which included attendance at the Healthwatch Advisory Group and at the Monitoring Evaluation Group for the the Confidential Inquiry into the Premature Deaths of People with Learning Disabilities and the Improving Health and Lives (IHAL) Public Health Observatory for learning disabilities in England. This observatory aimed to improve the health of people with learning disabilities and reduce health inequalities.

2012

Siraaj started work as a contracted member of the Changing Our Lives team. Prior to this Siraaj had worked for the organisation on a sessional basis. Siraaj's first major role was to co-lead a West Midlands regional health project promoting and checking on the experiences of people with learning disabilities within health settings.

2012

Siraaj was invited to speak to the All Parliamentary Group on Learning Disabilities in the House of Commons as part of a panel of experts in their field from the Learning Disability Health Observatory and the Confidential Inquiry into the Premature Deaths of People with Learning Disabilities.

From very early on Siraaj has always reflected on the positive role his mom and dad had in his success. After working in a locked hospital for people with learning disabilities, he made the following statement:

'Doing this work in locked hospitals has been an eye opener. Professionals don't see people as people, they see them as animals. Disabled people have human rights just like anyone else and these human rights are not being respected. I always think if mom and dad had not been proactive, I could have been in one of those situations.'

2013 - 2015

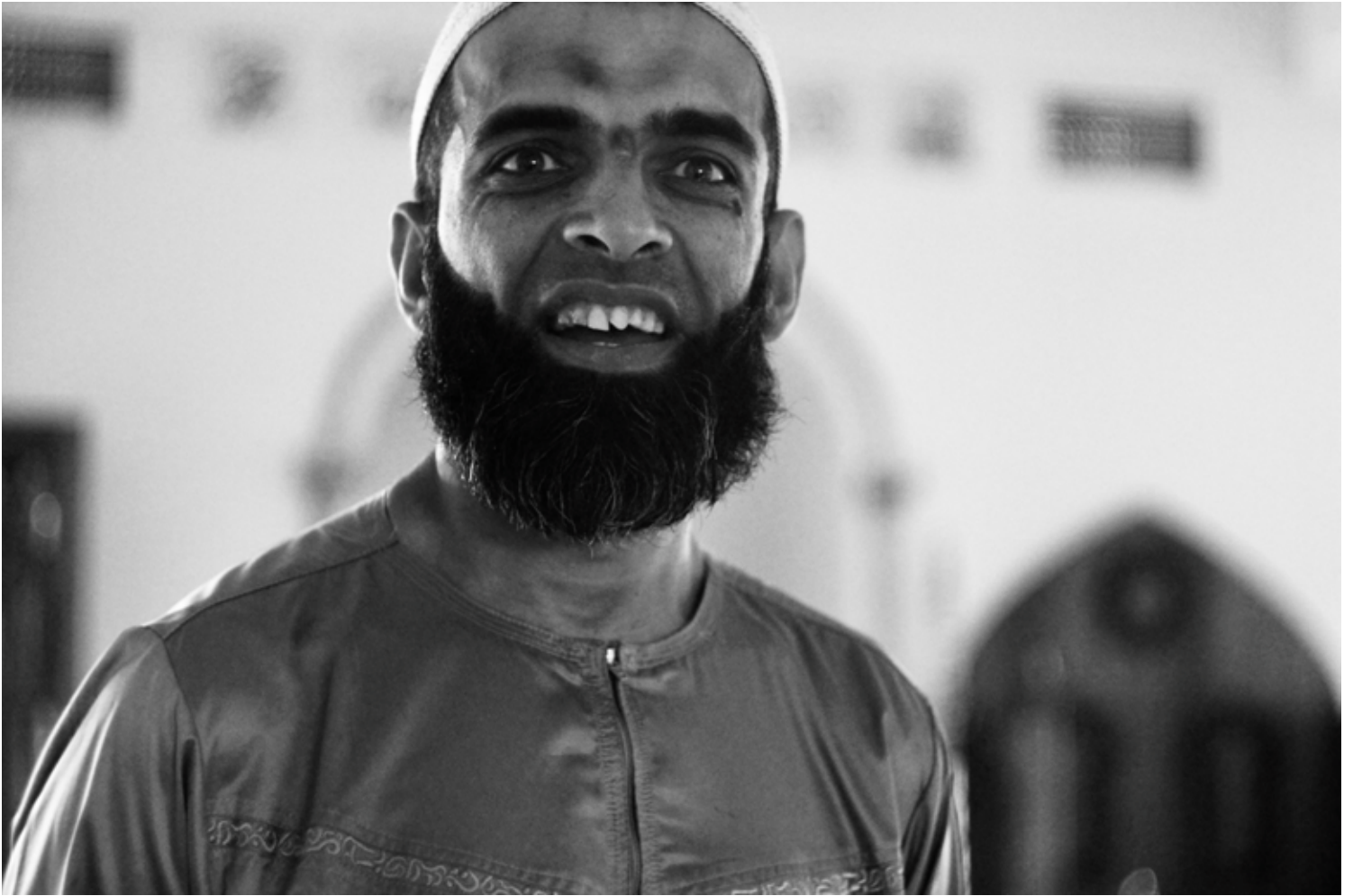
Siraaj worked on the development and delivery of the Rights for All leadership programme.

2015

Siraaj was promoted to a Senior Quality of Life Facilitator.

2015 - 2020

As part of his work for Changing Our Lives Siraaj worked with a variety of national groups all focusing on health inequalities. These included: Improving Health and Lives (IHaL), the Public Health Observatory for learning disabilities in England. At the time Changing Our Lives facilitated IHaL's Advisory Group, along with Inclusion North and Inclusion East. Siraaj was a long standing member of the advisory group and was also elected on to the IHaL steering group, working alongside colleagues from the Department of Health, NHS England, Public Health England, the Association of the Directors of Adult Social Services and Healthwatch England. Siraaj sat on the national advisory group for the Learning Disabilities Death Review (LeDeR) Programme. The LeDeR programme supported local areas to review the deaths of people with learning disabilities and build an understanding of why some people die prematurely and what helps to avoid this.



'Siraaj has made an invaluable contribution to the work of the Learning Disabilities Public Health Observatory. His contributions have helped shape our national work plan and he has represented the observatory in national meetings as well as co-chairing national events we have run. We have really valued his leadership in this field.'

Anna Marriott, Programme Manager for Improving Health and Lives 2017



2016

Siraaj worked on a range of Quality of Life reviews including ones focusing on peoples lives in day services, residential care and supported living. Siraaj also co-led a practice development training programme for staff within a residential home and was part of the Changing Our Lives team that developed a Quality of Life training pack.

2017

In January 2017, Siraaj was awarded the British Empire Medal in the Queen's New Year's Honours List in recognition of his achievements.

2017

From 2017, Siraaj has been working on a range of initiatives including; a Quality of Life review within a locked hospital setting; Quality of Life reviews of supported living, residential care and day services; Quality of Health review of an acute trust. Siraaj chaired Sandwell's Mental Health steering group, an interagency meeting; he worked with the national LeDeR advisory group looking at best practice in training in acute hospital trusts; trained and mentored new team members in Quality of Life review practice and worked on a series of Quality of Life reviews which were part of the 200 Lives research led by Chris Hatton at Manchester Metropolitan University.

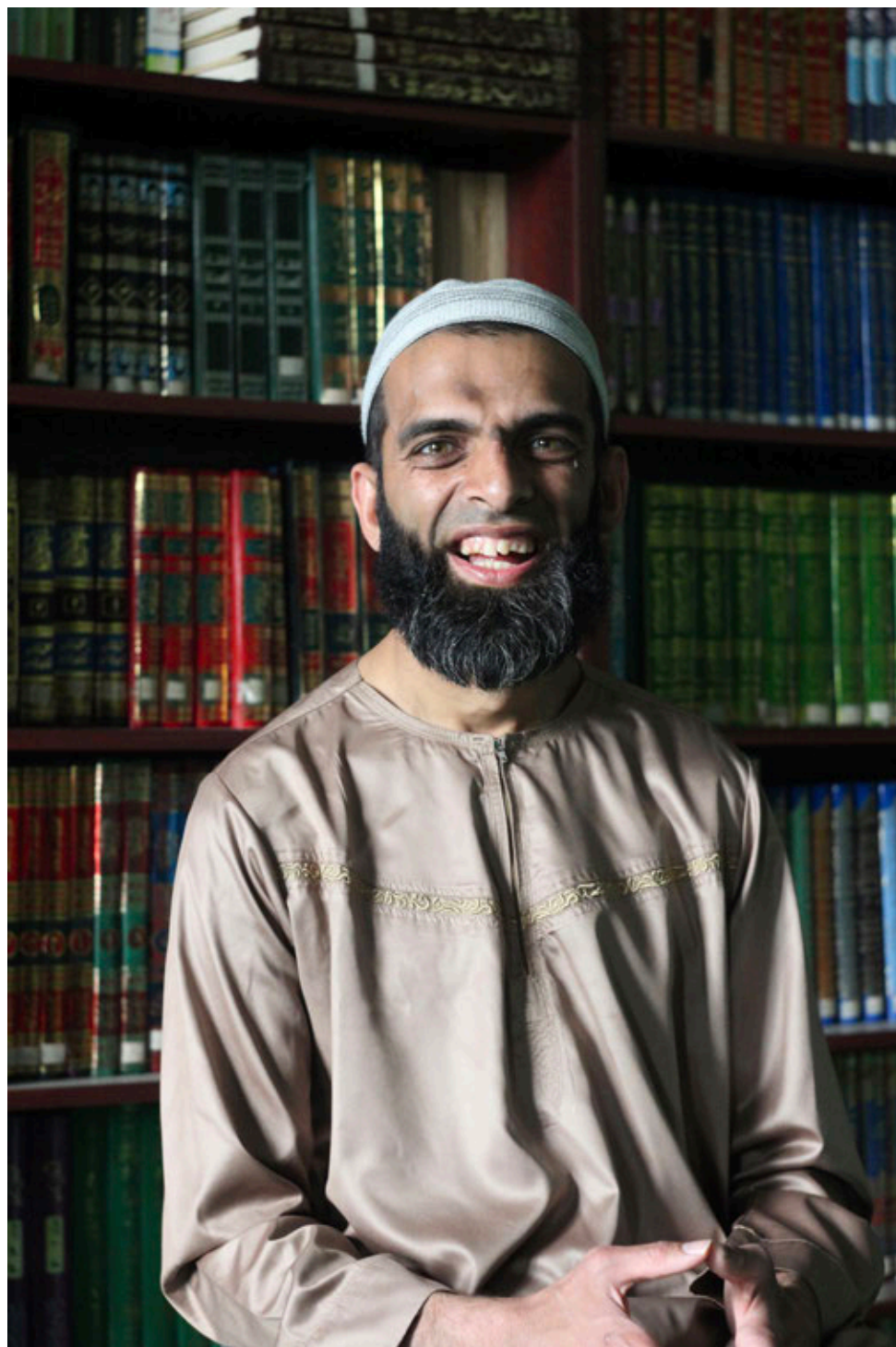
'When Siraaj first started going on his own to meetings, especially London, this was very worrying. We used to make sure he text us at different times. We just weren't used to him being so independent. But this gave him confidence to become more independent. I don't worry about him now as he looks after us. He's a tower of strength for the family. When he got his British Empire Medal in 2017, it was Siraaj that was directing me across London. All he needs to do now is pull a girl!'

Hasina Nadat, Siraaj's mom

'I have known Siraaj and his family for approximately 15 years, prior to becoming work colleagues. He is someone that I greatly admire and consider as both a colleague and friend. Siraaj is an influencer, incredibly experienced, recognised and respected nationally in his field of work; the honour he received in the shape of a British Empire Medal is a testament to this. His profile and success reflect his unwavering commitment to ensuring that the rights of disabled people are upheld, furnishing them with the opportunity to live ordinary lives. Something that he genuinely commits to in his own life, acting as a role model to others.

Over the years, I have watched Siraaj grow and develop into a formidable leader, working hard to learn, challenge himself and produce positive outcomes throughout his work. However, this is a journey that has often been plagued by the stench of societal stigma, related to both his race and disability. He has been forced to get up and dust himself down on numerous occasions, something he has always managed to do with such grace and professionalism. Consequently, Siraaj's journey has taught him many harsh lessons in relation to discrimination and the way that he is perceived in the world of health and social care. What I most admire and respect about Siraaj is the resilience he has shown in times of adversity in his life and how he has used these experiences to his own gains. Strengthening himself personally, sitting comfortably in the challenges he faces through his role and asserting his authority and responsibility to influence and lead others.'

Lucy Dunstan, Deputy CEO, Changing Our Lives





'You are breaking the barriers of both race and disability.'

Arif, Sirraaj's cousin

2020

During the Covid pandemic when people were allowed to attend the mosque but many were still afraid to be around other people, Siraaj had a key role within the mosque of encouraging and supporting people to return. As many people go to the mosque five times a day to pray, the impact of the mosque being closed during Covid was significant on mental health and community spirit. Siraaj is seen within the mosque as a brother; just another member of the community.

Siraaj's father passed away during the pandemic and his role within the family has developed as a result:

'My life changed when dad passed. I've had to step up my game and take responsibility. I see myself as a representative of dad so I do things he would be doing. This makes me very proud.'

'I have known Siraaj since he was small. To everyone in the community of the mosque he's just a member of the family, just like everyone else. As Muslims we don't really see anyone as different no matter the race, colour or disability. Siraaj is highly respected as was his dad who was the president of the mosque and he is now continuing his dad's legacy. He is well known in the local community and whenever he walks down the street, he always greets everyone with a smile and stops to talk to them.'

Shakir Pathan, secretary of Masjid Al Farouq Mosque, Walsall

Samee Ahmed

Arsenal enthusiast

Samee is a cheeky chap with a twinkle in his eye. Incredibly ambitious, Samee is now in his second year of university but planning future business ventures in recruitment and human resources. Being an Arsenal fan, his dream is to own his own bachelor pad overlooking the Emirates stadium.

2014

Samee hosted an Ideas Festival with Changing Our Lives which focused on challenging staff about their perceptions of young disabled people and raising aspirations across staff teams.

2014

Samee was part a Takeover Day with Changing Our Lives (now known as 'the Takeover Challenge'), led by the Office of the National Children's Commissioner for England. This day was aimed at exposing young disabled people to leadership experiences by putting them into real life decision making positions in organisations. In 2014 Samee took over the role of Service Director for Children and Families at Sandwell Metropolitan Borough Council.

'If anyone puts any barriers in your way if you know people in senior positions you can try and talk to them to make things better. This is what Take Over days taught me.'

2014 - 2015

Samee was part of the Rights for All leadership programme.

'Before Changing Our Lives I knew some things about my rights but working with the organisation helped enhance my knowledge. I was 14 at the time and the youngest member of Rights For All.'

2016

Samee left school and worked for his dad in his social housing and healthcare business. Samee continues this work today.

2020

Samee completed a foundation year in the run-up to university.

2021

Samee started a BA in Business Management at Wolverhampton University. Samee has chosen this degree as he is keen to start his own business with a focus on recruitment and human resources.





'I have a positive attitude and I'm a doer. If someone tells me I can't do something, I want to prove them wrong. This makes me feel good and like I have accomplished something.'



Kashmire Hawker

Aspiring politician



Kashmire lives and breathes politics. From very early on in his career, he has made his mark representing his peers and advocating for equality of opportunity for all. He has his sights firmly set on political office and has the determination and drive to make this happen.

2014 - 2015

Kashmire was part of the Rights for All leadership programme.

2014 - 2016

Kashmire starts his first paid employment as a Quality of Life Facilitator with Changing Our Lives. Projects he works on include: hosting a series of "Keep UP" practice development days, attracting professionals from education, health and social care staff from across the city of Wolverhampton; co-producing the tender process for new short breaks services in Wolverhampton; coproducing a Communications Strategy Wolverhampton's Local Offer which is information for disabled children and young people, enabling them to find support in their local area; working on a 'Your Rights, Your Future' training programme, ensuring that young disabled people have a better understanding of the Special Educational Needs and Disability reforms.

'Rights For All expanded my mindset and gave me much more confidence going forward. Gave me a solid platform to fight for what was right. This led to my first job which was with Changing Our Lives as a Quality of Life Facilitator. For my first employment this was fantastic. This gave me a real boost. It gave me a real platform.'

2015

Kashmire joined the Labour Party.

2016 - 2019

Bachelor of Arts (BA) with Honours in Politics, Sheffield Hallam University.

2019

Kashmire joins the West Midlands Trains Limited Stakeholder Equality Group, a forum for disabled passengers who use the transport network.

2019

Kashmire is a West Midlands Young Combined Authority Board Member and Co-Portfolio Lead for Transport 2020/2021 and Co-Chair of 2021/2022.

2020

After working as a steward at university, Kashmire accepted the role of a Silverstone Circuit Limited Volunteer Race Maker.

2020

Kashmire works as an Administrator of Ceremonies, Culture and the Queen's Baton Relay.

2020

Kashmire became an Associate for Changing Our Lives.

2021

Kashmire began a Business Administration Apprenticeship in 2021 for the Birmingham Organising Committee for the 2022 Commonwealth Games.

2021

Kashmire stood for a Labour Councillor in Wolverhampton at age 23. He was not successful but this was an essential step in a young political career.

2021

Kashmire becomes a Wolverhampton Labour Local Government Committee (LGC) Member.

2021

Kashmire sits on the Wolverhampton Wanderer's Equality, Diversity and Inclusivity Advisory Group.



'The average councillor across the country is 59 and his name is John. I'm a proud British Asian and standing as a local councillor I am keen to increase diversity in politics.'



'Being autistic has not held me back. To know there is so much to fight for and change drives me on.'



'In my heart I am a politician. I don't want to be a politician for politics sake. I want to be part of a group of people who make change and serve with respect and distinction.'

Gina Patel

Fierce and feisty



Gina describes herself as 'fierce and feisty.' Since her late teenage years, Gina has fought to develop her career, which resulted in her current employment as a Personal Assistant Support Administrator at Health Education England. She also pushes herself continually to be outside of her comfort zone, for instance giving a Tedx talk in 2021.

2010

Gina started a work placement at Changing Our Lives. From 2011 to 2016 Gina worked on a range of rights based initiatives with her peers.

2011

Gina worked with other young people on a Sexual Health and Relationships research project with Changing Our Lives, with the aim of finding out what young disabled people knew about their health, sexuality and relationships.

2011

As part of the Quality Crew team of young people, Gina carried out a review of a Children with Disabilities team, exploring how they interacted with young disabled people and what difference the team made to their lives.

2011 - 2012

Gina took part in two take over days of senior figures.

2014 - 2015

Gina was part of the Rights for All leadership programme.

2017 - 2019

Gina was an External Affairs Apprentice in the office of the Legal Ombudsman, the office that investigates complaints between consumers and legal service providers.

2019 - 2021

Gina was part of a West Midlands Young Combined Authority Leadership Programme. She worked alongside her peers on a mental health social media awareness campaign and a vision report.

2020

Gina accepted a job as an Assistant to the PA who works for the Midlands Health Education England Deanery, the department responsible for post-graduate programmes.

2021

Gina's Tedx Talk 'Disability and Ambitions' focuses on her experiences of disability and disability rights activism.

2021

Gina is a Mental Health First Aider for Mental Health First Aid England.

2021

Gina organised a campaign to raise awareness of World Cerebral Palsy day. This was featured in a GBNews interview, BBC West Midlands and the Express and Star.



'I'm never going to be able to do things two handed and I'm always going to walk a bit strange but these things make me, me! These things don't stop me from doing what I want to do.'



Caprice Haughton

A powerhouse of sass



Caprice is a powerhouse of sass; she lights up a room with her optimism, determination and great one liners. After living through a year of operations, physiotherapy and teaching herself to walk again when she was 13, she has never looked back. At 17 she enrolled in the Rights for All leadership programme. A year later she was in university and now she is training to be a solicitor.

2014 - 2015

Caprice joined the Rights for All programme after picking up a flyer in sixth form.

2014 - 2015

Caprice led a range of work within Changing Our Lives including working on the Local Offer film which provided information for disabled children and young people, enabling them to find support in their local area; Quality of Life audits as well as public speaking at events such as Got My Back a conference focusing on good postural care.

2014 - 2015

Caprice worked on a number of Care Quality Commission inspections.

2015 - 2018

Caprice gained a LLB Honours in Law at Manchester Metropolitan University.

2020

Caprice's first job within the legal call handling team.

2021

Caprice has a place on a legal apprenticeship scheme and will qualify as a solicitor in 2024.

2022

In her Associate role with Changing Our Lives, Caprice is working on the review of the Quality of Life standards and Equal Treatment, an anti-racism training programme.



'I see my life as before and after my 13th year because this is when I chose to have a series of operations which would mean I could walk. I was determined not to spend my life in a wheelchair. I had my foot broken, my tendons cut, my knee moved and my thigh twisted and plated. Then it was time to do my hip! After a year of this I began to walk.'







'I expect equality. I don't think I am doing anything ground breaking by expecting you to accept me as I am. [...] Being called inspirational is patronising. People say that upholding equality must be so rewarding. No, it's bloody exhausting when you have to do it everyday in your own life!'



'I could never see myself as just disabled. And I hope there are about 100 other things to talk to me about, other than me occasionally using a crutch!'

Andrew Faure

World traveller

Andrew is a quietly spoken, thoughtful and reflective individual, whose determination carried him through university to achieve both a BA in Business Management and Marketing and a MA in Marketing Management. In his down time, Andrew is a passionate clubber and likes to explore the globe and has been to New York, California, Cyprus, Greece, the Greek islands, Amsterdam, Turkey and on Caribbean cruises.

2014 - 2015

Andrew was part of the Rights for All programme.

2015 - 2018

Andrew attended Derby University, where he studied for a Business Management and Marketing and achieved a 2:1.

2017

Being a keen traveller and wanting to broaden his horizons and skills, Andrew went to Camp America, California.

2018 - 2019

Andrew studied on a Masters in Marketing Management at Derby University.

2019

Andrew is currently working in Amazon warehouse while he looks for a marketing position.

'Being independent is important to me. I like travelling because you are in control and independent. Also being in university made me more independent. I made good friends and travelled with one.'





'I'm proud to be a Black man with a Masters degree. Teachers in school didn't think I would amount to much, but look at me now!'



Monique Mehra

Dancing Queen



Monique's passion for equality and her love of life is boundless. Monique is a disability rights activist. She also works as an Expert by Experience for the Care Quality Commission as well as with Changing Our Lives as an Associate. She fills her life with music, dance and the arts, travelling each week to practice dance with a London dance studio. When she is not working Monique is planning her next travel adventure. Having already been to India, Amsterdam and Paris she's now looking further afield to Africa where she's planning to practice the AfroDesi dance style and other African fusion dance styles.

2010

Monique worked with Lisa Gunn, a disabled artist, on an art project of underwater photographs called Unlocked, which was displayed at Wolverhampton Art Gallery. This art exhibition had a profound effect on Monique, solidifying her love of the arts.

'I have the photo on my wall. I wake up to see it every day.'

2013

Monique became a young ambassador for the Include Me Too charity.

2013

In order to be more independent, Monique organised her own 'Night Life Tour', visiting a range of night clubs, in Worcester, Telford, Workington, Ashford.

2014

Monique started working with the Care Quality Commission as a member of their Children and Young People's Advisory Group. She also works as an Expert by Experience on inspections for the Care Quality Commission.

2014 - 2015

Monique took part in the Right for All leadership development programme.

2015

The BBC Asian Network interviewed Monique about disability rights. Monique spoke of the importance of speaking about disability in the Asian community as families can be made to feel embarrassed and are discriminated against.

'Just because I am disabled doesn't mean I want to be in a room with disabled people. There is a whole world out there. '



'Even if she can't walk, I brought Monique up to tackle barriers and overcome them. I'm happy for her to do her own thing. She needs to fly. I tell her to get on with it. People should not think of disability but think of what is possible.'

Meena Mehra, Monique's mum

2015

Monique has tackled many issues around disability access and rights over the years. In 2015, she approached the Youth Hostelling Association, working with them to ensure their venues were accessible.

2019

Monique took part in a range of theatre workshops and drama remains a strong driving force in her life.

'You have to be out there and grab each opportunity. Things aren't going to come to you. You have to go and get them. [...] I can't just sit here and be quiet; I need to interact with people. It's all about making connections with people, that's important to me.'

2019

Monique became an Associate of Changing Our Lives, her main project focusing on health inequalities experienced by disabled people.

'Work is very important for me because I can contribute financially to my own life. As I already need quite a lot of physical support in my life already, having my own money helps with my independence.'

2020

In collaboration with dance choreographer Rosie Kay, Monique made a film, 'I Am Soldier', which explores disability, dance and an unusual connection to the life of a soldier. It is featured on BBC Arts' New Creatives.

2020

Monique began weekly dance classes at a London dance studio. She makes dance videos with her video in May 2022 going viral with over 30,000 hits.

'I'm always dressed well and look good! Even if I don't get every dance move right, I still know I'm the best dressed in the room.'



'Being alone and lonely are two different things. Sometimes being disabled you have to work harder to make friends. I like my own company but it's good to socialise with others and over the years I've gradually built up a network of friends.'





Conclusion

All of the individuals featured in this book lead ordinary lives. They are not inspirational or exceptional because they are disabled; their successes are the successes many people achieve in their lives. They expect equality, they don't ask for it and it is this approach coupled with sheer determination that shapes their lives past and present. Whilst they recognise the achievements made by disability movements, they argue that improving disability rights means operating in the mainstream, challenging prevailing narratives and myths which speak about disability in relation to limitations and deficit, rather than possibility and assets. They choose not to operate as part of a disability only group or movement, in fact they see this as a potential barrier, but rather believe that their occupation of everyday spaces and achievement of individual successes are in themselves moving disability rights forward.

Our intention when we set out to write these histories was to record the hidden and invisible histories of disabled people from minority ethnic communities. The intersection of race and disability, although experienced by each individual differently, is the thread running through everyone's experiences, past and present. If people's disability was visible it tended to result in less overt racism and more obvious prejudice and discrimination in relation to disability. If people's disability was hidden, racism tended to be more overt and frequent. This meant that the fight for equality for all of the people who contributed to this book has to be two pronged, where individuals navigate both forms of discrimination and oppression simultaneously. However, everyone approached this challenge with expectations of equality and determination to push through negative social constructs.

Bibliography

- Aspis, Simone, (2002) 'Self-advocacy: vested interests and misunderstandings', *British Journal of Learning Disabilities*, 30:1, pp. 3-7
- Buchan, Ian and Walmsley, Jan (2006) 'Self-advocacy in historical perspective', *British Journal of Learning Disabilities*, (34:3), pp. 133-138
- Campbell, Jane (1997) 'Growing Pains: Disability Politics - The Journey explained and described' in Barton, L and Oliver, M (eds.) *Disability Studies: Past Present and Future* Leeds: The Disability Press, pp. 78 - 90
- Department of Health (2001) *Valuing People: a new strategy for learning disability in the 21st century*. London, Department of Health.
- Crenshaw, Kimberlé (1999) 'Mapping the Margins: Intersectionality, Identity Politics, and Violence Against women of Color', *Stanford Law Review*, 43:6, pp. 1241-1299
- Goodley, Dan (2000) *Self-advocacy in the lives of people with learning difficulties*, Buckingham: Open University Press
- Marks, Deborah (1999) *Disability: Controversial debates and psychosocial perspectives*, London: Routledge
- Oliver, Mike (2004) 'The Social Model in Action: if I had a hammer', in Barnes, C and Mercer, G (eds) *Implementing the Social Model of Disability: Theory and Research*, Leeds: The Disability Press, pp. 18-31
- Truth, Sojourner (1851) *Ain't I a Woman?*, Women's Convention, Ohio
- Shakespeare, Tom and Watson, Nicholas (2002) 'The social model of disability: an outdated ideology?', *Research in Social Science and Disability*, 2, pp. 9-28
- Walmsley, Jan (2019) 'A list of self-advocacy projects - and some thoughts about self-advocacy', www.janwalmsleyassociates.com



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