

PERSONS WITH ALBINISM

AND THEIR RIGHT TO
HEALTH, EDUCATION AND
EMPLOYMENT IN THE UK:

PRELIMINARY
RESEARCH FINDINGS

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FOREWORD

Albinism is a rare, non-contagious, genetically inherited condition which commonly results in the lack of melanin pigment in the hair, skin, and eyes, causing vulnerability to sun exposure. Those with albinism are often much lighter in complexion than the general population of the communities in which they live. There is a misconception among many that albinism is only found within black African populations or those of African descent. This is undoubtedly precipitated by the amount of information concerning attacks against persons with albinism in Africa, driven by the myth that their body parts have power to confer wealth or good fortune upon those who utilise them in ritual practices. Albinism, however, is a condition which occurs worldwide regardless of race, ethnicity or gender. While the killings of those with albinism in a number of African countries has without a doubt been the most heinous manifestation of stigma and discrimination against them, it is not the only form.

As the UN Independent Expert on the enjoyment of human rights by persons with albinism, there is no doubt that the bulk of my work will, and must, focus on these killings in these countries. However, such attacks must not obscure from the fact that there are persons with albinism throughout the globe and that persons with albinism throughout the globe experience stigma, discrimination, and violations of their rights.

In planning for this research, I wanted to understand the situation of persons with albinism in a country that many are not even aware has a population of persons with albinism. I wanted to uncover the challenges, if any, that those with albinism in this context experience. What this research uncovered was that stigma and discrimination occurs against persons with albinism regardless of the Gross Domestic Product (GDP) of a country, and regardless of the ethnicity of the person with albinism. Lack of knowledge about albinism and its impact often means that those with albinism are not able to enjoy



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the highest attainable standard of health. Furthermore, such lack of knowledge often leads to a failure to provide much needed reasonable accommodations at places of learning or in the workplace.

I hope that this research will spark interest amongst academics, civil society organisations, and policymakers in the need for further research on the situation of persons with albinism in the UK, as well as countries where their situation often goes unnoticed. I further hope such research endeavours will result in tangible policy changes to enable individuals with albinism to fully enjoy their human rights.

ACKNOWLEDGEMENTS

This research was commissioned by the UN Independent Expert on the enjoyment of rights by persons with albinism, Muluka-Anne Miti-Drummond, in conjunction with Staffordshire University. We would like to thank and acknowledge the individuals who have contributed to this report:

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Dr. Mark T. Carew is an Assistant Professor at the International Centre for Evidence in Disability at the London School of Hygiene and Tropical Medicine and a Non-Executive Director at the Disability Policy Centre. A social psychologist by background, Mark carries out research to inform disability-inclusive policy and practice in the UK and globally, particularly within low- and middle-income countries. He has authored several academic articles, books and policy-focused reports on various topics on disability, including about inclusive education, healthcare and stigma and discrimination. In 2019 and 2020, he was recognised as Part of the Disability Power 100 Community most influential disabled people in the UK. We thank him for his work in moderating the round table discussion which formed part of this report, analysing the findings of the survey, and for his invaluable work in transforming the initial draft into this report.

Note - Mark's inputs to the report were given in a private capacity, without acting as an employee or representing in any way the London School of Hygiene and Tropical Medicine.

Elodie Fellows



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Elodie graduated from Northwest University in South Africa in 2012 with a BA in Law and Political Science and from the University of South Africa in 2015 with an LLB. She spent three years working as a solicitor at Rogers Devachander Inc., where she focused on commercial law litigation. In her final year of practice, she represented clients in family and children's courts.

Elodie immigrated to the United Kingdom with her family in 2018 and started her post-graduate studies. She is currently completing her PhD in International Law. She is critiquing the Montevideo Convention on the Rights and Duties of States by assessing its relevance in contemporary issues of statehood and its need for

modernisation. Her research interests include public international law, international criminal law, humanitarian law, and positivist theory.

Elodie is an Associate Fellow of the Higher Education Academy and a member of the Socio-Legal Studies Association, the British Institute of International and Comparative Law, and the Society of Legal Scholars. The initial draft of this research was prepared by Elodie and we thank her for her contribution.

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Dr. Samantha Spence is the Co-Director of The International Network against Accusations of Witchcraft and Ritual Attacks, Deputy Chair of the UK National Working Group linked to Accusations of Witchcraft and Spirit Possession, Course Director of Postgraduate Studies in Law and Co-Director of the Violence Against Women and Girls Hub at Staffordshire University. She is also a Visiting Professor at REVA University, Bangalore, India. Dr. Samantha Spence greatly contributed to the conceptualisation of the research, as well as the final product.

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We would also like to thank the Albinism Fellowship UK for the support provided, including in the publication and distribution of the questionnaire for the study, as well as connecting us with relevant stakeholders. We extend particular gratitude to Kristina Venning Rose and Danielle Lawrence, who provided valuable input in the development and implementation of the research.

In addition, we also thank all who spoke to our consultant bilaterally, those who responded to the survey, as well as those who took part in the roundtable discussion held in London in June 2023. Without all these contributions, the findings of this report would not have been possible.

LIST OF ACRONYMS

ADs	Assistive Devices
CEDAW	Convention on the Elimination of All Forms of Discrimination against Women
CRC	Convention on the Rights of the Child
CRPD	Convention on the Rights of Persons with Disabilities
DLA	Disability Living Allowance
DSA	Disabled Students Allowance
EHC	Education, Health and Care
GMS	Genomic Medicine Service
GDP	Gross Domestic Product
GP	General Practitioner
HPS	Hermansky-Pudlak Syndrome
HSE	Health and Safety Executive
ICERD	International Convention on the Elimination of all Forms of Racial Discrimination
NHS	National Health Service
PIP	Personal Independence Payment
SEN	Special Educational Needs
UN	United Nations
UK	United Kingdom

INTRODUCTION

This report examines the situation of persons with albinism in the United Kingdom (UK), concerning their right to health and access to healthcare. It also explores the extent that persons with albinism can access education and secure employment, both of which are also human rights and help support the health and wellbeing of all persons worldwide. The report is based on formative research and provides a preliminary view of the situation of persons with albinism in the UK. Evidence is synthesised from several complementary avenues, including firstly; a scoping review of pertinent academic and grey literature. Secondly, interviews with key informants, including persons with albinism and their families living in the UK. Information was further obtained from a small-scale survey which was conducted of persons with albinism and their family members. There were 16 respondents of which 50% ($N=8$) were persons with albinism and 50% ($N=8$) were family members. Of the family members, most ($N=6$) were the parents of a child with albinism. The survey was shared on the website of the Albinism Fellowship UK and promoted on social media from 6 - 24 April 2023.

Lastly, a roundtable discussion was convened by the UN Independent Expert on the enjoyment of rights by persons with albinism, in collaboration with Staffordshire University and attended by the UN expert, 6 persons with albinism, 2 family members, as well as representatives of charities and academics working in the area of albinism and disability. The roundtable was held at Chatham House in London on 9 June 2023.

Country Overview

The UK is a high-income country located in North-Western Europe. It comprises England, Scotland, Wales, located on the island of Great Britain, along with Northern Ireland, located on the island of Ireland. Its population is estimated at 67 million, of which the majority reside in England (57 million).¹ The majority of the British population is White, standing at 81.7% of the population in England and Wales (59.6 million).² Approximately 2.5% of the British population identifies as being of Black African origin.³

Healthcare in the UK, including consultations with General Practitioners (GPs), hospital treatments and emergency services are provided free of charge to UK residents through the National Health Service (NHS).⁴ School-based education is compulsory, commencing with primary school enrollment at age 5 and extending until at least age 16.

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1. Office for National Statistics [ONS]. (2021). Population estimates for the UK, England, Wales, Scotland and Northern Ireland: mid-2021. London: UK Government
 2. Office for National Statistics [ONS]. (2021). Ethnic group, England and Wales: Census 2021. London: UK Government; The constituent countries of the UK possess significant devolved autonomy and statistical releases for Scotland and Northern Ireland are dealt with by other government bodies. As the majority of the UK population resides in England, this overview report focuses on statistical releases that apply to England, but observed patterns do not necessarily generalise to Northern Ireland or Scotland.
 3. Ibid
 4. UK Government (2016) NHS entitlements: migrant health guide. London: UK Government; Throughout, this overview report does not explore differences between constituent countries of the UK. For example, in England, patients must pay a nominal sum for prescriptions and medicines of approximately £10, whereas in Scotland, prescriptions are free of charge. Unless stated otherwise, information given about the UK refers specifically to England as the largest constituent country. Readers should be aware that systems in Northern Ireland, Scotland and Wales, may contain some variations.

Students progress to secondary school at age 11.⁵ As of June 2023, the number of people aged 16 to 64 in paid or self-employment in the UK reached a record high of 76%. Concurrently, the unemployment rate (i.e. people aged 16 to 64 actively seeking work) stands at 3.8%.⁶

Albinism and its prevalence

Albinism is a rare, non-contagious, genetically inherited condition which occurs worldwide regardless of ethnicity or gender. It is characterised by an absence or lack of melanin pigment in the hair, skin and eyes (oculocutaneous albinism), causing vulnerability to sun exposure, including increased susceptibility to skin cancer. Persons with albinism also possess some form of visual impairment, such as low visual acuity, photophobia, nystagmus, and/or strabismus. Although the level of visual impairment varies amongst persons with albinism, almost all require the use of assistive devices (ADs) to alleviate some of the difficulties experienced, with relevant devices including white canes, magnifiers, screen readers and voice-activated transcription software. Persons with albinism often also need to use sunscreen and sun protective gear to mitigate the risk of skin cancer. Thus regular access to dermatology and ophthalmology services for persons with albinism is essential.

Albinism can occur anywhere in the world regardless of ethnicity and gender, but robust prevalence estimates are lacking. A worldwide prevalence of albinism of 1 in 17,000 has been suggested, but Kromberg, Flynn and Kerr propose caution in determining a global estimate.⁷ From a systematic review of extant prevalence studies, they propose using (in the absence of other robust national prevalence data) an estimated range of 1 in 4,000 to 7,000 for African countries and a range of 1 in 12,000 to 15,000 for European countries. Kromberg et al. and others⁸ also acknowledge that albinism may be underdiagnosed in European populations, because the diagnosis is often not as apparent in fair-skinned populations, relative to other ethnicities.

In the UK, there has been no specific study carried out to assess the prevalence of albinism to date. Amongst the few UK media articles that have been published about albinism in the UK, figures similar⁹ or equal to¹⁰ the extant worldwide prevalence figure of 1 in 17,000 was given. As recently as 2016, the 1 in 17,000 figure was also provided within information given about albinism by the NHS.¹¹ However, as the findings of Kromberg et al. show, there is a need to update prevalence estimates for the UK, as well as those of other countries. A more robust estimate would entail the use of a nationally representative data source such as a household survey or health data held by the NHS. This review did not identify any suitable sources available or released at the time of writing. Where complete data are unavailable, more robust estimates would also take into account variation in the population demographics of the UK.

5. UK Government. (2012). Education System in the UK. London: UK Government https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/219167/v01-2012ukes.pdf

6. Office for National Statistics (ONS), (2023) Labour market overview, London: ONS

7. J. G Kromberg, K. A Flynn., & R. A Kerr, Determining a Worldwide Prevalence of Oculocutaneous Albinism: A Systematic Review. *Investigative Ophthalmology & Visual Science*, 64(10), (2023) p. 14-14.

8. N. Healey, E. McLoone, K. J. Saunders., A. J Jackson, & J. F McClelland, Are worldwide albinism prevalence figures an accurate reflection? An incidental finding from a Northern Ireland study. *British Journal of Ophthalmology*, 98(7), (2014) p. 990-990.

9. BBC News. (2017). Living with albinism: 'I'm the one-in-18,000 in the UK'. Retrieved from: <https://www.bbc.co.uk/news/uk-wales-40277164>

10. BBC News. (2016). Living with albinism in the UK. Retrieved from: <https://www.bbc.co.uk/news/uk-36499577>

11. Ibid.

HEALTH, EDUCATION AND EMPLOYMENT RIGHTS OF PERSONS WITH ALBINISM UNDER INTERNATIONAL LAW

Persons with albinism are safeguarded by international human rights conventions that ensure rights for every individual, along with those that provide safeguards for distinct categories of individuals who may also have albinism; such as women or children. For instance, the Convention on the Rights of the Child (CRC), the International Convention on the Elimination of all Forms of Racial Discrimination (ICERD), and the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) all contain relevant provisions that protect and secure the health of persons with albinism and their right to access health care.

Every person with albinism also has rights under the Convention on the Rights of Persons with Disabilities (CRPD), within which albinism is recognised as a disability.¹² Specifically, Article 1 of the CRPD describes persons with disabilities as:

“... those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”

Most participants of the survey and roundtable discussion held by the UN Independent Expert, also viewed albinism as a disability because of the visual impairment the condition causes. Some participants also noted barriers to social participation, which is consistent with the definition of disability presented in the CRPD, which acknowledges the interaction between the environment and someone's condition. For example, one survey respondent shared:

“Yes, [it is a disability] because with albinism comes the long term visual sensory disability that cannot be corrected. Also, due to the albinism condition, I have been disabled in many ways by society [sic] from living out my full potential...”

Article 4(1)(d) of the CRPD obligates State Parties to ensure that public authorities and institutions act in conformity with the obligations set out in the treaty. Concerning the health challenges of persons

12. See *Z v. Tanzania*, CRPD/C/22/D/24/2014, para. 7.2

with albinism, the State Parties must fulfil the obligations in terms of Article 25 which provides that persons with disabilities:

“...[have] the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to gender-sensitive health services, including health-related rehabilitation.”

Article 25 further explains the health rights of all persons with disabilities and describes various obligations of State Parties to the United Nations to fulfil it.

“...State Parties shall:

a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population- based public health programmes;

b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;

c) Provide these health services as close as possible to people’s own communities, including in rural areas;

d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;

e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;

f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.”¹³

13. The Convention on the Rights of Persons with Disabilities and its Optional Protocol (A/RES/61/106), adopted on the 13th December 2006 at the United Nations Headquarters in New York, and entered into force on the 30th March 2007, Article 25.

Considering that persons with albinism are subject to extreme forms of discrimination and exclusion worldwide on the basis of their disability, including access to healthcare,¹⁴ the set of protections offered by the CRPD are comprehensive. Connected rights set out by the CRPD, including the right to access education¹⁵ and the right to work,¹⁶ are also important elements to ensuring that persons with albinism are able to enjoy the highest attainable standard of health.

The requirement to “provide health services needed by persons with disabilities specifically because of their disabilities” is also essential for persons with albinism considering their vulnerability to skin damage and skin cancer, as well as their specific visual concerns.

The CRPD also protects the right that persons with disabilities (and therefore persons with albinism) have to access education. Specifically, Article 24(2)(a) states that persons and children with disabilities should not be excluded from education systems on the basis of disability. It further stipulates that State Parties should ensure:

“b) Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;

c) Reasonable accommodation of the individual's requirements is provided;

d) Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;

e) Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.”

These protections help to ensure that persons with albinism can access education on the same basis as others in their community and sets out that they, like other persons with disabilities, should receive reasonable accommodations and other support within learning environments that are tailored to their individual needs.

Protections are provided by the CRPD to persons with albinism in relation to work and employment. The CRPD in Article 27 places obligations on State Parties to recognise the right that persons with disabilities have to work on an equal basis to others, including the opportunity to gain a living through work freely chosen in the labour market. Amongst its protections, the CRPD also prohibits discrimination on the basis of disability in relation to employment and places obligations on State Parties to ensure access to favourable, equal and safe working conditions.

14. I Ero, S Muscati, AR Boulanger., & I Annamantadoo, People with albinism worldwide: A human rights perspective. (2021)

15. Article 24

16. Article 27

The CRPD also requires that reasonable accommodations are provided to persons with disabilities in workplaces. Such protections are important to ensure that persons with albinism can access work and employment on the same basis and under the same conditions as other individuals and have access to the support they need while doing so.

Key Frameworks and Policies ensuring Health Rights of Persons with Albinism in the UK

In the UK, albinism is a recognised medical condition and misperceptions about albinism that are present in some other communities worldwide, such as that albinism is associated with witchcraft, are generally absent. However, the general population may have little understanding of the condition itself and may assume, for example, that white hair is a deliberate cosmetic choice. Individual healthcare professionals may also have little knowledge about the condition. Moreover, although there is a paucity of research on the lived experience of persons with albinism in the UK, several media articles and information received by the UN Independent Expert from persons with albinism in the country highlight that, like persons with albinism globally, persons with albinism in the UK are frequently subjected to disability or race-related abuse on the basis of colour, stigma and discrimination because of the condition. Nevertheless, there are many key policies and frameworks applicable to supporting the right to health for persons with albinism in the country.

Equality Act

In the UK, discrimination on the basis of both disability and race are prohibited by law, notably within the UK Equality Act.¹⁷ The Act applies to many sections of UK society, including healthcare and education providers and employers.¹⁸ Disability, race, and other characteristics mentioned within the Act (e.g., age, sex), are known as protected characteristics. Race is defined as including:

“(a)colour;

(b)nationality;

(c)ethnic or national origins.”

and it is also recognised by the Act that a racial group may be composed of two or more racial groups. Disability is defined in Section 6 of the Equality Act as:

“a physical or mental impairment, [where] the impairment has a substantial and long-term adverse effect on [an individual’s] ability to carry out normal day-to- day activities.”

As this excerpt indicates, for the purposes of the Act, whether persons with any type of impairment are considered to have a disability is determined by reference to the effect that an impairment

17. UK Government. (n.d.). Equality Act 2010. <https://www.legislation.gov.uk/ukpga/2010/15/contents>

18. The Act does not apply to Northern Ireland.

has on that person's ability to carry out normal day-to-day activities. Guidance on the meaning of disability within the context of the UK Equality Act has also been published.¹⁹ This clarifies that an exception to the "effect" rule is made for those who are blind or severely sight impaired, except where this can be corrected by glasses or contact lenses. These individuals are automatically treated as experiencing a substantial adverse effect on daily activities due to their impairment without needing to show further evidence.²⁰ Considering that the visual impairment of persons with albinism can be helped, but not corrected, by glasses or contact lenses, those with albinism should also not be required to show further evidence. Cancer is also automatically deemed a disability, which is relevant to persons with albinism as they are at elevated risk of skin cancer induced by sun exposure. Lastly, severe disfigurement also falls under the category of automatic disabilities. An example is given in the Equality Act Guidance of a woman who possesses facial scarring and avoids crowds as people ask questions about her condition. Here, the substantial adverse effect on daily activities is created not through any impairment in functioning but through the discrimination the woman receives due to her facial scarring. In an analysis of the provision, Saunders²¹ highlights that, unlike the medical-oriented perspective of disability found in Section 6 of the Equality Act (mentioned above), the disfigurement provision seeks to address the harm related to one's appearance, which arises from societal attitudes. This perspective aligns more closely with the social model of disability.²² Few examples of severe disfigurements are provided in the Guidance which identifies only "scars, birthmarks, limb or postural deformation [and] diseases of the skin." There has been no further substantive guidance on the definition of severe disfigurement or clarification in case law. As suggested by the commentary above, Saunders argues that what is intended logically by the provision is to protect the broader category of those with appearance-related disadvantage, yet the use of the term disfigurement implies a narrower sub-set of appearance-related conditions.²³ Ultimately, due to the paucity of case law, the ability of severe disfigurement provision to protect the health rights of persons with albinism is unclear. However, most other applicable disability-related provisions in the Equality Act have a medicalised focus on functioning. Conversely, the severe disfigurement provision is more rooted in the social model and societal attitudes and may be useful in situations where a person with albinism has experienced barriers that are unrelated to bodily (e.g., visual) impairment.

The present report did not identify a particular example of the Equality Act being used to protect the rights of persons with albinism, but taken together, there are a number of avenues through which an individual with albinism could argue its applicability on the protected characteristics of race, disability and the sub-categories of blindness/severe sight impairment, and cancer.²⁴

19. UK Government. (2010). Equality Act 2010 Guidance https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/570382/Equality_Act_2010-disability_definition.pdf

20. Regulation 7 of The Equality Act 2010 (Disability) Regulations 2010 (S.I. 2010/2128).

21. H Saunders Difficult distinctions in anti-discrimination law: Disfigurement, appearance and disability. *International Journal of Discrimination and the Law*, 20(1), (2020). p. 21-44.

22. The traditional medical model views disability as arising directly from an individual's bodily impairment. In contrast, the social model of disability focuses on how societal barriers and attitudes create disability by excluding or disadvantaging individuals with impairments.

23. Ibid.

24. Note that this report is not suggesting that persons with albinism are severely disfigured, just that this part of the Act may be relevant under some circumstances.

The Equality Act prohibits discrimination on the basis of protected characteristics and imposes a duty upon stakeholders, including healthcare providers, schools, universities and employers, to make reasonable adjustments for persons with the protected characteristic of disability. As such, it is a crucial piece of legislation which supports persons with albinisms' right to health by providing them with a legal basis to challenge discrimination and request reasonable accommodation.

The Social Security (Personal Independence Payment) Regulations 2013

Many UK citizens are eligible for different forms of social protection, known as social welfare. A dedicated benefit for persons with disabilities that includes persons with visual impairment has existed since Disability Living Allowance (DLA) was created in 1992.²⁵ However, the British welfare system was reformed in 2012 and DLA for adults was replaced by Personal Independence Payment (PIP),²⁶ with DLA only retained for parents/caregivers of children with disabilities under 16. Both PIP and DLA take the form of direct bank transfers to the recipients' bank account. There are no restrictions on what it can be spent on, meaning eligibility is an important enabler of persons with albinisms right to health, as it can be used to pay for things like sunscreen and prescription medicine, assistive devices or transport to healthcare appointments.

Children and adults with albinism should receive DLA/PIP if they experience difficulties or barriers because of their condition. To qualify for DLA, parents must prove that the care they provide for the child is substantially in excess of the needs of another child who does not have disabilities or conditions that affect their day-to-day activities. Parents are also entitled to claim a carer's allowance should they care for the child more than 35 hours a week. An adult is awarded PIP if their daily living and/or mobility is considered to be limited by their physical or mental condition. Whether an individual's condition is considered to limit them is assessed via a points-based system set-out in The Social Security (Personal Independence Payment) Regulations 2013. Under these regulations, daily living is considered to have ten components, covering things like food preparation, washing, dressing, and managing a health condition, while mobility comprises two aspects: getting around and planning a journey. Scoring for the preparing food component is shown in the table below as an example.²⁷

25. Within the Social Security Contributions and Benefits Act 1992

26. The replacement of DLA for adults by PIP in the UK has been an on-going process since 2013 and was stopped over the period of the COVID '19 crisis. Consequently, some adults continue to receive DLA. Moreover, if a DLA receiving adult reaches the age of 65 before transition to PIP, they will remain on DLA indefinitely. In Scotland, PIP was replaced by a new benefit called Adult Disability Payment in 2022

27. Scoring for all components is given in the Appendix

Table 1 - Activity 1. Preparing food.

Can prepare and cook a simple meal unaided	Score 0
Needs to use an aid or appliance to be able to either prepare or cook a simple meal	Score 2
Cannot cook a simple meal using a conventional cooker but is able to do so using a microwave	Score 2
Needs prompting to be able to either prepare or cook a simple meal	Score 2
Needs supervision or assistance to either prepare or cook a simple meal	Score 4
Cannot prepare and cook food	Score 8

To qualify for the daily living or mobility component of PIP, a person must receive a combined score of at least 8, across all component categories. Applicants who score 12 qualify for an enhanced, additional payment. In the example above, an applicant judged not to be able to prepare food at all would automatically qualify for PIP, while another judged to have less difficulty would be required to demonstrate limitations in another area, like dressing or washing. As evidenced by the above scoring system, requiring the use of an assistive device or human supervision/assistance for a single aspect of daily living does not constitute automatic eligibility for PIP. However, an applicant is eligible for PIP if they are able to successfully show this support is needed across multiple areas.

As mentioned, persons with albinism have low visual acuity. Depending on the level of visual impairment, and taking into account nystagmus, persons with albinism may need to use assistive devices for a range of activities and therefore they, or their parents [if they are children], could qualify for PIP or DLA respectively. In addition, due to sensitivity to the sun, particularly with increased ultraviolet rays due to climate change, persons with albinism are likely to spend more on sunscreen, skin cancer screening and treatment. They therefore, may qualify for PIP under the 'managing a health condition' component.

The Children and Families Act 2014

Concerning pre-tertiary education, the Children and Families Act 2014, also places duties on stakeholders, including schools, local authorities and healthcare providers to identify and make provisions for learners with special educational needs (SEN). Learners with SEN are those that have

“a learning difficulty or disability which calls for special educational provision to be made for him or her.” It further defines a child as having learning difficulties or disabilities if he or she:

***has a significantly greater difficulty in learning than the majority of others of the same age, or
has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions.***

In practice, many children considered to have disabilities also have SEN, but the two groups do not always overlap. While children with albinism, unless they have a further condition, have the same ability in learning as their counterparts, their visual impairment means that they require additional facilities to those provided in mainstream schools. The Children and Families Act 2014 provides additional protections for children with albinism who may experience difficulties learning at school, placing duties on stakeholders to provide accommodations and support like extra time during examinations. The law also sets out the process of obtaining an Education, Health and Care (EHC) Plan through which children with albinism can be provided with access to assistive devices or other needed support.²⁸

The Education (Student Support) Regulations 2011

For higher education institutions, students who are considered to have a disability under the Equality Act also receive support as set out in the Education (Student Support) Regulations 2011. Notably, Disabled Students' Allowance is a government grant which can be used to purchase specialist equipment or non-medical help (e.g., note-takers) for students at university. Eligibility is generally demonstrated through the provision of medical evidence. Universities also have a duty under the Equality Act to make reasonable adjustments for these students (e.g., placing all lecture materials in accessible formats).

Frameworks specifically related to access to assistive devices

In the UK, the government provides full or partial funding for many assistive devices (ADs) and services under health, social care and support, education, housing, and employment schemes. This includes via the NHS, PIP/DLA, and Disabled Students Allowance, as well as through funding pots earmarked for social care (e.g., Better Care Fund) and supporting persons with disabilities to access employment (e.g., Access to Work).²⁹ Regarding employment, employers must ensure that

28. An Education, Health and Care Plan is a legally binding document that outlines the specific educational, health, and social care needs of children with special educational needs and disabilities. It is designed to ensure that they receive the necessary support and services to help them reach their full potential. EHCPs provide a comprehensive assessment of the individual's needs and set out the provisions and goals required to meet those needs. The Children and Families Act 2014 set out the duties of stakeholders involved in EHCP provision, maintenance and monitoring including local authorities and schools and healthcare.
29. V Austin, D Patel, J Danemayer, K Mattick, A Landre, M Smitova, M Bandukda, A Healy, N Chockalingam, D Bell, and C Holloway, . Assistive Technology Changes Lives: an assessment of AT need and capacity in England; Cabinet Office, HMG (2023)

reasonable accommodations are provided, which may include access to appropriate assistive technology. The Health and Safety Executive (HSE) has established a set of principles to support employers in both hiring and retaining disabled individuals in their workforce.³⁰ Access to assistive products is vital to ensure persons with albinism enjoy their right to health and are able to learn and work on the same basis as others.

Genetic testing

Persons with albinism, like other persons in the UK, are able to access genetic testing and support free of charge on the NHS, if referred by a GP. Information about genetic testing and support for persons with albinism is given on the NHS website.³¹ Access to genetic testing and support helps persons with albinism and their right to health in several ways. Notably, genetic testing can help identify the type of albinism that an individual has, in particular whether they have one of the rarer forms of albinism, such as Hermansky-Pudlak Syndrome (HPS) which is associated with bleeding problems and bruising, as well as lung and bowel disorder in some cases.

Challenges to ensuring the Right to Health for Persons with Albinism in the UK

Coverage and accessibility of disability benefits

Since persons with albinism are persons with disabilities, where the latter's rights are violated in the UK, persons with albinism are also affected. The treatment of persons with disabilities since the UK's welfare reform has been the subject of much domestic and international criticism and concern. In 2016, an inquiry by the Committee on the Rights of Persons with Disabilities [CRPD Committee] identified that the UK's welfare reforms have led to grave and systematic violations of the rights of persons with disabilities.³² One general finding is that persons with disabilities have been regularly portrayed negatively by government representatives as dependent or making a living out of benefits, committing fraud as benefit claimants, being lazy or putting a burden on taxpayers. It is against this backdrop that PIP was launched with much tighter eligibility criteria compared to DLA. The CRPD committee noted that the UK government foresaw that 620,000 fewer people would be eligible for PIP, representing a 20% saving in expenditure. This report could not identify a data source of how many persons with albinism have been affected by the transition to PIP from DLA.

To obtain PIP, applicants present written medical evidence and subsequently undergo an assessment at a centre by a health professional. In 2018, the then Shadow Secretary of State for Work and Pensions

30. Health and Safety Executive. (n.d.). Principles to Support Disabled Workers and Workers with Long-Term Health Conditions. <https://www.hse.gov.uk/disability/best-practice/accessible-communication.html>

31. NHS . Albinism. <https://www.nhs.uk/conditions/albinism/> (2023)

32. Committee on the Rights of Persons with Disabilities (2016). Inquiry concerning the United Kingdom of Great Britain and Northern Ireland carried out by the Committee under article 6 of the Optional Protocol to the Convention. Geneva: United Nations; A recent review (August, 2023) of the UK government's response to these violations by the CRPD has concluded little progress has been made. The UK government did not attend this review.

commented that PIP assessments are often dehumanising, inaccurate and worsens existing health conditions.³³ At that time, 68% of all PIP decisions appealed by the applicant were overturned at tribunal³⁴; this figure appears to remain the same as of March 2023.³⁵

This report identified a handful of first-hand accounts by persons with albinism of the PIP assessment process within grey literature or media sources. They describe the process as a “nightmare”³⁶ and “intrusive, humiliating and completely pointless.”³⁷ Two accounts point to the lack of knowledge of health professionals carrying out the PIP assessment, about albinism and associated conditions, for instance linking nystagmus to a condition that can be corrected with glasses rather than an issue with the visual pathway and cortex within the brain.³⁸ Two accounts also question why, since albinism is a congenital condition, PIP assessors did not refer to established medical records held by NHS, in lieu of performing a new assessment.³⁹ In one example, the applicant notes that she was disallowed PIP in part, because she did not possess a Certificate of Visual Impairment, despite the fact that PIP legislation states claimants should not be asked to provide further evidence if it can be obtained elsewhere, such as NHS medical records. She notes this is a breach of the UK Equality Act, as it imposes additional conditions on her due to her impairment that are not proportionate means of achieving a legitimate aim.⁴⁰ Participants in the roundtable discussion on albinism in the UK, held by the UN Independent Expert, also spoke about difficulties in obtaining support for children with albinism including difficulty filling out lengthy and onerous PIP/DLA forms, within which many questions were irrelevant or did not capture the barriers encountered by persons with albinism. While these negative experiences of the PIP process are not unique to persons with albinism, they show how their rights were eroded alongside the rights of other persons with disabilities by the UK’s welfare reforms.

Lack of effective protections offered by the Equality Act

The Equality Act’s ability to protect the rights of persons with disabilities (and therefore, persons with albinism) has been criticised, notably in a 2016 review carried out by a House of Lords Select Committee convened to review the Act. A key conclusion of the report was that the grouping of

33. D Abrahams, . More damning evidence that PIP and ESA assessments are not fit for purpose. <https://labour.org.uk/press/damning-evidence-pip-esa-assessments-not-fit-purpose-debbie-abrahams/> (2018)

34. Ibid.

35. Benefits and Work. Appeals Backlog Rises as Success Rates Fall for All but PIP. (2023) <https://www.benefitsandwork.co.uk/news/appeals-backlog-rises-as-success-rates-fall-for-all-but-pip>

36. L Ellis, G Douglas., & H Clarke, Personal Independence Payment (PIP) and Disability Living Allowance (DLA): report based upon fourteen case studies of people with sensory impairments engaged in application for PIP. University of Birmingham. (2015).

37. R Crossan, (2017). This is a PIP disability assessment: intrusive, humiliating and completely pointless. The Guardian. <https://www.theguardian.com/society/2017/jun/13/pip-disability-assessment-intrusive-election-conservative-government>

38. UK Parliament. Evidence on PIP and ESA Assessments: Written evidence from Name Withheld (PEA 0175) (2017). <https://committees.parliament.uk/writtenevidence/82837/html/>; Crossan (n 40).

39. UK Parliament (n 41).; Ellis, Douglas and Clarke (n 39).

40. The reasoning for the Equality Act breach is not given in the source. This is the present report authors analysis. In the Equality Act unfavourable treatment does not constitute discrimination if treatment is a proportionate means of achieving a legitimate aim. Because PIP legislation states claimants should not be asked to provide further evidence if it can be obtained elsewhere, additional requests for evidence on the basis of the claimant’s condition were not proportionate nor legitimate.

disability with other protected characteristics does not in practice benefit persons with disabilities and that disability rights were better protected under previous legislation.⁴¹ In particular, the report notes that for many protected characteristics equality of opportunity is generally achieved by equality of treatment, and yet for persons with disabilities, equality of opportunity often requires different treatment which thereby addresses the inequalities. A practical example illustrates that employers have the capability and obligation to treat persons with disabilities “more favourably” compared to other individuals due to the Act. This may involve providing access to devices and other reasonable adjustments, which individuals without disabilities may not require. However, in practice, many employers fail to recognise this and instead apply uniform treatment to all, potentially resulting in discrimination.

The Committee draws the conclusion that combining disability with other protected characteristics in the Equality Act masks differences that apply uniquely to disability and has led to a lack of focus on disability discrimination and a feeling of loss of rights amongst persons with disabilities.

The Equality Act places upon service providers an anticipatory duty to make reasonable adjustments for persons with disabilities, irrespective of whether they are expected to access the service. The Committee found that this was not widely understood compared to awareness of the need to make reactive reasonable adjustments (i.e. adjustments enacted when a person with a disability needs to use a service). However, in both cases there is also low awareness amongst many duty bearers about what the duty to make reasonable adjustments means and how to comply with it.

The report also notes that the burden on asserting the rights protected by the Equality Act falls primarily on the holder of protected characteristics.⁴² The UK has made substantial cuts to the funding and availability of both criminal and civil legal aid over the past ten years. Consequently, workplace-based discrimination now falls outside the scope of legal aid, effectively resulting in prohibitively high costs for any individuals seeking legal recourse after experiencing discrimination at work based on a protected characteristic. Furthermore, Section 14 of the Equality Act prohibits discrimination based on two or more protected characteristics. However, this provision was never enacted by the Government, it was deemed an unnecessary burden to businesses.⁴³ Compared to other persons with disabilities, persons with albinism may be particularly disadvantaged by this gap in the protections offered by the Equality Act, as the discrimination they experience often has both a disability and race-related element on the basis of colour.⁴⁴ It may also have an age or sex bias when dealing with a woman, older person or child with albinism.

41. Select Committee on the Equality Act 2010 and Disability. *The Equality Act 2010: the impact on disabled people*. London: House of Lords. <https://publications.parliament.uk/pa/ld201516/ldselect/ldseqact/117/117.pdf> (2016).

42. *Ibid.*

43. Select Committee on the Equality Act 2010 and Disability. (2016). *The Equality Act 2010: the impact on disabled people*. London: House of Lords. <https://publications.parliament.uk/pa/ld201516/ldselect/ldseqact/117/117.pdf>

44. UK Parliament (n 41).

Barriers to accessing reasonable adjustments

The reasonable adjustment duty outlined in the Equality Act of 2010 has been described as a cornerstone of disability discrimination law by the UK government,⁴⁵ and there are accounts from persons with disabilities affirming instances of good practice by individual duty bearers.⁴⁶ At the international level, the requirement for State Parties to provide access to reasonable adjustments, referred to as reasonable accommodations, is also provided for in Article 5 of the CRPD. However, the constraints of the Equality Act (i.e. lack of awareness of duty bearers to make reasonable adjustments and barriers faced by individuals in enforcing their rights) have meant that many persons with disabilities (and therefore likely persons with albinism) have experienced barriers in accessing the reasonable adjustments they are entitled to when seeking healthcare, employment or education. Read et al. note that reasonable adjustments under the Equality Act fall into three categories.⁴⁷ The first is changing the physical features of a service so that persons with disabilities can access it (for instance, making buildings wheelchair accessible), the second is changing existing practices or procedures of services (for instance, length and location of hospital appointments), and the third is providing auxiliary services or aids (namely, information in different formats). From primary research with persons with disabilities who sought healthcare in the UK, Read et al. conclude there is a mixed picture as to whether hospital providers were making reasonable adjustments for all those who require them. Research also indicates barriers to reasonable adjustment provision amongst employers⁴⁸ and higher education providers.⁴⁹ However, there is a paucity of research concerning the barriers that persons with albinism experience specifically. In this regard, a capacity assessment of assistive technology in England has characterised provision as sporadic with significant regional variations in the availability and provision of devices.⁵⁰ The report notes several barriers of provision of devices to users, including affordability, lack of knowledge amongst users about what is available, and a lack of knowledge and training related to assistive devices amongst providers. These barriers likely add to difficulties persons with albinism face in accessing reasonable adjustments and securing their right to health.

The experiences of persons with albinism in the UK and their access to healthcare, as well as education and employment was discussed further in the roundtable discussion.

Challenges accessing healthcare needed specifically for albinism

As mentioned, due to visual impairment and susceptibility to skin damage from the sun, persons with albinism require access to dermatological and ophthalmological services. In line with the CRPD, they

45. Select Committee report

46. Select Committee report; Health paper

47. S Read, P Heslop., S Turner, V Mason-Angelov, N Tilbury, C Miles, & C Hatton, Disabled people's experiences of accessing reasonable adjustments in hospitals: a qualitative study. *BMC Health Services Research*, 18(1), (2018) p. 1-10.

48. 53 J Davies, B Heasman, A Livesey, A Walker, E Pellicano, & A Remington. Autistic adults' views and experiences of requesting and receiving workplace adjustments in the UK. *PLOS One*, 17(8), e0272420., (2022)

49. 54 L Kendall, Supporting students with disabilities within a UK university: Lecturer perspectives. *Innovations in Education and Teaching International*, 55(6), (2018) p. 694-703.

50. 55 V Austin, D Patel, J Danemayer, K Mattick, A Landre, M Smitova, M Bandukda, A Healy, N Chockalingam, D Bell, and C Holloway, . *Assistive Technology Changes Lives: an assessment of AT need and capacity in England*; Cabinet Office, HMG (2023)

should receive these services as a right.⁵¹ However, there was a mixed picture as to whether survey respondents or their family member had ever been referred to a dermatologist or ophthalmologist. Some individuals had been referred to both, while others had only been referred to one. Two respondents stated they had not received a referral. Additionally, five respondents mentioned that they, or their family member had never had skin cancer screening, while six divulged they did not have access to reliable healthcare information at the time of albinism diagnosis.

In addition, although albinism is a recognised medical condition in the UK, roundtable participants spoke about a lack of knowledge and understanding displayed about the condition by healthcare providers when children with albinism are born. This is an issue for persons with albinism throughout their lives. One participant gave the example of having frequent eye tests due to nystagmus⁵² and being seen by different opticians each time, each of whom questioned why his eyes could not be kept still.

Parents of children with albinism also lamented not receiving any information on the need to care for, and how to care for, their child's skin when their child with albinism was born. This was particularly a concern for mothers of African descent who admitted to never using sunscreen themselves and therefore not understanding the importance of it.

“When she was still a baby, I took her to the beach. I didn’t know about sunscreen. I never used it myself. I didn’t know she needed it. She turned red. The next day I was so scared because her skin was peeling. I took her to the doctor in tears. The doctor asked me if I used sunscreen on her. She told me she was sunburnt, and I should always use sunscreen on her. I didn’t know. No one I know ever used sunscreen. It was something that white people did. I didn’t know. No one had told me she needed it.”

Mother of a child with albinism

Parents and children with albinism of African descent spoke about facing additional discrimination. Specifically, they noted instances of healthcare providers contesting the identity of fathers, suggesting that (for example) since their child has fair skin whether the father could actually be White, due to lack of knowledge about albinism.

51. In terms of Article 25(b) states should, “Provide those health services needed by persons with disabilities [including albinism] specifically because of their disabilities [albinism], including early ... intervention as appropriate, and services designed to minimise and prevent further disabilities, including among children and older persons”

52. Nystagmus is a condition associated with albinism involving rhythmical, repetitive and involuntary movement of the eyes.

Roundtable participants also spoke about medical doctors giving traumatic and overly pessimistic medical advice about children with albinism's future functional ability, sometimes accompanied by misperceptions about what a child with albinism will be able to achieve in society:

“Another thing is a lot of doctors tell the parents that they’ll be blind, that their children won’t see, and think about special education and sending them to a special school, because they won’t achieve. That’s what they said about me to my parents when I was born. But they are still saying it in 2023 that their children are going to be blind. Well, if that is the first thing you hear when your child is born, that’s horrible.”

Person with albinism

These examples underpin the importance of raising awareness and ensuring training on albinism for public and private healthcare professionals, in line with the provisions of the CRPD.⁵³

Furthermore, the “postcode lottery” of healthcare provision for albinism was mentioned, indicating that the level of support individuals were able to receive, and the ease of accessing it, is dependent on the area of the UK in which individuals reside. One roundtable participant noted that many cases of albinism in the UK are usually diagnosed through searching for the cause of a diagnosis of nystagmus. Immediate tests involving looking at the back of the eye can diagnose some cases of albinism, while others require genetic testing, but the availability and ease of access of both tests differs based on geographical location. This can cause additional barriers to children with albinism and their families living in different parts of the UK. The lack of access to genetic testing to enable early identification of albinism, particularly amongst groups where albinism is not easily identifiable, runs contrary to the requirements under the CRPD.⁵⁴ Roundtable participants also suggested there was a reluctance by healthcare professionals to make referrals for genetic testing unless an individual was directly affected by a condition. As one participant shared:

“Another thing that is not readily available is gene testing. OK, because I had a conversation with my GP and I said ‘OK, is it possible?’ Obviously I carried the gene. My husband carries the gene. That’s why she has albinism. Is it possible to test my other kids. Do they all have the gene? No, no, they can’t refer me for genetic testing. I don’t know why. It’s just no they don’t. Unless you have a problem or you have you’re sick, then you can’t just request for a genetic test to see if your children also have it.”

Parent of a child with albinism

53. Article 25(d)

54. Article 25 requires states to b) Provide early identification and intervention as appropriate

Education

Most respondents of the small survey carried out and participants of the roundtable discussion said that they or their family member with albinism had access to some form of reasonable adjustments at work or school (80% ; $N = 15$). Examples given of adjustments include large-print handouts, extra time for examinations and provision of a note-taker. However, three respondents from the survey said they or their family member was unable to obtain Disabled Students Allowance (DSA) during higher education. Of those that did obtain it, the process was generally described as somewhat challenging and time-consuming. Participants of the roundtable discussion, also noted difficulties obtaining all needed educational support, such as assistive devices or reasonable accommodations across primary, secondary and tertiary education. Frequent examples mentioned were that school and university support services were unaware of what type of accommodations or devices would be able to support learners with albinism, placing the onus on the individual or their parents to explain and request accommodations. One participant shared her experience of accessing support at university:

“[My University requested] an access assessment meeting with me...to understand what kind of support I’ll be needing, which I had with one of the disability support team members and to be honest, they didn’t really understand what kind of support they could give to me. We had to speak it through. I was explaining what I would need to have a better experience in school and we just arrived at the fact that I can submit my assessments 2 weeks later than the deadline.”

Person with albinism

Cases of support services requesting medical proof were also brought up by participants, placing further pressure on individuals with albinism.

In addition, issues with the timely supply of requested assistive devices, underpinned by arguments about funding sources within school management were found to have disrupted educational journeys for at least one person with albinism:

“Unfortunately, she had to pull out of A-level ⁵⁵ biology because they were ordering her microscope. It didn’t come. She missed so many practicals... You know, initially there was [this situation of], who was going to order it? Where was the fund coming from? And they kept going backwards and forwards. And by the time these funds came to order the microscope it was too late because she missed too many practicals. So she had to drop that subject.”

Parent of a child with albinism

55. Taught at age 16 for two years.

Even where persons with albinism had access to support and assistive devices, roundtable participants noted that their ability to use them to support learning and education was often hampered by the lack of training of school staff:

“I hear from parents a lot that the children are given equipment, but the school isn’t prepared to help them set it up or says ‘Oh we don’t know how. We don’t have the ability. We don’t understand the technology.’ So they have this stuff, but they’re not able to use it because the teachers or the school aren’t prepared to spend the time or they’re like, ‘oh yeah, our IT guy, he doesn’t know how to do that kind of thing.”

“I don’t think they’ve thought it through because for my daughter in primary school she had a laptop and they were connecting it to the teachers screen, but the problem was anything the teacher was doing [on her laptop], she [my daughter] was seeing it too. So, you know, sometimes when as a teacher you’re teaching, you freeze the board for the class. So, of course everybody’s working, looking at the board which is frozen... she [my daughter], however, was just seeing everything that the teacher was doing [instead of the screen frozen for all other students]. Because the teacher just thinks the board is frozen.”

Parent of a child with albinism

The latter example refers to when a teacher may “pin” a computer window to an interactive blackboard for the class to work from and continue with their own work on a different non-shared window. However, because the teacher’s laptop and that of the learner with albinism have a direct connection, their screens are mirrored and the student can no longer see the exercise, unlike the rest of the class. This highlights how important it is to ensure that teachers have the knowledge and skills to engage in inclusive classroom delivery alongside reasonable adaptations and classroom support for learners with albinism. As one roundtable participant shared, teachers may also be a source of explicit discrimination against learners with albinism, espousing some of the same problematic attitudes as found in UK society more generally:

“I took my monocular out of school and my teacher just laughed in my face and said ‘You’re a pirate!’, you know? When you’re like 13.”

Person with albinism

Taken together, this underscores the imperative to educate teachers and school leaders about albinism, in addition to groups such as health professionals.

It also appears that, where reasonable adaptations are provided, these mainly relate to visual impairments and not vulnerability to skin damage from the sun or other sensitivity to the sun such as photophobia. Another student with albinism related how she would wear transition glasses which would go dark once she was in the sun due to her photophobia. However, it would take some time for the glasses to transition back once she returned to class after being outside and she was compelled to remove her glasses because the teacher would not let her wear “sunglasses” in class. This meant that until her glasses transitioned back to clear, she would not be able to see anything in class.

Employment

Similar barriers to accessing reasonable accommodations were identified in the context of employment, for example that the onus is on the individual, not the institution to secure support.

“Yeah, I think there are things available, but it’s quite similar to the discussion we’ve been having. The burden of care. It’s on you. It’s not institutionalised. It’s on you. It’s on you. Having to explain, having to send several emails, have conversations before you can get [them]...In the e-mail I sent, I was very, very specific... I needed a laptop that I can use both for typing and then also should have a touch screen where I can zoom easily. [Employer] couldn’t understand why I needed it.”

Person with albinism

Moreover, similar to experiences within schools and universities, roundtable participants also highlighted issues with the timely assessment and supply of work-related assistive devices issued to support them under the government scheme, Access to Work⁵⁶:

“As everybody knows there’s something called access to work and that’s a government scheme. And you can apply to access to work to get technology or anything that you need in order for you to be able to do your job the same as anybody else...But it is a joke because you can it takes so long to have an assessment that you’ve started your job before you’ve actually been assessed, and if you need something like zoom text or any screen reading enlargement software, you literally can’t do it. You can’t start your job.”

Person with albinism

Participants also noted that the process of proving entitlement for Access to Work, which involves undertaking the assessment for PIP, was demeaning, and further exacerbated the pressure placed onto individuals to secure support.

Another recurring subject was stigma and discrimination and its impact on persons with albinism.

Stigma and Discrimination

Stigma and discrimination were highlighted in the roundtable as a widespread and cross-cutting issue that affects the health rights of persons with albinism, as well as their access to education and

56. Access to Work is a discretionary grant scheme that provides personalised support to disabled people who are. Eligible support categories include support workers (e.g., a sign language interpreter), specialist equipment and subsidised taxi fares.

employment. Roundtable participants of various ethnicities highlighted that the social barriers and the discrimination that persons with albinism face also directly create health issues, notably mental health impacts, as well as create unsafe environments at schools and workplace that erode equal access to education and employment. Some participants gave the examples of bullying at school:

“The mental health [impact], the bullying is just off the scale...[the] teacher had to do a whole lesson in [my child's] class about albinism and got the class to look at animals with albinism and people living with the condition, because there is no awareness...she's got kids asking her if she's adopted...and [children with albinism] have to deal with that, in addition to all the things they have to deal with.”

Parent of a child with albinism

“I was bullied mercilessly. They would pull my hair out because they said it wasn't real and they'd make me open my eyes and shove my head at the sun and the kids were burning cigarettes in the back of my neck because they said I had devil eyes.”

Person with albinism

Roundtable participants raised examples of being discriminated against at work:

“You know, literally they just told me that I was an embarrassment and that I couldn't work with celebrities and I couldn't work with people because I looked different.”

Person with albinism

“I've been kicked off of scholarships because employers weren't accommodating to me...I've been told like we just don't want to accommodate

for you. We don't have to. We can employ someone else... One of the things I wanted to do was work in the lab and then I've been told like, no, you can't.”

Person with albinism

As the latter example shows, in addition to the mental health impacts of being discriminated against, stigma toward persons with albinism in the workplace leads to lost opportunities, and inability to pursue their chosen occupation.

Good Practices

The NHS Genomic Medicine Service

As of 2023, the NHS has launched the Genomic Medicine Service (GMS), having opened 7 hubs in England.⁵⁷ The GMS is the first national genomic testing service that will be delivered as routine care. This service will sequence the entire genome system to provide early diagnosis and collect genomic data to provide treatments and improve the health care offered to the patients.⁵⁸ The service also affords patients the opportunity to take part in the research about their conditions which will potentially benefit those diagnosed in the future.⁵⁹ The GMS has the potential to improve availability and access to genetic testing for persons with albinism and their families which supports their right to health. The development of the GMS and its purpose to improve healthcare and access to services is in line with the CRPD, which obligates State Parties to collect appropriate information to enable them to formulate and implement policies that give effect to the Convention.⁶⁰

Civil society

The right to health of persons with albinism in the UK is supported by the work of a number of civil society organisations. The most well-known is dedicated to supporting persons with albinism specifically is the Albinism Fellowship UK.⁶¹ This small charity is run by volunteers and seeks to provide information about albinism, raise positive awareness of the condition, hold networking events and encourage dialogue about the condition. They have also run workshops to provide support on accessing benefits for persons with albinism or parents of children with albinism. Persons with albinism can also seek support from organisations that serve broader groups (e.g., persons with visual impairments) or persons with related conditions. Two such organisations are the Nystagmus Network⁶² and the Royal National Institute of Blind People⁶³, the latter of which is one of the UK's largest disability charities.

Recommendations

This preliminary research report has highlighted that while the UK possesses frameworks and legislation that can in principle safeguard the right to health of persons with albinism, such as the Equality Act, in practice many face barriers in enforcing these rights. Specifically, persons with albinism in the UK face difficulties in accessing benefits and social protection (such as PIP) and experience a multitude of barriers in getting healthcare, as well as accessing education and employment on equal terms with others individuals.

57. NHS England. NHS Genomic Medicine Service. <https://www.england.nhs.uk/genomics/nhs-genomic-med-service/>

58. Ibid.

59. Ibid.

60. Article 31

61. Albinism Fellowship of UK and Ireland. About the Albinism Fellowship. <https://www.albinism.org.uk>

62. Nystagmus Network. Supporting People Living with Nystagmus. <https://nystagmusnetwork.org/>

63. RNIB. Home. <https://www.rnib.org.uk/>

An overarching recommendation from this formative work is that there needs to be more in-depth research. Although preliminary, this research makes a number of specific recommendations based on initial findings:

Recommendations specific to persons with albinism and their families

The UK authorities must adopt measures to:

- Improve the provision of healthcare information to persons with albinism and their families from the moment a child with albinism is born.
- Improve the availability of healthcare services, including genetic testing, to persons with albinism and their families living across the UK.
- Sensitise and train healthcare workers and other professionals (teachers, employers) on albinism and conditions likely to affect persons with albinism, as appropriate to stakeholder job role.
- Combat societal stigma and discrimination and support persons with albinism and/or their families who experience it.

Recommendations applicable to persons with albinism and other persons with disabilities

The UK authorities must:

- Widen access to assistive devices.
- Reform the disability benefits system to remove barriers to accessing help for those that need it, and ensure that the welfare application and assessment process is not demeaning or overly difficult or stressful for applicants and their families.
- Implement measures to support enforcement of the provisions of the Equality Act by institutions, and thus lessen the same burden of enforcement on rights-holders.

APPENDIX

1. PIP Daily living and Mobility Descriptors

Daily living activities and descriptors;

Activity 1. Preparing food.

a. Can prepare and cook a simple meal unaided.	Score 0
b. Needs to use an aid or appliance to be able to either prepare or cook a simple meal.	Score 2
c. Cannot cook a simple meal using a conventional cooker but is able to do so using a microwave.	Score 2
d. Needs reminding or encouraging to be able to either prepare or cook a simple meal.	Score 2
e. Needs supervision to help me stay safe or physical help to either prepare or cook a simple meal.	Score 4
f. Cannot prepare and cook food.	Score 8

Activity 2. Taking nutrition.

a. Can take nutrition unaided.	Score 0
b. Needs to use an aid or appliance, or supervision to help them stay safe, or physical help to be able to cut up food to be able to eat or drink;.	Score 2
c. Needs a therapeutic source to be able to eat or drink.	Score 2
d. Needs reminding or encouraging to eat or drink.	Score 2
e. Needs physical help to be able to manage a therapeutic source to take nutrition.	Score 4
f. Cannot convey food and drink to their mouth and needs another person to do so.	Score 8

Activity 3. Managing therapy or monitoring a health condition.

a. Can manage medication or therapy, and monitor their health condition without help.	Score 0
b. Needs to use an aid or appliance to be able to manage their medication; or needs supervision to help them stay safe, or reminding or encouraging, or physical help to manage their medication or monitor a health condition.	Score 1
c. Needs supervision to help them stay safe, or reminding or encouraging, or physical help to be able to manage therapy that takes no more than 3.5 hours a week.	Score 2
d. d. Needs supervision to help them stay safe, or reminding or encouraging, or physical help to be able to manage therapy that takes more than 3.5 but no more than 7 hours a week.	Score 4
e. Needs supervision to help them stay safe, or reminding or encouraging, or physical help to be able to manage therapy that takes more than 7 but no more than 14 hours a week.	Score 6
f. Needs supervision to help them stay safe, or reminding or encouraging, or physical help to be able to manage therapy that takes more than 14 hours a week	Score 8

Activity 4. Washing and bathing.

a. Can wash and bathe unaided.	Score 0
b. Needs to use an aid or appliance to be able to wash or bathe.	Score 2
c. Needs supervision, reminding, encouraging, or reassuring to be able to wash or bathe.	Score 2
d. Needs physical help to be able to wash either their hair or body below the waist.	Score 2
e. Needs physical help to be able to get in or out of a bath or shower.	Score 3
f. Needs physical help to be able to wash their body between the shoulders and waist.	Score 4
g. Cannot wash and bathe at all and needs another person to wash their entire body.	Score 8

Activity 5. Managing toilet needs or incontinence.

a. a. Can manage toilet needs or incontinence unaided.	Score 0
b. Needs to use an aid or appliance to be able to manage toilet needs or incontinence.	Score 2
c. Needs supervision to help them stay safe or reminding or encouraging to be able to manage toilet needs.	Score 2
d. Needs physical help to be able to manage toilet needs.	Score 4
e. Needs physical help to be able to manage incontinence of either bladder or bowel.	Score 6
f. Need physical help to be able to manage incontinence of both bladder and bowel.	Score 8

Activity 6. Dressing and undressing.

a. Can dress and undress unaided.	Score 0
b. Needs to use an aid or appliance to be able to dress or undress.	Score 2
c. Needs reminding or encouraging to be able to dress, undress or not undress inappropriately, or needs reminding or encouraging, or physical help to be able to choose appropriate clothing.	Score 2
d. Needs physical help to be able to dress or undress their lower body.	Score 2
e. Needs physical help to be able to dress or undress their upper body.	Score 4
f. Cannot dress or undress at all.	Score 8

Activity 7. Communicating verbally.

a. Can express and understand verbal information unaided.	Score 0
b. Needs to use an aid or appliance to be able to speak or hear.	Score 2
c. Needs need help from someone trained or experienced in helping me to be able to express or understand complex verbal information.	Score 4
d. Needs help from someone trained or experienced in helping them to be able to express or understand basic verbal information.	Score 8
e. Cannot express or understand verbal information at all even with help from someone trained or experienced in helping them.	Score 12

Activity 8. Reading and understanding signs, symbols and words.

a. Can read and understand basic and complex written information either unaided or using spectacles glasses or contact lenses.	Score 0
b. Needs to use an aid or appliance, other than spectacles glasses or contact lenses, to be able to read or understand either basic or complex written information.	Score 2
c. Needs reminding, encouraging or reassuring to be able to read or understand complex written information.	Score 2
d. Needs reminding, encouraging or reassuring to be able to read or understand basic written information.	Score 4
e. Cannot read or understand signs, symbols or words at all.	Score 8

Activity 9. Engaging with other people face to face.

a. Can engage with other people without help from an aid or appliance or a person.	Score 0
b. Needs reminding, encouraging, or reassuring to be able to engage with other people.	Score 2
c. Needs help from someone trained or experienced in helping them to be able to engage with other people.	Score 4
d. Cannot engage with other people because it either makes them feel so anxious or distressed that they cannot function, or because it causes them to behave dangerously, and either they or another person might get hurt.	Score 8

Activity 10. Making budgeting decisions.

a. Can manage complex budgeting decisions without help from an aid or appliance or a person.	Score 0
b. Needs reminding, encouraging, or reassuring, or physical help to be able to make complex budgeting decisions.	Score 2
c. Needs reminding, encouraging, or reassuring, or physical help to be able to make simple budgeting decisions.	Score 4
d. Cannot make any budgeting decisions at all.	Score 6

Mobility activities and descriptors**Activity 1.** Planning and following journeys.

a. Can plan and follow the route of a journey without help from an aid or appliance or a person. - Score 0	Score 0
b. Needs reminding, encouraging, or reassuring to be able to undertake any journey to avoid it making them feel so anxious or distressed that they cannot function. - Score 4	Score 2
c. Cannot plan the route of a journey - Score 8	Score 2
d. Cannot follow the route of an unfamiliar journey without another person, assistance dog, or orientation aid. - Score 10	Score 2
e. Cannot undertake any journey because it would make them feel so anxious or distressed that they cannot function. - Score 10	Score 4
f. Cannot follow the route of a familiar journey without another person, an assistance dog, or an orientation aid. - Score 12	Score 8

Activity 2. Moving around.

a. Can walk more than 200 metres, either aided or unaided.	Score 0
b. Can walk more than 50 metres but no more than 200 metres, either aided or unaided.	Score 4
c. Can walk unaided more than 20 metres but no more than 50 metres.	Score 8
d. Can walk using an aid or appliance more than 20 metres but no more than 50 metres.	Score 10
e. Can walk more than 1 metre but no more than 20 metres, either aided or unaided.	Score 12
f. Cannot, either aided or unaided, (i) stand; or (ii) move more than 1 metre.	Score 12

2. Online Survey

Health Rights for persons with albinism in the UK

*** 1. Age**

- | | |
|-----------------------------------|--------------------------------|
| <input type="checkbox"/> Under 18 | <input type="checkbox"/> 45-54 |
| <input type="checkbox"/> 18-24 | <input type="checkbox"/> 55-64 |
| <input type="checkbox"/> 25-34 | <input type="checkbox"/> 65+ |
| <input type="checkbox"/> 35-44 | |

2. What is your nationality?

3. What is your ethnicity?

- | | |
|-------------------------------------------------|-------------------------------------------------|
| <input type="checkbox"/> White - British | <input type="checkbox"/> Black or Black British |
| <input type="checkbox"/> Asian or Asian British | <input type="checkbox"/> Prefer not to say |
| <input type="checkbox"/> Mixed | |
| <input type="checkbox"/> Other (please specify) | |

4. What is your gender identity?

- | | |
|--------------------------------------------------------------|--------------------------------------------|
| <input type="checkbox"/> Male | <input type="checkbox"/> Non-binary |
| <input type="checkbox"/> Female | <input type="checkbox"/> Prefer not to say |
| <input type="checkbox"/> Transgender | |
| <input type="checkbox"/> Not specified above, please specify | |

5. What is your sexual orientation?

- | | |
|------------------------------------------------------------|--------------------------------------------|
| <input type="checkbox"/> Asexual | <input type="checkbox"/> Pansexual |
| <input type="checkbox"/> Bisexual | <input type="checkbox"/> Queer |
| <input type="checkbox"/> Gay | <input type="checkbox"/> Prefer not to say |
| <input type="checkbox"/> Heterosexual or straight | <input type="checkbox"/> Lesbian |
| <input type="checkbox"/> None of the above, please specify | |

6. Which of the following best describes your current relationship status?

- Married
- In a registered civil partnership
- Widowed
- Divorced
- Separated
- Cohabiting with a significant other or in a domestic partnership
- Single, never married
- Prefer not to answer

7. Do you identify with any of the following religions? (Please select all that apply.)

- Christianity
- Judaism
- Islam
- Buddhism
- Hinduism
- No religion
- Prefer not to say
- Other (please specify)

*** 8. Do you or a family member have albinism?**

- Me
- My child/children
- Other (please specify)

*** 9. What type of albinism do you/your family member have?**

- | | |
|-------------------------------------------------|---------------------------------------------|
| <input type="checkbox"/> OA | <input type="checkbox"/> OCA4 |
| <input type="checkbox"/> OCA1 | <input type="checkbox"/> HPS |
| <input type="checkbox"/> OCA2 | <input type="checkbox"/> CHS |
| <input type="checkbox"/> OCA3 | <input type="checkbox"/> Griscelli syndrome |
| <input type="checkbox"/> Other (please specify) | <input type="checkbox"/> I don't know |

*** 10. Do you see albinism as a disability? (Please explain your answer)**

*** 11. Which of the following categories best describes your employment status?**

- Employed, working full-time
- Employed, working part-time
- Not employed, looking for work
- Not employed, NOT looking for work Not able to work
- Student
- Retired
- Prefer not to say

12. Do you or the person with albinism in your care have access to reasonable adjustments at work or school?

- Yes
- No
- I don't work/I am not a student
- Other (please specify)

13. Do you/your family member with albinism have an Education and Health Care (EHC) Plan in place?

- Yes
- No
- I don't work/I am not a student
- Other (please specify)

14. What has been your experience in trying to obtain EHC Plan?

- Positive - not too challenging
- Slightly challenging and time-consuming
- Challenging and time-consuming
- Very challenging and time-consuming
- Impossible - highly unlikely to obtain/unable to obtain

15. Does the plan include reasonable adjustments for sensitivity to the sun

- Yes
- No

16. Please specify what type of support or adjustments are included.**17. Does the plan include reasonable adjustments for low vision?**

- Yes
- No

18. Please specify what type of support or adjustments are included.**19. Are you satisfied with the EHC plan? Please elaborate****20. If you are in tertiary education, have you been able to access Disabled Students Allowance?**

- Yes
- No
- Other (please specify)

21. What has been your experience in trying to obtain DSA?

- Positive - not too challenging
- Slightly challenging and time-consuming
- Challenging and time-consuming
- Very challenging and time-consuming
- Impossible - highly unlikely to obtain/unable to obtain
- Other (please specify)

22. What reasonable adjustments has your institution of higher education put in place for you?**23. Have you or a person with albinism in your care ever been referred to a dermatologist/ophthalmologist?**

- Dermatologist only
- Ophthalmologist only Both
- None of the above
- Other (please specify)

24. Did you have to request this referral?

- Yes
- No

25. Have you or a person with albinism in your care ever had skin cancer screening?

- Yes
- No

26. When you found that you, your child, or a person in your care has albinism, did you find that you had access to reliable healthcare information?

- Yes
- No
- Other (please specify)

27. When you found that you, your child, or a person in your care has albinism, did you find that you received more support from:

- NHS
- A For Profit Business
- A Charitable Organisation/Non Profit
- All the above
- Other (please specify)

27. When you found that you, your child, or a person in your care has albinism, did you find that you received more support from:

- The Albinism Fellowship UK and Ireland
- The Nystagmus Network
- Royal National Institute of Blind People (RNIB)
- Royal Society for Blind Children (RSBC)
- Visually Impaired Children Taking Action (VICTA)
- Other (please specify)

29. Have you received information regarding protection of your skin/ your child's skin as a person with albinism

- Yes
- No
- Other (please specify)

30. Which of these disability benefits do you think you are entitled to?

- Disability Living Allowance
- Personal Independence Payments
- Disabled Students Allowance
- Attendance Allowance
- Employment and Support Allowance
- Access to Work Grant
- None of the above
- Other (please specify)

31. Which of these benefits have you had access to previously?

- Disability Living Allowance
- Personal Independence Payments
- Both
- None of the above
- Other (please specify)

32. What challenges have you experienced in obtaining these benefits? (If this does not apply to you, write 'N/A')

33. Have you ever had to travel to another county in the UK to receive better healthcare provisions? If yes, please elaborate

34. Would you be willing to be contacted to discuss the answers you have provided? If so, please provide your contact details below

