Submission of the Independent Expert on the enjoyment of human rights by persons with albinism[[1]](#footnote-1)

Re: Outline for a General Comment on Article 27 of the Convention on the Rights of Persons with Disabilities, on the right of persons with disabilities to work and employment.

**The interconnection of article 27 of the CRPD with the 2030 Agenda for Sustainable Development (SDGs)** - **Introduction of the Outline**

1. Goal 8 of the SDG presents one of the significant challenges faced by persons with disabilities including persons with albinism, owing to discrimination, a general lack of reasonable accommodation in the workplace and a lack of security for persons with albinism in parts of Africa. Due to the need to be protected from dangerous sunrays common in working outdoors in tropical or hot climates, access to indoor work and related vocational training is fundamental for persons with albinism, which also requires raising awareness among employers.
2. Goal 8 and related targets 8.5 and 8.8, also aim at significantly increasing the number of persons with disabilities enjoying decent work in safe and healthy conditions, with equal pay for work of equal value, with progress measured through: (a) average hourly earnings of female and male employees, by occupation, age, and disability; and (b) unemployment rate of persons with albinism. Regarding decent work, target 8.8 relates to the protection of labour rights and a safe and secure working environment. Indicator 8.8.2, on the increase in national compliance in respect of labour rights, could be complemented by targets in [national action plans](#NAP) measuring the proportion of persons with albinism with jobs, whether indoor or with adequate protection against the sun, as well as reasonable accommodation including for both visual impairment and through safeguards for self-protection against attacks.
3. It is essential to collect data on persons with disabilities, particularly constituents such as persons with albinism, whose situation are poorly understood by many. Their contextual characteristics, including their socioeconomic situation regarding housing, health, education and employment are necessary to measure progress under the SDGs.

**Relationship with other provisions of the CRPD (Item #4 of Outline)**

Right to Life (article 10)

1. For persons with albinism, the right to work is directly related to the right to life. In the African, Caribbean and Latin American regions, the Independent Expert has received reports indicating that a lack of reasonable accommodation, significant bullying from teachers and students alike, and fear of attack in the Africa region, often result in early drop out from school. Consequently, persons with albinism often do not generally attain the qualifications to find work, particularly work indoors. Many end up working outdoors as peddlers and street vendors where they are:
   1. Exposed to the risk of contracting skin cancer which remains the highest killer of persons with albinism in all tropical climates.
   2. Exposed to the risk of hate crimes in the form of attacks and mutilation in the Africa region.
   3. Vulnerable to exploitation in the form of trafficking in the Africa region.

Right to an adequate standard of living and social protection (article 28)

1. Owing to prejudice and barriers in accessing employment, most persons with albinism tend to depend on public social security programs. The Independent Expert has noted that social protection and poverty reduction programmes are available for persons with disabilities in many countries. However, knowledge on how to access them is generally lacking among persons with albinism in developing countries. Furthermore, several reports indicate that persons with albinism, who have access to those programs, were often denied such an essential support for failing to meet a medical test for disability. Consequently, persons with albinism are unlikely to benefit from them unless they have relatively severe visual impairment or other disabilities. Many have to wait several years before they are enrolled. Navigating the enrolment process requires funding and rights awareness, in addition to having the confidence and advocacy skills, most of which are often lacking among persons with albinism who are often poor, historically marginalized and disempowered.

1. Furthermore, medical tests for access reduces albinism to a vision impairment and, given the variation in vision impairment from person to person, that approach effectively excludes many people with albinism from the aforementioned social benefits. As a result, persons with albinism have had to resort to the court system to defend their rights putting both a legal and financial burden on the applicant with albinism and their family members. It is strongly recommended that access tests to social security programmes should be revised to conform to the CRPD. Moreover, social security should be granted to persons with albinism, taking into account, vision impairment or skin impairment, or both.
2. The Independent Expert was informed that while waiting to be enrolled in social security programmes, most persons with albinism depend on the support of family members, which can have an extremely negative impact on their self-esteem and aggravate the burden of care on an often already poor family. The Independent Expert was told that in some cases where children received the social benefit, an entire family lived on that amount alone.
3. Moreover, persons with albinism have difficulties accessing loans. Financial loans to start businesses are often inaccessible to persons with albinism owing to lack of sufficient collateral, given that they are often from an economically disadvantaged background.
4. Persons with albinism also miss crucial opportunities to earn capital in situations in which they are disinherited by family members because of their condition.
5. Many social protection programmes also fail to take into account multidimensional poverty, such as lower educational attainment, fewer employment opportunities for persons with albinism in countries with high levels of stigmatization and low levels of knowledge concerning the condition. Consequently, these measures fail to promote the social, economic, and political inclusion of persons with albinism as required by target 10.2 of the Sustainable Development Goals.
6. Effective social protection measures require levelling the playing field in relation to health, education, and work opportunities for persons with albinism, which in turn assists in reducing poverty and providing education and employment opportunities. Additionally, attacks against persons with albinism must be mitigated. In addition to national laws protecting persons with disabilities and minorities, [national action plans](#NAP) are needed to tackle attitudinal barriers to accessing work and providing appropriate legal and policy framework, including requiring workplaces to make reasonable accommodations and affirmative action programmes for persons with disabilities. Social protection measures such as the provision of free transport, vocational and skills training will further assist in increasing opportunities for work.

**Interpretation of article 27 (i): The obligation to provide reasonable accommodation in the workplace and the denial of reasonable accommodation as a form of disability-discrimination, including in recruitment processes (Item #XI of Outline)**

1. Reasonable accommodation should be expanded to include flexible work schedules that maximize the safety and security of persons with albinism, particularly in the Africa region. Persons with albinism in countries with reports of attacks against them, often have to limit their working hours to daylight hours. Employers ought to accommodate such requests with the necessary flexibility and without punitive measures.
2. Parents of children with albinism with records of attacks should be extended reasonable accommodation as many have difficulty finding childcare due to myths surrounding albinism, while others are unable to safely outsource the drop-off and pick up of their child with albinism from school. Refusal to grant reasonable accommodation on these grounds ought to be considered as discrimination “on the basis of disability” pursuant to article 5 (2) of the CRPD.[[2]](#footnote-2)

**Interpretation of article 27 (b) part III: Measures to eliminate discriminatory attitudes and harassment, particularly against women, migrants and refugees with disabilities (Item #V of Outline)**

1. Attitudinal barriers form a formidable obstacle to employment of persons with albinism. Carefully crafted training and awareness raising is needed on an ongoing basis for potential employers in both public and private sector enterprises with incentives.
2. Attitudinal barriers faced by persons with albinism are often intersectional in nature. The compounded issue of a commonly repulsed or racialized appearance combined with visual impairment, which requires reasonable accommodation, tend to influence the ways in which employers and co-workers regard people with albinism. Persons with albinism are often turned away on the grounds of their colour or appearance. They have been reportedly told in various countries including in Africa and in Europe that they would frighten customers if retained in the entry-level roles that are often provided to persons with disabilities. In some cases, both employers and employees express resistance to working with someone with albinism due to prejudices about albinism.
3. Persons with albinism who have their own businesses also face discrimination because potential clients do not wish to buy from someone with albinism due to various myths and presumption about the condition in various parts of the world, particularly in the regions of Africa and South Asia. Moreover, once their low vision is known, persons with albinism face other forms of discrimination similar to persons with disabilities in general.
4. Reports from Latin America indicate that some employers fear the liability that may arise from hiring persons with albinism. Injury in the work place due to low vision and sun exposure apparently threaten additional costs to employers who know little about the condition and are unwilling or unable to invest their resources in learning about it or providing support. This problem is prevalent in rural and socio-economically poor communities and threatens to consign persons with albinism – who are already poor – to a lifetime of poverty.
5. Awareness raising should target employers and employees with incentives. Trainings should consist of examples of a wide variety of specific impairments to bridge the gap between the theory and practice of affirmative action. Emphasis should be placed on impairments with significant attitudinal barriers of conditions that are little known or historically denigrated through cultural norms.
6. In some countries, many women with albinism as well as mothers of children with albinism, are often abandoned by their partners or husbands. Consequently, many are the sole breadwinner and often work in the informal sector, pursuing work in agriculture or street peddling. This exposes women with albinism to skin cancer, threatening their lives and ultimately denying long-term care for their children. In addition, women with albinism in Africa often cannot work night shifts due to the threat or fear of attacks. A similar fear exists in mother of children with albinism. Many of these women alter their working hours to ensure that they work only during daylight, which in turn limits their employment and income-generation opportunities. In addition, employers generally do not have security measures in place to ensure the protection of women with albinism from sexual harassment and exploitation, including ritual rape which may be instigated by harmful myths and misconceptions.
7. In other instances, particularly in private enterprises, both female and male employees with albinism are vulnerable to general and sexual harassment as well as ritual rape by employers due to the erroneous belief that such acts bring wealth and good luck in business.

**Interpretation of article 27 (h): Affirmative action programs and special attention to persons with disabilities who are particularly excluded from the labour market (Item #X of Outline)**

1. Several countries[[3]](#footnote-3) have adopted affirmative action measures in order to specifically provide persons with disabilities with economic empowerment opportunities, but such measures are not fully implemented and often do not include persons with albinism because employers or public servants may not consider persons with albinism as persons with disabilities.

**Best practices**

1. The Independent Expert in her reports on Best Practices in the protection of the right of persons with albinism[[4]](#footnote-4) and in her Albinism Worldwide report[[5]](#footnote-5) compiled several specific measures on the right to employment including the following.
2. In Kenya and Mali, civil society organizations of persons with albinism have been funded by the private sector to develop Apps for Android and iOS systems to demystify albinism. This created employment for App Developers and Administrators. The opportunity in the technology sector and the success of these programmes indicate that Governments should invest in the growth of employment in the technology sector, and training youth with disabilities to work in this field both as employees and as entrepreneurs.
3. Also in Kenya, the *Mr & Ms Albinism* showcase re-invented pageantry using the opportunity to highlight educated persons with albinism and to amass public pledges of employment from various sectors including in the telecommunications, banking and education sectors – nearly all of which were fulfilled – placing persons with albinism in both entry level and intermediate level positions.
4. **National Action Plans** with specific measures on employment of persons with albinism in high public office should be put in place. Accordingly, qualified persons with albinism have been appointed to high-level government and public positions in Kenya, Malawi, South Africa and the United Republic of Tanzania. National Action Plans also have targets that are measurable in the short, medium and long terms. See for instance the Regional Action Plan on Albinism in Africa (2017-2021) at [www.actiononalbinsim.org](http://www.actiononalbinsim.org), which provides a framework for action and for collaboration in the region. This will be replaced by the Plan of Action to End Attacks and Other Human Rights Violations Targeting Persons with Albinism in Africa (2021–2031).
5. In Côte d’Ivoire, the State policy on socio-professional integration has led to the recruitment of 18 persons with albinism to public service.
6. The Government of Kenya’s National Council on Persons with Disabilities has set aside a grant to support the self-employment and entrepreneurship of persons with disabilities.[[6]](#footnote-6)
7. Since 2013, the Government of Kenya has specifically allocated an annual fund of 100 million Kenya shillings (an estimate of $1 million USD) for persons with albinism to nationally implement measures set out in the Regional Action Plan.[[7]](#footnote-7)
8. In Australia and New Zealand, there are public measures consistently implemented to assist persons with disabilities including persons with albinism as a constituency of persons with disabilities.
9. In Japan, collaborative learning is being encouraged. Each school must promote interaction with children with and without disability. In addition, a significant amount of practical and academic research on albinism is being conducted in Japan, as well as the training of teachers on albinism as part of a larger training on visual impairment.
10. In Fiji, Kenya, Malawi and Nigeria, associations of persons with albinism have worked with the authorities in the development of national policies on albinism and have been empowered to provide services to communities, including through the implementation of awareness raising programs.
11. In Argentina, associations of persons with albinism have been involved in the development of the National Bill on Albinism. The Federal government of Nigeria also worked with the Albino Foundation of Nigeria in producing the national education policy and national guidelines on reasonable accommodation measures for persons with albinism.
12. In countries where the frameworks and policies governing the rights of persons with disabilities are robust and well-implemented, persons with albinism are more likely to benefit from existing services and programmes, thus enhancing the enjoyment of their right to work. For example, in Denmark, this includes financial aid to families of children with disabilities below the age of 18 years. In other countries, such support take the form of social and tax benefits for parents of children with disabilities and persons with disabilities.

**ANNEX**

**Mandate**

In 2015, the Mandate of the UN Independent Expert on the enjoyment of human rights by persons with albinism was established for three years via Human Rights Council Resolution 28/6 and renewed for another three years in 2018 via Resolution 37/5. More information on the duties of the mandate-holder are provided at the following link: <https://www.ohchr.org/EN/Issues/Albinism/Pages/Mandate.aspx>

**Albinism and disability**

Albinism is a relatively rare, non-contagious, genetically inherited condition resulting in little to no pigmentation in the skin, hair and eyes. The condition affects people worldwide regardless of ethnicity or gender. Due to a general lack of understanding of the condition and accompanying misinformation, myths, superstitions and wrong beliefs, persons with albinism are vulnerable to human rights violations. These include harmful practices related to accusation of witchcraft and ritual attacks (HPAWR), and discriminatory practices negatively impacting their education, health, and employment opportunities.

Persons with albinism often face discrimination on intersecting grounds, namely on the basis of their colouring which is the result of an impairment of melanin production, as well as on the basis of their vision impairment which occurs in varying degrees in a majority of persons with albinism. The absence of melanin in the skin makes persons with albinism highly vulnerable to skin cancer, leading to early deaths in many cases. Vulnerability to skin cancer in sunny or tropical climates can be as high as 1,000 times more than in person without albinism.

1. Information on the mandate in the annex of this document [↑](#footnote-ref-1)
2. See General Comment No.6 CRPD/C/GC/6 [↑](#footnote-ref-2)
3. <https://undocs.org/A/HRC/43/42>, paragraph 67 [↑](#footnote-ref-3)
4. <https://www.ohchr.org/Documents/Issues/Albinism/A-75-170-Addendum.pdf> [↑](#footnote-ref-4)
5. <https://undocs.org/A/74/190> [↑](#footnote-ref-5)
6. For details see report on country visit to Kenya, para 89 at

   <https://ap.ohchr.org/documents/dpage_e.aspx?si=A/HRC/40/62/Add.3> [↑](#footnote-ref-6)
7. Ibid, para 40. [↑](#footnote-ref-7)