Violations Of Rights Faced By Individuals With Albinism

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PRESENTATION

Albinism Association was established in 2013 by individuals with albinism and their families, as it was seen that the information they shared was greatly beneficial for both parties when they came together. The aims of our association are as follows:

- To raise awareness about albinism in Turkey, to increase the quality of life of individuals with albinism and their families.
- To ensure adults, young people, and families with children with albinism have sufficient knowledge about albinism and to bring together individuals with albinism.
- To support all individuals with albinism living in our country, to carry out monitoring and advocacy studies for the improvement of their education, health, and social rights.
- To raise awareness about albinism and to organize training for individuals with albinism, their families, teachers, people around them, and healthcare teams and for this purpose, to develop cooperation with the Ministry of Family and Social Services, the Ministry of National Education, and the Ministry of Health.

With its large area, Turkey is a country that is difficult to manage from a single center. For this reason, one of our goals is to provide regional representations to solve albinism-related problems locally and to increase coordination and cooperation among health-related organizations. As of now, we have representatives in 13 provinces and TRNC apart from our Istanbul headquarter. As needed, the number of our regional representatives will increase day by day.

Our most important goal is to increase scientific studies in the field of albinism and to support scientists. For this purpose, our association carries out activities to establish centers that will work on the genetic diagnosis of albinism by bringing together scientists working abroad with scientists in Turkey to research on HPS (Hermansky Pudlak Syndrome) and CHS (Chediak Higashi Syndrome), which are life-threatening types of albinism; and to increase the number of centers providing services in the field of low vision rehabilitation.

With this study, which was supported by the “Etkiniz EU Programme”, it was determined that there is no previous study carried out by public institutions on albinism in Turkey, in line with the answers to information requests. It is understood from the findings and participant opinions in this study that it is necessary to carry out all activities by both our association and ministries to obtain devices that are helpful on vision, sunscreen, and large font materials, which are needed for the full reintegration of individuals with albinism, to prepare training programs to inform families and to organize training for professional staff such as educators and healthcare workers by increasing social awareness.

Serkan ÖZORMAN
President of Albinism Association

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1. Introduction

1.1. What is Albinism?

According to the Turkish Language Association (TDK), albinism, translated from the French word "albinos" to Turkish as "akşın", means white in the hair and eyes, and sometimes in the skin (animal or human) since there is no congenital dye. As stated by TDK, albinism can be seen in plants as well as in animals and humans (Ünal, 2020).

Albinism is a genetic mutation that results from the lack of the melanin pigment that gives skin, hair, and eyes their usual color. Albinism is characterized by missing or decreased pigment in people's eyes, skin, or hair. Lund, Maluleke, Gaigher, and Gaigher (2007) noted that people with albinism inherit genes that do not produce melanin, which is essential for the full development of the retina, which leads to visual impairment. Together with the two types of albinism discovered by French scientists in June 2020, a total of 21 different types of albinism have been reported in the literature (Albinism Association, 2019; French Association of Albinisms, 2020). See Annex 1

Although it is not known exactly how albinism occurs, which is reported to be one in 17,000 people in the world, it is a genetic inheritance from parents (Doğramacı, 2011; Karaman and Öztürk, 2008). The only effect of this difference that occurs before birth is not appearance. Important symptoms can also be seen in the physiological structure of the eye (Şendil, 2014). Individuals with albinism are born with vision problems such as astigmatism, strabismus (strabismus), nystagmus (involuntary flickering of the pupil). This situation also leads to vision loss that varies from person to person. Individuals with albinism, who are mostly classified as having low vision, are directed either to inclusive education or to schools for the visually impaired (Ünal and Coşkun, 2021). Individuals with visual acuity between 20/70 and 20/200 in the well-sighted eye despite all interventions are called low vision. It is important to evaluate functional vision while planning education for individuals with low vision. Individuals with low vision need large-size materials, magnifying glasses or assistive technologies (Ocak, Özçelik, İnal, Ocak, Önmez, & Gökyiğit, 2018; Özyürek, 1995, 1998; Şafak, 2012).

The eyes of individuals with albinism are hypersensitive to light (photophobia) and therefore they squint their eyes excessively when they are exposed to sunlight or an intense light source**.** Focusing on one point is very weak due to nystagmus, which is an involuntary right-to-left or up-to-down movement of the eyeball while visual acuity is low. Behaviors, such as bringing objects closer to their eyes or keeping their head tilted, can be seen to make the most of their vision. In addition, they continue their lives independently through assistive technologies (Özkan, 2013).

Individuals with albinism are also vulnerable to some skin diseases due to the lack of melanin pigment, which protects the body against UVA/UVB rays. As stated by Chantorn, Lim, and Shwayder (2012), Horkay, Emri, Varga, Simics and Remenyik (2008), Kahn (1986), Naka, Shwayder, and Santoro (2016), skin diseases that may even lead to skin cancer can be prevented by using high factor sunscreen, sunglasses, protective clothing against ultraviolet rays and by not to be outdoors at certain hours unless necessary.

Many of the difficulties faced by people with albinism are directly or indirectly due to their medical condition and psychological and sociological factors. Sometimes the problems faced by people with albinism may be related to the lack of comprehensive and accessible information about albinism currently available (Lookingbill, Lookingbill, & Leppard, 2005). Being tagged with albinism can cause pain and embarrassment for individuals with albinism, their parents, and people in general (Lund, 1996). According to Miller and Major (2000), tagging and discrimination are defined as sources of depression, guilt, and anger among people with albinism.

Unlike the biological characteristics of people with albinism, environmental and cultural factors and conditions that negatively affect their daily psycho-social well-being can be changed. Medical professionals, “naturalists,” sociocultural policymakers, and social workers have not been successful in transforming prejudice, labeling, and discrimination against people with albinism to protect their basic human rights (Nzelwa, 2016).

Individuals with albinism in different parts of the world have been the subject of research in terms of different situations. When these studies were examined, it was seen that most of them were made in African countries and the subjects were determining the distribution in the country, genetic studies, peer interaction, attitude and acceptance, researching eye diseases, education of families and peers, negative effects of the sun and protection (Ünal and Coşkun, 2021).

Some of these studies point out that the psychosocial effects of albinism are mostly caused by the physiology of people with albinism, resulting in false myths and misunderstandings caused by a lack of knowledge of the etiology of the disease. This raises numerous psychosocial challenges embedded in the diverse socioeconomic, environmental and political structures of society (Nzelwa, 2016). This includes problems in accessing social services such as education and health due to discrimination (Ünal, 2020).

1.2. Purpose of the Research

People with albinism are exposed to be tagging and discrimination in various socio-economic and political structures, which creates barriers to their psychosocial development. This situation is even worse especially in African countries (Kagore and Lund, 1995). However, when a literature review is conducted on studies on the psychosocial problems of albinism, it is seen that the subject repeats mostly in medical and scientific researches in Turkey (Ünal, 2020). Not only there are not enough studies on individuals with albinism in the social sciences literature, but also there is no reporting study covering individuals with albinism in the field of civil society. For this reason, there is a need for monitoring and reporting in the field of civil society regarding the rights violations faced by individuals with albinism in Turkey.

Within the scope of this study, the violations of rights by individuals with albinism in Turkey was investigated within “Article 4 General Obligations”, “Article 8 Awareness Raising”, “Article 9 Accessibility”, “Article 20 Personal Mobility”, “Article 24 Education”, “Article 25 Health”, “Article 26 Habilitation and Rehabilitation” of the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

2. Methodology

2.1. Model of the Research

This study was designed according to the case study, one of the qualitative research methods. A case study is a detailed examination of a single person, an environment, a single type of document, and an event (Kazak, 2001). The most important feature of the case study is the limitation of the object of the study, namely the situation (Merriam, 2013). The subject is handled in-depth and with all its dimensions as it is (Yıldırım & Şimşek, 2016). In this study, the violations of rights of individuals with albinism arising from CRPD are handled as a case in Turkey.

2.2. Participants

Participants were included in the study by contacting those who met the criteria listed below through the Albinism Association (Ünal and Coşkun, 2021). The purpose of the criterion sampling method is to study the situations that meet a set of predetermined criteria (Büyüköztürk, 2008; Yıldırım & Şimşek, 2016). A total of 34 people who meet the criteria were included in the study, such as 15 parents who have children with albinism attending primary or secondary school, 5 individuals with albinism attending high school, 5 individuals with albinism attending university, 5 individuals with albinism who have a profession, and 4 representatives of non-governmental organizations operating in the field of the visually impaired. 14 of the participants live in Istanbul, 5 in Ankara, 5 in Izmir, 4 in Bursa, 3 in Balikesir and the other 3 in Bolu, Denizli and Malatya. 17 of the participants were female and 17 were male. Criteria for the selection of participants are listed below:

1) Being the parent of a child with albinism who attends primary or secondary school,

2) Being an individual with albinism who is studying at high school,

3) Being an individual with albinism who is studying at university,

4) Being an individual with albinism who is working as a professional,

5) To be the representative of a non-governmental organization (NGO) that carries out human rights-based activities in the field of the visually impaired.

2.3. Data Collection Tool

In this study, two different semi-structured interview forms were used to determine the violations of rights faced by a specifically varied individuals with albinism in Turkey, to be more clear, parents with children with albinism, high school and university students with albinism, working individuals with albinism, and representatives of non-governmental organizations. A semi-structured interview questionnaire allows the researchers to go beyond the previously determined questions within the purpose of the research, in addition to ask the questions in a certain order (Berg & Lune, 2015).

2.4. Data Collection and Analysis

The date and time of the meeting with individuals with albinism and representatives of non-governmental organizations were set according to the schedule of the participants due to volunteerism. In the first meeting to schedule the following meetings, the participants were informed about the purpose and importance of the study. In line with demand of the participants, the study was conducted online and preferably with the camera open. Before starting to interview, the participants were informed that all interviews will be recorded. After the verbal consent of the participants was obtained, the questions in the semi-structured interview form were asked to the participant and the data collection process was completed.

In the study, in order to reflect the views of the participants in a remarkable way, the data was analyzed with the descriptive analysis method and direct quotations from the participants were included. Concepts and themes that could not be revealed with a descriptive approach were analyzed and the answer to the question of "why" was sought. It is aimed to reach the whole of the related theme by examining each code with the determined approach and to convey the findings to the reader with an inductive approach (Yıldırım & Şimşek, 2016).

It is taken into account whether this study clearly describes the method and its applications, there is a connection between the results and the data, or the data of the study can be analyzed by others (Miles & Huberman, 1994). In this study, the reliability co-efficient between encoders was calculated and a consensus co-efficient of 89.58% was reached.

2.5. Limitations of the Research

Within the scope of this study, an application was made on 19.04.2021 to the Ministry of Family, Labor and Social Services, the Ministry of National Education, and the Ministry of Health, under the "Right to Information Act" numbered 4982, through the Albinism Association. While the Ministry of Family and Social Services and the Ministry of National Education did not respond to these applications, the Department of Autism, Mental, Special Needs and Rare Diseases affiliated to the Ministry of Health and the General Directorate of Health Information Systems refuse to respond by showing reason the Article 7 of the Law No. 4892, which can be quoted as *"Institution and organizations may give a negative response to the applications made for a kind of information or document that can be created as a result of a separate or private study, research, examination or analysis."* With the separation of the ministries, the Social Security Institution of the Ministry of Labor and Social Security responded to the application on issues falling within its field of work.

Within the scope of the study, 4 associations working in the field of dermatology were tried to get contacted via the given phone numbers and e-mail addresses on their websites or various channels, but could not be reached out.

The inability to obtain data from information applications according to the “Right to Information Act” and lack of information about the opinion of dermatological associations are the limitations of this study.

3. Findings

The findings of the study are presented under two separate headings: findings related to representatives of non-governmental organizations working in the field of visually impaired individuals and findings related to individuals with albinism and their families.

3.1. Findings Related to NGO Representatives Working in the Field of the Visually Impaired

4 NGO representatives, who carry out rights-based activities in the field of the visually impaired, stated the total number of members by indicating that they do not collect separate data about the number of low visions, in response to the question directed to them to indicate the total number of members and the number of members with low vision. Among these NGOs, Altı Nokta Association for the Blind has 10,000 members, the Foundation for the Blind has 350 members, the Association for the Visually Impaired in Education has 245 members, and the Association for Accessible Access has 40 members.

Table 1

Activities of NGOs Involving Low Vision	*f*	*%*
Symposium / Information Workshop	*2*	*50*
No Activities for Low Vision	*2*	*50*
Reporting and Advocacy	*1*	*25*
Vocational Course	*1*	*25*
Sports Tournaments	*1*	*25*
Low Vision Rehabilitation	*1*	*25*

When the answers given by NGO representatives to the question in Table 1 regarding their activities involving low vision individuals are evaluated, 2 out of 4 representatives stated that they do not have any direct activities for people with low vision.

Table 2

Accessibility Regulations for Low Sighted People	*f*	*%*
Large Sized Material	*3*	*75*
Screen Enlargement Software	*3*	*75*
Lighting	*2*	*50*
Contrast in Physical Accessibility	*1*	*25*

As seen in Table 2, NGO representatives stated that they make accessibility arrangements for individuals with low vision in all their activities. Looking at the accessibility arrangements, 3 of the representatives stated that they used larger font sized materials for the participants with low vision in their activities, 3 representatives stated that they used screen magnification software on the website or during the activity, 2 representatives stated that they provided appropriate lighting in line with the participant's opinions, and 1 representative stated that they provided the contrast of the stairs in physical accessibility.

Table 3

Problems Faced by Individuals with Low Vision	*f*	*%*
Inadequacy of Low Vision Rehabilitation	*3*	*75*
The Society's Unfamiliarity with the Concept of Low Vision	*3*	*75*
No Physical Accessibility Arrangements	*2*	*50*
Not Providing Large Font Materials	*2*	*50*
Not Being in a Demanding Position of Low Visions	*2*	*50*
Failure of Low Vision Persons to Reach the Stage of Acceptance and Adaptation	*2*	*50*
The Unfamiliarity of Decision Makers with the Concept of Low Vision	*1*	*25*
Lack of Statistical Data on Low Vision	*1*	*25*
Lack of Habilitation Services	*1*	*25*
Teachers' Discrimination	*1*	*25*
Lack of Working in the Low Vision Field of Associations for the Visually Impaired	*1*	*25*
Lack of Information on the Rights of Families	*1*	*25*

In Table 3, we can see the results regarding the problems faced by individuals with low vision in accessing education, health, and other social rights.

3 of the NGO representatives stated that the rehabilitation of low vision is insufficient and the society is unfamiliar with the concept of low vision, while 2 of them stated that physical accessibility arrangements were not made and large-scale materials were not provided, stated that those with low vision are not in a demanding position and those with low vision have not yet reached the stage of acceptance and adaptation. Opinions of NGO representatives regarding these findings:

T1: "There are no accessibility regulations for low vision in hospitals. When we go to the examination, we cannot read the screens on which the names and rotation numbers are shown."

T2: "Accessibility regulations in public transport vehicles are not sufficient, people with low vision cannot read the numbers of the vehicles while waiting at the stop."

T3: "Decision-makers and society perceive the visually impaired as only those who have no vision and they do not have information about low vision people who make up the majority of visually impaired people."

T4: "There is not enough rehabilitation center for the low vision individuals and current rehabilitation services are only trying to teach how to use white canes, even though they are not needed by the people with low vision, contrary to popular belief... There is a need for numerical and statistical data to plan the services for people with low vision, however there is no data on how many people there are with low vision in our country."

Table 4

Solution Suggestions for the Problems of Individuals with Low Vision	*f*	*%*
Rehabilitation for Low Vision Should Be Improved and Extended	*3*	*75*
Physical Accessibility Arrangements Should Be Made	*2*	*50*
Habilitation Services Should Be Extended	*2*	*50*
Low Vision Platform	*2*	*50*
Workshop for Low Vision	*2*	*50*
Inclusive Education and Instructional Adaptations	*1*	*25*
Advocacy by NGOs	*1*	*25*
Awareness of Professional Staff	*1*	*25*
Low Vision Should Ask for Accessibility Regulations	*1*	*25*

The suggestions of NGO representatives regarding the solution of the problems faced by those with low vision are given in Table 4. 3 of the NGO representatives stated that low vision rehabilitation should both be made more qualified and expanded. While 2 of the representatives stated that physical accessibility should be made to include individuals with low vision and that habilitation services should be made widespread with a multidisciplinary approach. In addition, they emphasized that NGOs can also organize workshops by establishing a platform with low vision. The views of some NGO representatives are given below:

T1: "Although it is necessary to carry out studies for the low vision people to make the best use of their current vision, some rehabilitation centers teach people how to use a white cane even though they don't need it."

T4: "Unfortunately, there is no system to guide the family by giving correct information after the child is born. With a multidisciplinary approach, the family should be informed about the child's condition, and the child should be followed up by doctors and the rehabilitation process should begin in the early period.

Table 5

Opinions on Low Vision Assistive Technologies	*f*	*%*
Not Enough Information	*4*	*100*
Should Be Covered by Social Security	*3*	*75*
Legislation Should Be Created	*2*	*50*
R&D Studies for Assistive Technologies Should Be Done	*1*	*25*

When the opinions of the NGO representatives regarding the assistive technologies needed by individuals with low vision are examined, it is seen that 4 representatives stated that there is not enough information about assistive technologies, 3 of them emphasized that assistive technologies should be included in the scope of social security, and 2 representatives explained that there is a need for legislation on assistive technologies. A representative, on the other hand, stated that R&D studies should be carried out to ensure domestic production in assistive technologies due to their high cost. Statements of some NGO representatives are given below:

T2: "I think assistive technologies should be included in the scope of social security. In other words, these devices are not medical devices after all, and separate legislation should be created rather than being included in the health practice communiqué."

T3: "There is no detailed information about assistive technologies and most people do not know what assistive technologies are. They once called from a university and said what software to buy. I said that I would research and get back to you, but when I searched, I could not find enough information."

Table 6

Suggestions for Awareness Studies	*f*	*%*
Information Studies Should Be Done	*3*	*75*
Visibility Should Be Increased in the Achievements of Individuals With Low Vision	*1*	*25*
Employment in Qualified Labour Should Be Provided	*1*	*25*
Publications on Low Sighted People Should Be Developed	*1*	*25*
Low Vision Studies in NGOs Should Be Increased	*1*	*25*
Visibility Studies on social media Should Be Done	*1*	*25*

When Table 6 is examined, it is seen that NGO representatives present various examples in their awareness studies for individuals with low vision. Three of the representatives expressed a common opinion that information studies on low vision should be carried out. The statement of an NGO representative is given below:

T3: "Society cannot perceive low vision. Therefore, they experience different problems in social life, including education. Informative activities about low vision should be done, including professional staff.

3.2. Findings Related to Individuals with Albinism and Their Families

In this heading, findings obtained from interviews with 30 people were given. 15 of them have children with albinism attending primary or secondary school. All other 15 people are with albinism, while 5 of them attending to high school, 5 of them attending university, and 5 of them working in any profession.

Table 7

Sources of Information on Albinism and Problems Encountered	*f*	*%*
There are not Enough / Accurate / Reliable Information Sources	*21*	*70*
Internet	*17*	*57*
Albinism Association	*16*	*53*
Doctor	*13*	*43*
People with Albinism	*6*	*20*
Family	*6*	*20*
Social Media Groups	*3*	*10*
Primary / Secondary Education Textbook	*3*	*10*
Psychological Counselor and Advisory Teacher	*1*	*3*

When Table 7, which includes the problems faced by individuals with albinism or families with children with albinism, is examined, 57% of the participants stated that they obtained information from websites, 53% from the Albinism Association, while 70% stated that the information sources were not sufficient and that especially emphasizes that internet sites are not accurate and reliable sources. Opinions of some participants:

K18: "I first learned what albinism was from the internet and the situation in Tanzania really scared me. There was not enough information about Turkey. The doctors did not give proper information, they just said that he has albinism. I felt relieved when I met the Albinism Association. I met many families there."

K27: "After giving birth, three doctors entered the room. Two said he had albinism, but one said he wasn't sure and that we would stay in the hospital for a while for some tests.

Table 8

Problems Faced by People with Albinism as a Low Vision	*f*	*%*
Inability to See the Blackboard at School	*18*	*60*
Absence of Large Sized Materials	*17*	*57*
Inaccessibility of Public Transport Vehicles	*10*	*33*
Teachers' Discriminatory Discourse / Attitude	*7*	*23*
Peer Bullying	*4*	*13*
Inaccessibility of Public Areas	*3*	*10*
Inaccessibility of Mobile Applications / Business Software	*3*	*10*
Restriction of Social Life / Stress	*2*	*7*
The Society's Unfamiliarity with the Concept of Low Vision	*2*	*7*
Overprotective Family Attitude	*1*	*3*

When the problems faced by individuals with albinism as low vision are examined in Table 8, it is seen that indirect discrimination is made in educational environments through the discriminatory attitudes and discourses of teachers and school administrators, as well as not making instructional adaptations according to individual characteristics and not providing large print materials. In addition, the participants state that the inaccessibility of public vehicles, public mobile applications, and business software also causes problems in full and effective participation in social life. Here are some opinions of some participants:

K4: “I can't see the blackboard at school. Sometimes I pull the school desk forward. If there were a camera that sees the board, or even if I had a screen or a tablet at my desk, I could read what is written on the board more easily. Larger fonts need to be used in books.”

K5: “My teachers do not believe that I am low-sighted. They say I am deceiving them. Some of my teachers do not even give my exam paper in large print. I can't read what's written on the board, so I take a picture of it and then write it in my notebook."

K14: “I cannot read the information screens of the buses. There was a mobile application that had been developed but it is still not enough. People out there can't understand that you are low-sighted. When I ask them, they can scold me, "Don't you see what you wrote?"

Table 9

The Problems Faced by Individuals with Albinism Encounter Regarding Their Physical Appearance	*f*	*%*
To Be Mocked	*18*	*60*
Disturbing Look	*17*	*57*
Peer Bullying	*11*	*37*
Perceived as an Advantage	*9*	*30*
Exclusion	*7*	*23*
Discriminatory Attitudes and Discourses	*4*	*13*

In Table 9, 60% of individuals with albinism stated that they were mocked because of their appearance, 57% stated that they were exposed to disturbing looks, 11% stated that they were bullied by peers, and 30% stated that the effect of albinism on appearance is perceived as an advantage by people who do not know.

Regarding to this, the effect of the popularity among women without albinism related to the woman with albinism who have platinum-colored hair was emphasized. Opinions of some participants are listed below:

K7: "My hair is light blonde. Some of my friends like it when they see it. They say that they wished to have the same hair colour. Sometimes it can be seen as an advantage."

K9: "There were times when I was mocked at school because of my appearance. It's not happening at the university right now, but while walking in the street, someone always looks back. It's annoying, but I don't care anymore. If the other children in the school were informed or had social awareness, at least I wouldn't feel bad."

K11: "I was excluded because of my appearance. They don't know what albinism is. In fact, there are people with many differences like us, not just albinism. I think there should be a lesson where differences are taught in school. This is how society becomes conscious and can respect it when it sees someone who looks or behaves differently."

Table 10

Assistive Technologies Needed by Individuals with Albinism, Encountered Problems and Suggestions	*f*	*%*
Should be Covered by Social Security	*24*	*80*
Telescopic Glasses	*16*	*53*
Smart Board - Camera - Tablet	*13*	*43*
Types of Magnifiers	*11*	*37*
Screen Magnifying Software / Accessible Mobile Applications	*9*	*30*
Not Enough Information	*9*	*30*
There Should Be R&D and Domestic Production	*3*	*10*
Tax Reduction Applicable	*2*	*7*

Table 10 presents the assistive technologies needed by individuals with albinism and suggestions regarding the problems encountered in accessing these technologies. 80% of individuals with albinism stated that they have limited financial access to assistive technologies such as telescopic glasses, and that their inclusion in the social security system will both facilitate access and facilitate their participation in daily life. 43% of the participants emphasized that a tablet which provides a simultaneous display with a smartboard or a closed-circuit television system with a camera, especially in educational environments, will increase their efficiency in terms of education and will eliminate the difficulty in seeing the board. Statements of some participants:

K15: "I am a veterinarian, and I can perform surgery as a low-sighted person. Thanks to these telescopic glasses. However, it is a very costly product and anyone who needs it should be able to afford it. For this reason, the state must provide support for such products. In addition, different software can be developed, which will make our daily life easier."

K22: "We saw and researched the telescopic glasses in a Facebook group, and the price was very high. Friends who used it said that they were satisfied. I think the state should provide such assistive technologies. Also, it has a high cost, because it is imported. I think it can be produced in our country as well."

T4: "The most important technology that will facilitate the daily lives of people with low vision is telescopic glasses. The support of the state in this regard is very important. We import this product from abroad. However, there are production sites in Turkey that produce binoculars and optical cutting devices. Telescopic glasses are produced with the same logic, but unfortunately, no one knows each other."

Table 11

Opinions on the Mechanisms that Individuals with Albinism and Their Families Can Apply When They Need	*f*	*%*
Habilitation Services Are Not Sufficient	*28*	*93*
Albinism Association	*17*	*57*
Hospital	*8*	*27*
Guidance and Research Centers	*4*	*13*
Psychologist	*3*	*10*
Special Education and Rehabilitation Centers	*2nd*	*7*

When Table 11 is examined which includes the opinions of the participants about the mechanisms that individuals with albinism and their families can apply to if they encounter any problems, it can be seen that 93% of the participants stated that the rehabilitation services that require a multidisciplinary approach, providing guidance to the family with the start of the diagnosis process and planning medical follow-up and early education programs for the child with albinism, are insufficient., while 57% of them stated that they can be applied to the Albinism Association, which they can reach the correct information and that guides them. Opinions of some participants:

K7: "There is no system that guides us about what albinism is, where and which specialists we should go to, and what our rights are. If families are not informed, both the family and the child can be worn out at this stage. I think more detailed information can be given at the hospital. Referrals can be made to the rehabilitation center or the Guidance Research Centers."

K29: "The doctor in the hospital said that the child may not see at all. They even said the light might be bothering for the child. We sat at home with close curtains and in the dark for a while. Later on, when we went to other doctors, we learned that he would see less. When we reached the Albinism Association, they supported us a lot. We got more accurate information there. I recommend that other families also apply to the Albinism Association."

Table 12

Awareness Work Recommendations Related to Albinism	*f*	*%*
Social Awareness Studies	*13*	*43*
Awareness of Teachers	*13*	*43*
Informing Peers	*9*	*30*
Informing Through Social Media	*7*	*23*
Integrative Activities	*7*	*23*

Table 12 shows the suggestions of the participants regarding awareness work on albinism. While 43% of the participants emphasized that the correct approaches should be adopted by raising awareness of teachers, who are role models in schools and have direct effect on peer attitudes, together with social awareness activities. 23% of them emphasized that integrative activities that allow peers with and without albinism to come together and interact might be helpful to prevent negative behaviours such as peer bullying. Opinions of some participants are given below:

K10: "Teachers and peers can be informed in schools. Peers with or without albinism can be brought together to share experiences. Promotional activities can be done on social media."

K11: "Most doctors do not know about albinism. There are health agencies. By collaborating with them, awareness of albinism can be raised at least in some specialties, by drawing their attention to albinism through some promotions, brochures, seminars."

Table 13

Advice for Families with Children with Albinism	*f*	*%*
It Should Not Be Approached with an Overprotective Attitude	*27*	*90*
Supporting / Guiding	*19*	*63*
Acceptance and Adaptation Phase	*17*	*57*
Participation in Family Education	*6*	*20*

When Table 13 is examined, which includes the recommendations of individuals with albinism and families with children with albinism, to other families with children with albinism, 90% of the participants stated that the overprotective approach affected the child's self-confidence and self-perception negatively due to the child's low vision and different appearance, while 63% of the parents stated that families must be supportive and in a guiding position, 57% of them stated that families must have an accepting attitude, and 20% of them stated that other families must know about albinism and its rights by attending family training. Opinions of some participants:

K5: "My family does not allow me to go out alone because I am low-sighted. Although I said several times that I could go to the market alone, they did not send me alone. They're very protective. I think other parents shouldn't be so protective so that their children can learn to act independently. It can affect the child's self-esteem negatively."

K19: "I think they should accept the situation. As parents, it is natural for them to follow their children everywhere they go, but they should give them some space and opportunity to do some things on their owns. It is important for the children to adapt to life more easily. It is necessary to remind them to put on their *glasses or to apply sunscreen while going out and leave the rest to them. We just need to follow them from afar."*

Table 14

Advice to NGOs	*f*	*%*
Experience Should Be Shared	*11th*	*37*
Promotional Activities Should Be Increased	*7*	*23*
Family Education Should Be Given	*6*	*20*
Low Vision Studies Should Be Increased	*6*	*20*
Awareness Studies Should Be Increased	*4*	*13*
Rights Advocacy Should Be Done	*4*	*13*
Coordination Between NGOs	*2nd*	*7*

In Table 14, the suggestions of the participants to NGOs regarding the problems faced by individuals with albinism are given. 37% of the participants suggested that NGO's must organize experience sharing activities that allows peers with albinism and their families to come together, 20% of them suggested that family training must be organized by NGOs so that families can learn about albinism and their rights, and low vision studies must be increased by NGO's who operates in the field of low vision, 13% of them suggested that NGO's must increase their rights advocacy activities with awareness activities, and finally, 7% of them suggested that people who work for the same or similar purposes should be coordinated whit structures such as networks and platforms. Opinions of some participants:

K8: "Some families do not know how to approach. Albinism Association can organize training for families. It was done before the pandemic and it can still be continued. They can host a webinar. Activities that bring together children with albinism and their peers can be organized."

K11: "Actually, the basis of many problems encountered is that people do not know the differences. They can focus on social awareness activities.

K14: "Associations can advocate for rights by working together through networks. We can make our voice heard more publicly."

4. Conclusion

This study aims to reveal the current situation regarding the rights violations faced by individuals with albinism in Turkey. Accordingly, on 19.04.2021, an application was made to the Ministry of Family, Labor and Social Services, the Ministry of National Education, and the Ministry of Health, through the Albinism Association, to obtain information with the questions in Annex-2 within the scope of the “Right to Information Act” numbered 4982.

Within the scope of this study, an application was made on 19.04.2021 to the Ministry of Family, Labor and Social Services, the Ministry of National Education, and the Ministry of Health, under the “Right to Information Act” numbered 4982, through the Albinism Association. While the Ministry of Family and Social Services and the Ministry of National Education did not respond to these applications, the Department of Autism, Mental, Special Needs and Rare Diseases affiliated to the Ministry of Health and the General Directorate of Health Information Systems refused to respond by quoting the Article 7 of the Law as a reason. 4892, which is *"Institution and organizations may give a negative response to the applications made for a kind of information or document that can be created as a result of a separate or private study, research, examination or analysis.”* With the separation of the ministries, the Social Security Institution of the Ministry of Labor and Social Security responded to the application on issues falling within its field of work.

Although the Social Security Institution, affiliated with the Ministry of Labor and Social Security, responded to the application for information, they stated that there is no study to cover the payment of sunscreen needed by individuals with albinism, while telescopic glasses are covered for 610.50 TL for single lens and 1.221 TL for double, and that assistive technologies such as magnifiers, electronic magnifiers, and screen magnification software will not be covered.

In addition to asking for statistical data on albinism, information about the services currently being carried out or planned by the ministries was also requested in the applications. Paragraph 2 of Article 31 of CRPD titled “Statistics and Data Collection” is as follows: *“The information collected pursuant to this Article should* *be ensured, where appropriate, to be disseminated and used to evaluate the practices of States parties under the present Convention and to highlight the difficulties faced by persons with disabilities in exercising their rights.”*

When evaluated from this perspective, it was seen that the Ministry of Health and the Ministry of Labor and Social Security did not collect/segregate data on the subject, and other ministries did not comply with both the “Right to Information Act No. 4982 and the relevant article of CRPD.

The second step of the study consists of interviews with 4 different NGO representatives who carry out rights-based activities in the field of the visually impaired. First of all, NGO representatives were asked to state the total number of members and the number of members with low vision. Despite their work in the field of the visually impaired, NGOs did not reveal data on members with low vision, similar to the perception that the society's perception of visual disability consists only of blind individuals.

When the activities of NGOs covering low vision and the accessibility arrangements made in these activities are examined, it is seen that 4 NGOs include the accessibility regulations needed by those with low vision in their activities. It is understood that UNHCR attaches importance to accessibility in line with the demands of people with low vision by Article 9 titled “Accessibility”.

When the views of NGO representatives regarding the problems faced by people with low vision in accessing education, health, and other social rights are evaluated, the reasons for the problems faced by people with low vision in their participation in social life are the fact that the society is unfamiliar with low vision, the lack of accessibility arrangements, reasonable arrangements in educational environments, and habilitation and rehabilitation services do not respond to the needs of those with low vision, and those with low vision not accepting their situation and not making demands for their needs.

From this perspective, it is understood that Article 8-1/a “Awareness-raising” of CRPD, which is *“To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities”,* has not yet been fully implemented; that the regulations in Article 9 “Accessibility” are not be implemented for people with low vision; that Article 24-2/c, which is "*Reasonable accommodation of the individual's requirements is provided*" is not fulfilled and because of this the discrimination occurs; and that the provisions regarding the prevalence, quality and early start of the services included in the title of Article 26 "Habilitation and Rehabilitation" are not yet in a quality that meets the needs.

Considering the solution proposals of NGO representatives regarding the problems of low vision, it is concluded that low vision habilitation and rehabilitation should be made more qualified and widespread with the training of professionals on this subject. It is thought that it would be appropriate to organize a workshop with the participation of both public institutions and NGOs so that the problems of those with low vision can be brought to the agenda and solutions can be implemented. In this process, including those with low vision in the decision-making processes will provide a more effective and sustainable solution. In addition, the coordinated work of NGOs by establishing networks/platforms on low vision problems will make significant contributions to the field of low vision in civil society.

NGO representatives stated that individuals with low vision have problems in accessing assistive technologies they need and will facilitate their daily lives, since these assistive technologies are imported and it is hard to reach due to socio-economic imbalances. The lack of sufficient information resources on assistive technologies also prevents both the increase and spread of the use of these technologies. Article 4-1/h of CRPD is "*It undertakes to provide access information regarding mobility facilitating vehicles including new technologies, assistive technologies and other auxiliary and supporting services and facilities accompanying them"*.

Furthermore, NGO representatives stated that the Social Security Institution only paid for products with medical supplies, while assistive technologies have a significant impact on enabling individuals with low vision to participate more actively in social life and to facilitate their daily lives, therefore, assistive technologies must be included in the scope of social security; that it would be appropriate to meet the assistive technologies with a new legislative arrangement rather than the Health Implementation Communiqué (SUT); and it is important to carry out R&D activities to ensure domestic production to reduce the high cost due to importing. In this regard, Article 20/b "Personal Mobility" of CRPD is *"To facilitate access of persons with disabilities to quality tools and equipment, assistive technologies, people providing assistance and tools at an affordable cost."*

The last step of the study consists of interviews with individuals with albinism and families with children with albinism. When the source of the information obtained by individuals with albinism and their families on albinism is examined, it is seen that the Albinism Association plays an important role in accessing accurate and reliable information. The internet resources from which the most information is obtained contain misleading information about albinism, and they can mislead people. Although many participants state that information sources are not sufficient, the misleading information obtained from the hospital regarding albinism, which is a condition that can be diagnosed at birth, concretely shows that professional staff should be informed as well.

When the findings related to the problems faced by individuals with albinism and their families, individuals with albinism as low vision are examined, it is seen that the inability to see the blackboard at school, the absence of large-scale materials, the inaccessibility of public transport, and public spaces, the discriminatory attitudes and discourses of teachers, not accessible electronic systems used for correspondence in public institutions and mobile applications came into prominence. The fact that large print materials are not sent to schools despite the demand of people in need is contrary to Article 24 "Education" of CRPD provision, but it is seen that indirect discrimination is practiced by not making reasonable arrangements.

When the discriminatory attitudes and discourses of teachers are evaluated regarding Article 5-2 "Non-Discrimination and Equality" of CRPD, which is *"States parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds",* it is understood that it is urgent to implement the provisions specified in the Article 8 "Awareness Raising".

When the problems faced by individuals with albinism because of their appearance are examined, it is seen that they are exposed to discriminatory attitudes and discourses such as disturbing looks, tagging by mocking, and exclusion in social life. This shows that the society has no respect for individuals with differences or do not accept and support differences, and the provisions of Article 5 “Non-Discrimination and Equality” of CRPD is not implemented in practice, with discriminatory attitudes and discourses. It is clear that it is a necessity to focus on awareness-raising activities in this regard. Another prominent point about the appearance of individuals with albinism; especially, some women with albinism have platinum hair color and this is perceived as an advantage by women who do not have albinism in their social circles.

The main reason for the difference in appearance is the insufficient production of melanin pigment in the body. This indicates that people with albinism are also unprotected against UVA and UVB rays. Although not among the findings of the study, dermatological sunscreens are a basic need for skin protection rather than a luxury for people with albinism. For this reason, sunscreens, which is mentioned in Article 25/b titled “Health” as “*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*” must be included in the scope of social security.

When the opinions of individuals with albinism and their families regarding the assistive technologies needed are evaluated, it is seen that many individuals with albinism cannot access these products due to the fact that assistive technologies such as telescopic glasses are costly products, as well as using a wide variety of technologies. Assistive technologies are a basic need for individuals in terms of eliminating the obstacles they encounter in daily life due to their disability, and enabling individuals to participate in all areas of social life independently and actively. Therefore, as stated by the participants, assistive technologies should be included in the scope of social security.

In this regard, Article 20/b titled “Personal Mobility” of CRPD is as “*Facilitating access by persons with disabilities to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost”* and Article 20/d of CRPD is as

"*Encouraging entities that produce mobility aids, devices and assistive technologies to take into account all aspects of mobility for persons with disabilities*." It is also among the findings of the research that there is no source informing potential users about assistive technologies. Article 4/h of CRPD is as "*To provide accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities.*"

Among the working people with albinism those who are employed in public similarly stated that, the software and mobile applications they have to use as a requirement of their job, do not include accessibility regulations for those with low vision. Moreover, it was emphasized that the stairs do not contain contrast arrangements. As Article 27/i of CRPD titled "Work and Employment" states that "*ensure that reasonable accommodation is provided to persons with disabilities in the workplace*". As can be seen, it is obvious that public and private sector employers must fulfill their obligations regarding the situation.

Another issue among the findings of this study is the absence of a system that directs families to services during the medical diagnosis of a child with albinism. Participants stated that referral to "other polyclinics, where the baby with albinism should be followed up after the medical diagnosis process is completed in the hospital"; to "relevant institutions to start education in the early period"; to "sources to obtain information about their rights"; to both medical and low vision rehabilitation; and to "habilitation services, which requires psychosocial support and are maintained with a multidisciplinary approach", are not sufficient and widespread.

Regarding this finding, Article 26-1/a of CRPD titled "Habilitation and Rehabilitation" is as habilitation and rehabilitation services and programs should "*begin at the earliest possible stage and are based on the multidisciplinary assessment of individual needs and strengths"*, and Article 26-1/b of CRPD is as "*support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.*"

As seen in the study, it is clear that NGOs, individuals with albinism, and families with children with albinism experience similar accessibility problems in many cases. It is seen that there are deficiencies in the implementation of national legislation and CRPD, to which Turkey is currently a party, and the society's perception of disability is not at the expected level. Considering that societies will progress by accepting and supporting differences, various responsibilities fall on the public, society and NGOs working in the field of disability to ensure this transformation.

5. Suggestions

As a result of the findings obtained from the study, recommendations for the relevant ministries, NGOs, and families with children with albinism are included in this title.

5.1. Suggestions to Relevant Ministries

1. Statistical data, of which has great importance in the planning of the services to be provided, should be collected with a separable system.
2. Public awareness of disability awareness, which forms of the basis for many problems, should be increased and respect for differences should be mainstreamed.
3. Assistive technologies should be included in the scope of social security, and active and effective participation of individuals with albinism in all areas of the production society, especially in education, should be ensured.
4. As assistive technologies do not qualify as medical supplies in many respects, separate legislation should be created on this subject rather than being included in the Health Practice Communiqué. In this process, the reimbursement costs of visual aid technologies, which are currently included in the Health Implementation Communiqué, should be increased and access to those in need should be provided.

5. Due to the high cost of acquiring assistive technologies from abroad, R&D activities should be carried out to ensure domestic production and increase product diversity.
6. Sunscreens, which are a basic need for the health of individuals with albinism, should be included in the scope of social security and reimbursed.
7. Rehabilitation for low vision should become more qualified with specialist training and should be expanded.
8. Studies should be carried out to adopt a multidisciplinary approach to expand habilitation services to include family education.
9. Professional staff, especially teachers and doctors, should be made aware of differences such as albinism.
10. Low vision should also be taken into account in physical accessibility arrangements.
11. Public websites, software, and mobile applications should be made accessible to those with low vision.
12. Large print materials should be provided in educational environments upon the request of individuals, and the use of digital tools should be expanded for students with low vision in order to increase efficiency in education.
13. For people with disabilities, including individuals with albinism, reasonable arrangements should be made in the workplace, and quality in the workforce should be increased.
14. In order to solve the problems encountered in an effective and sustainable way, people who have experienced the situation or the formations they have come together with should be included in the decision-making processes.

5.2. Suggestions to NGOs

1. A low vision platform or network should be established regarding the problems faced by individuals with albinism due to low vision.
2. A workshop should be held with the relevant parties to identify the problems of people with low vision and to create a strategic plan.

3. Relevant NGOs should increase their advocacy efforts regarding the problems experienced by people with low vision.
4. Activities should be carried out to improve the advocacy capacity of individuals with low vision and make them demanding.
5. Integrative activities should be organized where individuals with low vision can share their experiences.
6. Awareness activities should be carried out to raise awareness to ensure that society respects differences such as albinism and has a supportive attitude instead of seeing them as a mockery. In this regard, materials such as public service ads, documentaries, social media content, posters, and brochures should be increased.
7. An informative guide including user experiences on assistive technologies for people with low vision should be created.

5.3. Suggestions to families

1. Many individuals with albinism recommend that families should be in the position of guiding the child with albinism with an attitude of acceptance, rather than an overprotective attitude, so that the child's self-confidence and self-perception are not adversely affected.
2. It would be appropriate for families with children with albinism to reach the Albinism Association, so that they can reach the right information about albinism and can be guided correctly.
3. They should support NGOs that advocate for rights, especially the Albinism Association, in solving the problems faced by individuals with albinism.

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7. Appendix

Annex 1: Types of Albinism

Chromosome	Place in Chromosome	Related Gene	Type of Albinism	Albinism Type
11th	14.3	TYR	Oculocutaneous Albinism	OCA1A
11th	14.3	TYR		OCA1B
15	12 and 13.1	OCA2		OCA2
9	23	TYRP1		OCA3
5	13.2	SLC45A2		OCA4
UNKNOWN YET				OCA5
15	21.1	SLC24A5		OCA6
10	22.2 and 22.3	C10orf11		OCA7
UNKNOWN YET		DCT		OCA8
X	22.2	GPR143	Ocular Albinism	OA1
16	23.3	SLC38A8	FHONDA Syndrome	FHONDA
1	42.3	LYST	Chedlak-Higashi Syndrome	CHS1
10	24.2	HPS1	Hermansky Pudlak Syndrome	HPS1
5	14.1	AP3B1		HPS2
3	24	HPS3		HPS3
22	12.1	HPS4		HPS4
11th	15.1	HPS5		HPS5
10	24.32	HPS6		HPS6
6	22.3	HPS7		HPS7
19	13.32	HPS8		HPS8
15	21.1	HPS9		HPS9
NOT YET KNOWN		AP3D1		HPS10
NOT YET KNOWN		BLOC1S5		HPS11

Annex 2: Questions in the Application for Obtaining Information

Questions Addressed to the Ministry of Family, Labor, and Social Services:

1) Is data on individuals diagnosed with albinism separated in the national disability database of your ministry? If yes, what is the number of individuals with albinism, type of albinism, gender, age, distribution by province?
2) According to the data held by your ministry on the employment of people with disabilities, how many individuals with albinism work in public institutions and organizations? What is the age, gender, staff and title distribution of individuals with working albinism?
3) Are there activities for people with albinism among the activities of your ministry for people with disabilities? If yes, what is the subject and number of these activities?
4) Are there accessibility arrangements, such as large font and contrast, for individuals with albinism due to low vision in the written and visual works carried out within your ministry? If so, what are these regulations?
5) Are accessibility studies, such as large font and contrast, carried out due to the low vision of individuals with albinism in the websites and mobile applications offered by your ministry? If so, what are the websites and mobile application examples?
6) Does the Social Security Institution, which is related to your ministry, work on reimbursement of high factor sunscreen that individuals diagnosed with albinism need due to skin sensitivity? If so, what are these studies and what is the estimated date for it to be taken affect?
7) Does the Social Security Institution, which is affiliated with your ministry, work on the reimbursement of assistive devices and technologies such as magnifiers, electronic magnifiers, screen magnification programs, telescopic glasses, sunglasses, etc., which are needed in daily life by individuals with a diagnosis of albinism due to their low vision? If so, what are these studies, and what is the estimated date for it to be taken affect?

8) Is there a psychological family support program for the parents of new-born diagnosed with albinism? If it is implemented, how many parents have benefited from it since the beginning of the program?

Questions Addressed to the Ministry of National Education:

1) Is data on students diagnosed with albinism separated in the databases of your ministry? If yes, what is the number, education level, gender, age, distribution of students with albinism by provinces?
2) What is the distribution of the students with albinism in the databases of your ministry according to special education schools, special education classes, and mainstreaming classes?
3) How many of the students with albinism who are being educated in schools affiliated with your ministry benefit from supportive education services? How many students with albinism have benefited from this service for years since the start of support education services?
4) Are the textbooks distributed free of charge by your ministry sent in large print to students and teachers with albinism due to their low vision? If so, how many large print books were sent to students and teachers with albinism in the 2020-2021 academic year?
5) Are assistive devices and technologies such as magnifying glasses, electronic magnifiers, screen magnification programs, telescopic glasses, etc., which are needed in daily life by students and teachers with albinism due to their low vision provided and distributed by your Ministry? If the distribution was made, how many students and teachers with albinism were benefited from this service, and which of the assistive devices were distributed?
6) Are there accessibility studies such as large font and contrast, due to the low vision of individuals with albinism, on the websites and mobile applications offered by your ministry? If so, what are these websites and mobile applications?

7) Are there accessibility arrangements such as large font and contrast for individuals with albinism due to low vision in the written and visual works carried out within your ministry? If so, what are these regulations?
8) Are there modules on the education of people with low vision and educational adaptations in the in-service training carried out by the institutions affiliated with your Ministry? If yes, how many teachers have received this training?
9) Is low vision rehabilitation for individuals with albinism implemented in rehabilitation centers under the control of your Ministry? If so, how many albinism students were applied by how many trainers in how many rehabilitation centers?

Questions Addressed to the Ministry of Health:

1) Is data on individuals diagnosed with albinism separated in the databases of your ministry? If yes, what is the number of individuals with albinism, type of albinism, gender, age, distribution by province?
2) Does your ministry have separate data on people with low vision? If any, what is the ratio of individuals with albinism to individuals with low vision?
3) What is the total number of individuals diagnosed with skin cancer or different skin diseases due to albinism?
4) Are there accessibility arrangements such as large font and contrast for individuals with albinism due to low vision in the written and visual works carried out within your ministry? If so, what are these regulations?
5) Is there a psychological family support program for the parents of newborns diagnosed with albinism? If it is implemented, how many parents have benefited from it since the beginning of the program?
6) Are there accessibility studies such as large font and contrast on the websites and mobile applications offered by your ministry for individuals with albinism due to the low vision? If so, what are these websites and mobile applications?

Annex-3: Semi-Structured Interview Form

Questions for NGO Representatives Working in the Field of the Visually Impaired:

1) What is the total number of members of your association? How many of your members are low vision?
2) What are the activities of your association involving people with low vision?
3) Do you make accessibility arrangements for individuals with low vision in the activities carried out by your association? If so, what are they?
4) What problems do you think individuals with low vision encounter when education, health, and other social rights are considered?
5) What are your suggestions for solutions to the problems of people with low vision?
6) What can be done to provide assistive technologies for people with low vision?
7) In your opinion, what are the awareness activities that can be done about low vision?

Questions for Individuals with Albinism and Families with Children with Albinism:

1) From which sources did you get information about albinism? Are you facing any problems with this?
2) What are the problems faced by individuals with albinism as low vision? What are your suggestions on behalf of solving these problems?
3) What are the problems faced by individuals with albinism regarding their appearance? What are your suggestions on behalf of solving these problems?
4) What are the support technologies that individuals with albinism need? What are your suggestions for supplying them?

5) Where can individuals with albinism or their families turn to if they encounter any problems?
6) What are the awareness activities that can be done on albinism?
7) What are your suggestions to families with children with albinism regarding the problems experienced by individuals with albinism?
8) What are your suggestions to non-governmental organizations working on albinism?

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