PEOPLE WITH ALBINISM IN NEW ZEALAND

Hazem Ahmed Abd Elkader

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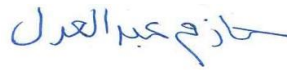Faculty of Culture and Society

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Attestation of Authorship

I Hazem Ahmed Abd Elkader hereby declare that this submission is my work and that to the best of my knowledge and belief it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the reward of any other degree or diploma of a university or other institution of higher learning.

Signature

حازم عبدالعزل

21/08/2015

Hazem Ahmed Abd Elkader

Date

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Abstract

Albinism is an inherited genetic condition that reduces the amount of melanin pigment formed in the skin, hair, and/or eyes. As a result of this condition, people with albinism have vulnerability to the sun and bright light, and all of them are visually impaired and more likely to develop skin cancer. This is a multi-strategy research (research that combines quantitative and qualitative research) aims to determine the needs of people with albinism and assess how well these are being met against the objectives of the New Zealand Disability Strategy of 2001 and the requirements of the United Nations Convention on the Rights of Persons with Disabilities of 2006. It was found that New Zealanders with albinism face socio-economic challenges because their condition is often misunderstood.

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List of Abbreviations

The strategy	The New Zealand Disability Strategy
The Convention	The United Nations Convention on the Rights of Persons with Disabilities
The Trust	New Zealand Albinism Trust
OCA	Oculocutaneous albinism
OC	Ocular albinism
The Blind Foundation	The Royal New Zealand Foundation of the Blind
BLENNZ	The Blind and Low Vision Education Network NZ
RTV	Resource Teachers Vision
MSD	Ministry of Social Development
ACC	The Accident Compensation Corporation
DHB	District Health Board
DSS	Disability Support Services
ODI	Office for Disability Issues
WHO	The World Health Organisation
UPIAS	The Union of the Physically Impaired Against Segregation
ICIDH	The international classification of impairments, disabilities, and handicaps
ICF	The International Classification of Functioning, Disability and Health
NGOs	Non-governmental organisations

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Introduction

The ethical status of a nation can - to some extent - be judged by the way it treats its poorest, weakest, and most dependent citizens (Beatson, 2004). According to the New Zealand Disability Survey of 2013, 24 percent of the New Zealanders were identified as disabled, a total of 1.1 million people (Statistics New Zealand, 2014). This high rate means the well-being of disabled people is an important policy issue that needs to be dealt with[1]. New Zealand governments have introduced a variety of interventions to promote the well-being of its disabled members. The New Zealand Disability Strategy (The Strategy) of 2001 is the most prominent intervention which was introduced by the Labour-led government (Judy McGregor, Sylvia Bell, & Margaret Wilson, 2015). The aim of the Strategy is to eliminate the barriers disabled people face wherever they exist, and to guide government departments and agencies while they deal with disabled New Zealanders (Ministry of Health, 2001). The Strategy provided the basis for New Zealand's prominent role in the development of the United Nations Convention on the Rights of Persons with Disabilities (The Convention) (Office for Disability Issues, 2011). The Convention gives voice, visibility and legitimacy to issues facing disabled people in all over the world (Independent Monitoring Mechanism of the Disability Convention, 2012). In September 2008, New Zealand ratified the Convention and agreed to implement it (Office for Disability Issues, 2011).

The nature of impairment has a significant effect on an individual's experience of disability. Also factors such as gender, age, ethnicity and culture can have profound and sometimes compounding effect on the experience of disability (Office for Disability Iissues, 2005). However, impairment can be intellectual, psychiatric, physical, neurological or sensory, and be temporary, intermittent or ongoing.   Depending on the impairment type, disability includes a lot of sub-groups. All of these sup-groups should benefit from the implementations of both the Strategy and the Convention.

This thesis aims to investigate whether the implementation of the Strategy and the Convention provide people with albinism - as a disabled group - with the support they need. In order do so the research will try to determine the needs of people with albinism and assess how well these needs are been met against the objectives of the Strategy and the requirements of the Convention.

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[1] As used In the New Zealand Disability Strategy, the term "disabled people" was used throughout the thesis to refer to those who experience disability as a result of their impairments.

Albinism is a rare, non-contagious, non-treatable, genetically inherited condition which is present at birth. In almost all types of albinism, both parents must carry the gene for it to be passed on to their children, even if they do not have albinism themselves. The condition is found in both genders, and occurs in all racial and ethnic groups throughout the world (United Nations High Commissioner for Human Rights, 2013). Albinism is characterised by hypopigmentation (lack of the pigment melanin) which creates the comparative lightness of skin, eyes, and hair (Stevenson, 1966). As a result, people with albinism have vulnerability to the sun and bright light, and all of them are visually impaired and more likely to develop skin cancer (United Nations High Commissioner for Human Rights, 2013).

A review of the existent literature and consultation with New Zealand Albinism Trust (the Trust) revealed that this research will be the first project to target people with albinism and their needs in New Zealand.

In 2013 the United Nations High Commissioner for Human Rights published the first-ever world report on people with albinism (United Nations High Commissioner for Human Rights, 2013). That report aimed first to review the current situation of people with albinism around the world (United Nations High Commissioner for Human Rights, 2013). Secondly it made recommendations for action at national and international levels in order to promote the well-being, dignity, social inclusion, and human rights of people with albinism around the world (United Nations High Commissioner for Human Rights, 2013). This preliminary report called for further study to be done to evaluate and address the needs of people with albinism, and to ensure that existing disability policies enable such people to have adequate access to health care, social services, employment and education (United Nations High Commissioner for Human Rights, 2013).

This thesis includes five chapters. Chapter one discusses the term "disability" and provides an historical overview of disability sector in New Zealand. The chapter also includes information about "Albinism" as a medical condition and problems associated with it, including information about albinism in New Zealand. Then chapter two explores social theories about disability and includes a review of relevant literature. After that chapter three explains the research methodology. Chapter four presents the research findings. At the end of the thesis, chapter five discusses the study's findings and summarises the knowledge gained through the process of doing this research.

Chapter One: Disability and Albinism

This chapter aims to provide a background on disability and albinism in New Zealand. First it explores definitions of disability and explains albinism as a condition. After that, it outlines the Strategy and the Convention. Then a historical overview on disability in New Zeeland takes place, followed by a clarification of sources of data among disability and albinism. Also the chapter provides information about disability, vision impairment, and albinism rates and costs. At the end, it explores what service are available in New Zealand for disabled people generally, and people with albinism particularly before the conclusion.

1.1 Disability

What is meant by "disability" and who is considered "disabled"? Generally disability relates to a person who is unable to perform the 'normal' physical and mental functions expected of a "healthy" human being.

According to the United Nations Declaration on the Rights of Disabled Persons, proclaimed by the Geneva Assembly's Resolution 3447 of 9 December 1975, the term "disabled person" means "any person unable to ensure by himself or herself, wholly or partly, the necessities of a 'normal' individual and/or social life, as a result of a deficiency, either congenital or not, in his or her physical or mental capabilities".

In 1976, the Union of the Physical Impaired Against Segregation (UPIAS) in Britain distinguished between impairment and disability from a socio-political perspective (Barnes & Mercer, 2003). Table 1 contains the UPIAS definitions:

Table 1: The UPIAS definitions of impairment and disability	
Impairment	**Disability**
Lacking part or all of a limb, or having a defective limb, organ or mechanism of the body	The disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities
Adopted form Box 1.1, 'Disability' (Barnes and Mercer , 2003: 11)	

On the other hand, the World Health Organisation (WHO) produced its international classification of impairments, disabilities, and handicaps (ICIDH) in 1980 (Barnes & Mercer, 2003). This classification highlighted the social consequences associated with

impairment and/or disability (Barnes & Mercer, 2003). Table 2 contains the WHO definitions:

Table 2: The WHO definitions of impairment, disability, and handicap		
Impairment	Disability	Handicap
Any loss or abnormality of psychological, physiological or anatomical structure or function	Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being	A disadvantage for a given individual, resulting from an impairment or disability, that limits or prevent the fulfilment of a role (depending on age, sex, social and cultural factors) for that individual
Adopted form Box 1.2, 'Disability' (Barnes and Mercer , 2003: 13)		

In 2001 WHO introduced International Classification of Functioning, Disability and Health (ICF). The ICF emphasises environmental factors in creating disability, which is the main difference between this new classification and the previous ICIDH. According to the ICF disability arises from the interaction of health conditions with contextual factors – environmental and personal factors.

According to Article 1 of The United Nations Convention on the Rights of Persons with Disability, disabled people include 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.

From a social model perspective, the New Zealand Disability strategy defines disability as the process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have.

The previous review shows how the definition of disability has evolved from the 1970s till today. Initially, disability was a personal issue. People were considered disabled only because of their impairments or physiological defects. But nowadays disability defines as a social phenomenon. People are now considered disabled due to a combination of personal and social factors.

1.2 Albinism

Albinism was one of the first genetic diseases to be discovered in the human population (Oetting, 1999). The word albinism has developed from the Latin word 'albus' meaning white (Wan-Kee-Cheung, 2002). Albinism is a rare, non-contagious, non-treatable, genetically inherited condition which is present at birth. In almost all types of albinism,

both parents must carry the gene for it to be passed on to their children, even if they do not have albinism themselves. The condition is found in both genders, and occurs in all racial and ethnic groups throughout the world (United Nations High Commissioner for Human Rights, 2013). Albinism is characterised by hypopigmentation (lack of the pigment melanin) which creates the comparative lightness of skin, eyes, and hair (Stevenson, 1966). As a result, people with albinism have vulnerability to the sun and bright light, and all of them are visually impaired and more likely to develop skin cancer (United Nations High Commissioner for Human Rights, 2013). The abnormal development of the retina and abnormal patterns of nerve connections between the eye and the brain cause serious vision problems for people with albinism. Some of the complications of the condition include nystagmus (regular horizontal back and forth movement of the eyes), strabismus (muscle imbalance of the eyes, or an eye that deviates out), photophobia (sensitivity to bright light and glare), and refractive error (farsighted or near-sighted and usually have astigmatism) (National Organization for Albinism and Hypopigmentation, 2013).

These vision problems are not correctable with eyeglasses and many sufferers have sufficiently low vision to be considered legally blind (National Organization for Albinism and Hypopigmentation, 2013). Various optical aids have recently been developed to help them to do some usual activities within work and study (National Organization for Albinism and Hypopigmentation, 2013).

Depending on degrees of melanin deficiency and the affected organs, there are different types of albinism. Oculocutaneous albinism (OCA) is the most common type which affects the skin, the hair and the eyes (United Nations High Commissioner for Human Rights, 2013). Recent research has used analysis of DNA to reveal types and subtypes of OCA (National Organization for Albinism and Hypopigmentation, 2013). Another less common form is ocular albinism (OA), which only affects the eyes (United Nations High Commissioner for Human Rights, 2013). Also a more rare form of albinism is known as hermansky-pudlak syndrome (HPS) and is accompanied by bleeding disorders and large bowel (colitis) and lung diseases (United Nations High Commissioner for Human Rights, 2013). However, people with albinism have the same life expectancy, similar variation in intelligence, and the same general health problems as the general population (Stevenson, 1966). The prevalence of albinism varies across the world. Reports suggest that in North America and Europe an estimated one in every 20,000 persons has some form of albinism (United Nations High Commissioner for Human Rights, 2013). In other parts of the world

such as African countries, the occurrence can be as high as one in 1,000 (United Nations High Commissioner for Human Rights, 2013). Socially, people with Albinism are at risk of isolation because the condition is often misunderstood. Social stigmatisation can also occur, especially within communities of colour, where the race or paternity of a person with albinism may be questioned (National Organization for Albinism and Hypopigmentation, 2013).

1.3 Disability in New Zealand

1.3.1 Historical overview

Attitudes toward disability in New Zealand have changed radically over the past 150 years (Office for Disability Iissues, 2014). As any other social policy changes, these shifts reflect changing attitudes overseas. However, three main shifts can be traced over the last two centuries, (1) the Second half of the 19th century, (2) from 1920s to 1970s, and (3) from 1970s to 21st century.

(1) The Second half of the 19th century;

During this period, Government policies aimed at minimising financial aids as well as containing the number of disabled people living in New Zealand (Office for Disability Iissues, 2014). Legislations such as the Imbecile Passengers' Act of 1882 and the Immigration Restriction Act of 1899 were enacted to prevent disabled people from overseas immigrating to New Zealand (Office for Disability Iissues, 2014). At this time, New Zealanders with disabilities usually received small and temporary financial support (Office for Disability Iissues, 2014). For the most part, their needs were expected to be met through their families and/or charitable organisations (Office for Disability Iissues, 2014). Moreover, special institutions were designed and established to house those who were dangerously insane (Office for Disability Iissues, 2014). Later persons with intellectual disabilities were placed into these institutions with each sex kept apart so they could not have children (Office for Disability Iissues, 2014). Also schools for deaf children began to be opened. The paradigm of the government at this point of time was actually reflecting the exclusion of disabled people.

(2) From the 1920s to the 1970s;

As a result of the establishment of support organisations - at the end of the 19th century - such as the Royal NZ Foundation of the Blind in 1890, the awareness of disabled people

and the number of services available increased (Office for Disability Iissues, 2014). At the same time there was a growing knowledge of medical and technical advances which increased the emphasis on medical treatment (Office for Disability Iissues, 2014). Also solders who became ill or disabled because of the world wars (Office for Disability Iissues, 2014). All of that led to an increase in the need for better services. In 1924, legislation was passed allowing a pension for blind people, Followed by the introduction of the invalids benefit for those permanently unable to work and the sickness benefit for those temporarily experiencing ill health in late 1930s (Office for Disability Iissues, 2014). The paradigm of governments at this point of time was reflecting the adoption of the medical model of disability where disability was seen as an individual problem caused by physiological defects and disorders.

(3) From the 1970s to the 21st century;

As a result of the disability movement in Great Britain in 1970s followed by international year of disability in 1981, alongside the increasing criticism of the medical model, a very important paradigm shift occurred, putting into account the social and environmental barriers disabled people face. A number of prominent initiatives reflected the adoption of social model of disability. One of the most important interventions was the Accident Compensation Act of 1972 which gave people who were impaired by accident the right to receive assistance on an individual entitlement basis (Beatson, 2004). Also The Industrial Relations Act of 1973 established the under-rate workers' permit. This enabled a person with impairment to work in the open labour market and receive a wage that matched their productivity (Office for Disability Iissues, 2014). In 1975 the Disabled Persons Community Welfare Act set up a comprehensive system of disability support services for those whose impairments were not caused by accident (Beatson, 2004). In 1983, the Disabled Persons Assembly was formed to represent disabled people in front of local and central government (Beatson, 2004). Also the introduction of the Education Act of 1989 enabled disabled children to be admitted into a 'normal' school environment (Office for Disability Iissues, 2014). In 1993 the Human Rights Act made it illegal to discriminate on the grounds of disability (Beatson, 2004). All of these initiatives helped pave the way for introducing the New Zealand Disability Strategy in 2001 and led to develop and ratify the United Nation Convention on the Rights of Persons with Disabilities in September 2008.

1.3.2 New Zealand Disability Strategy

The Strategy is a long-term plan which was introduced in 2010 by the Labour-led government. The aim of the strategy is to eliminate the barriers disabled people face wherever they exist, and to guide government departments and agencies while they deal with disabled New Zealanders (Ministry of Health, 2001). The Strategy was developed in consultation with disabled people and the extensive disability sector. During the consolation process, 700 submissions were received and 68 meetings were conducted around New Zealand (Ministry of Health, 2001). The Strategy includes fifteen Objectives, and 113 detailed Actions[2]. These Objectives are:

Objective 1: encourage and educate for a non-disabling society;
Objective 2: ensure rights for disabled people;
Objective 3: provide the best education for disabled people;
Objective 4: provide opportunities in employment and economic development for disabled people;
Objective 5: foster leadership by disabled people;
Objective 6: foster an aware and responsive public service;
Objective 7: create long-term support systems centred on the individual;
Objective 8: support quality living in the community for disabled people;
Objective 9: support lifestyle choices, recreation and culture for disabled people;
Objective 10: collect and use relevant information about disabled people and disability issues;
Objective 11: promote participation of disabled Maori;
Objective 12: promote participation of disabled Pacific peoples;
Objective 13: enable disabled children and youth to lead full and active lives;
Objective 14: promote participation of disabled women in order to improve their quality of life;
Objective 15: value families, whanau and people providing ongoing support (Ministry of Health, 2001).

1.3.3 Convention on the Rights of Persons with Disabilities

The Convention is an international agreement which was developed by the United Nations to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all disabled people, and to promote respect for their inherent dignity (United Nations, 2014). The Convention includes fifty articles which cover all areas of life, all ages, and life stages[3]. The Convention also has an optional protocol that allows the United Nations' Committee on the Rights of Persons with

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[2] Full copy of the strategy is available in the appendices (see appendix 13).
[3] Full copy of the Convention is available in the appendices (see appendix 14).

Disabilities to receive and consider reports from or on behalf of individuals or groups of individuals about the implementation process.

Based on its experiences with developing and implementing the Strategy, and the involvement of its non-governmental organizations (NGOs), New Zealand made a significant contribution in the development of the Convention (Judy McGregor et al., 2015). The government signed the UN Convention in 2007, and ratified it in 2008. New Zealand has not yet ratified its Optional Protocol, but has begun the process of examining consistency with Treaty of Waitangi obligations.

1.4 Data on Disability and Albinism in New Zealand

Since 1996, and after every census, Statistics New Zealand conducts a national disability survey. Currently, it is the most important source of data on disabled people and their needs in New Zealand. It includes data about special equipment, help received, health services, housing, safety, employment, education, transport, social contact, leisure, and care. The survey data help government to evaluate and develop policies and legislation on issues that affect disabled people in New Zealand. Moreover, disabled people's organisations, community groups, and academics use this data for research, planning, and advocacy. Also the data is used to report and monitor the New Zealand Disability Strategy and the UN Convention.

In the same field, the Disability Stocktake was prepared by Statistics New Zealand in 2007 as part of the Programme of Official Social Statistics (POSS). The main purpose of the project to assist the Office for Disability Issues (ODI) to monitor the implementation of the Disability Strategy through determining the sources and nature of administrative data or record of services that held electronically by government organisations about disabled people. The Disability Stocktake found a total of 19 datasets from six source agencies have been identified as containing information about disabled people. None of them include albinism as a type of impairment or disability.

Focusing on albinism, there are six specialised low vision clinics that might hold information about New Zealanders with albinism: These clinics are:

1. Greenlane Low Vision Clinic in Auckland;
2. Burwood Low Vision Clinic in Canterbury;
3. University of Auckland Optometry Clinic;
4. Wanganui Low Vision Trust;
5. Wellington Low Vision Clinic;
6. Dunedin Low Vision (LITMUS, 2015).

In addition, some non-for-profit organisations provide support and services to people with low vision and their families in New Zealand can possibly hold some information about people with albinism, such as in table 3.

Table 3: NGOs that provide support and services to people with albinism and their families in New Zealand

Organisation	Activities
The Royal New Zealand Foundation of the Blind (Blind Foundation)	The Blind Foundation is the country's main provider of sight loss habilitation and rehabilitation services for approximately 11,700 New Zealanders who are blind or have low vision.
Blind and Low Vision Network New Zealand (BLENNZ)	BLENNZ is funded through the Ministry of Education and is a school made up of a national network of educational services for children and young people (aged 0-21 years) who are blind, deafblind or have low vision in New Zealand.
Enable NZ and Accessable	Enable NZ and Accessable are contracted by the Ministry of Health to administer its equipment and modification services.
Visual Impairment Charitable Trust Aotearoa (VICTA)	VICTA is a charity established in 2013 to address the unmet needs of people with low vision especially those who don't qualify for Blind Foundation assistance.
Workbridge	Workbridge provides professional employment services for people with low vision. Also it is contracted to administer some support funds on behalf of the Ministry of Social Development.
Association of Blind Citizens (Blind Citizens NZ)	Blind Citizens NZ is founded on 1945 to advocate on blindness-related issues and assist government and health agencies, local authorities, utilities and other organisations in improving services to blind people. The organisation is also part of the NZ Convention Coalition. This coalition has established to report on the progress of implementing UN Convention on the Rights of Persons with Disabilities (CRPD)
Albinism Trust	Albinism Trust is a voluntary not for profit organisation established in 2007 to emphasising positives and achievements by people with Albinism.

1.5 Rate and cost of vision impairment in New Zealand

According to the New Zealand Disability Survey of 2013, approximately 4 percent of New Zealanders (168,000) are estimated to be vision impaired. Over 55 percent of them

(93,000) have vision impairment - such as albinism - that cannot be corrected by glasses, contact lenses, medicine, or surgery (LITMUS, 2015).

As any other type of impairment, vision loss or blindness add cost on both individual and societal levels. It was estimated that the total financial, time, and opportunity cost of blindness in New Zealand was approximately $816 million in 2006 (Gravitas Research and Strategy Ltd & Market Economics Ltd, 2006). $526 million of this was identified as individual and family cost of blindness (Gravitas Research and Strategy Ltd & Market Economics Ltd, 2006). The individual cost by itself was estimated to be between $353 and $719 per week per person (Disability Resource Centre, 2010). These costs were mostly relate to carrying out domestic tasks, transportation, shopping, recreation, and use of specialised equipment.

1.6 Disability and Albinism services in New Zealand

There are three broad sources of assistance for those who have physical, sensory, or mental impairments in New Zealand: family, civil society, and government (Beatson, 2004). Traditionally, family is the primary source of assistance in both Maori Aotearoa and colonial New Zealand. With the establishment of the welfare state in the 1930s, the family's responsibility for its member(s) with disabilitie(s) was taken over by local and central governments (Beatson, 2004). As a result of the expansion of free market policies in 1990s, NGOs have become a key partner that is expected to provide or deliver services instead of the government.

Government supports disabled people, people with albinism, and their families in different ways and through several agencies.

(1) **Ministry of Health** and its Disability Support Services (DSS) and District Health Boards (DHBs) provides and funds a range of services for people with different impairments. DSS services are generally available for people under 65. Services include environmental support services (equipment and modifications), home and community support services, respite and carer support, and information and advisory services. Many of these services are accessed through a Needs Assessment and Service Co-ordination

(NASC)[4] (Ministry of Health, 2015a). People over 65 years old have their support services available through DHBs (Ministry of Social Development, 2015).

In case of vision loss including albinism, DSS provides free vision checks for children under 5 years (Ministry of Health, 2015b). For children aged 5 to 15 years they may be able to get the Spectacles Subsidy, glasses and vision tests every year (Ministry of Health, 2015b). For adults over 15, DSS can fund equipment such as mobility canes, screen-reading software, magnifiers, sonar canes, and closed-circuit television (video magnifier) (Ministry of Health, 2015b).

As people with albinism have ongoing need for sun protection, a number of sunscreens are subsidised by PHARMAC[5] (New Zealand Albinism Trust, 2015).

(2) The Accident Compensation Corporation (ACC) provides and funds a range of support services for people who become disabled because of injury and/or accident (Accident Compensation Corporation, 2015). Albinism is not covered by ACC because it exits at birth. However, people with albinism still have access to ACC services as anyone else in case of injury or accident.

(3) Ministry of Education provides a variety of services to support students with impairments and their families to learn and develop in equal basis with other students. Services and advice can be provided for a child from soon after they are born or as soon as a difficulty is picked up, and it can be continued until they start school (Ministry of Education, 2015). These services include early intervention service, assistive technology, in-class support, School property modifications, school transport, and many more (Ministry of Education, 2015).

Students with vision impairments are in regular early childhood education centres and local schools (Ministry of Education, 2015). Support services and equipment are available to meet their needs (Ministry of Education, 2015). The Blind and Low Vision Education Network of New Zealand (BLENNZ)[6] has Resource Teachers Vision (RTV) observe and

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[4] NASCs are organisations contracted to the DSS, which work with disabled people to help identify their needs and to outline what disability support services are available. They allocate Ministry-funded support services and assist with accessing other supports.

[5] The government's drug-buying agency.

[6] The Blind and Low Vision Education Network NZ (BLENNZ) is a national school that provides services for children and young people who are blind, deafblind or have low vision in New Zealand. Services through BLENNZ are available for parents, teachers, teacher aides, education support workers.

assess a child's needs in a one-on-one, classroom and home context (Ministry of Education, 2015).

(4)The Ministry of Social Development (MSD) provides a variety of services to help disabled people to have meaningful employment and to make sure that they have income that support their independence and their choices (Ministry of Social Development, 2015). Moreover, MSD manages applications for social housing has responsibilities for making sure that disabled people live in a secure, accessible, affordable, quality home in the community. Services through MSD can be divided into:

a- Vocational services that help disabled people to find part-time or full-time work, get training, or become self-employed (Ministry of Social Development, 2015).

b- Financial assistance that provide living costs for disabled people. The Supported Living Payment is available for those who are not able to work because of disability (Ministry of Social Development, 2015). Also the Jobseeker Support is available for those who are working fewer hours because of disability. Also assistance are available to in certain circumstances such as funding for workplace changes to make it easier for disabled people to stay in or get work.

As well as providing services, MSD provides specific allowances to help disabled people meet certain costs such as the Disability Allowance, the Child Disability Allowance, and the Special Disability Allowance.

(5) The New Zealand Transport Agency provides facilities for passengers with disabilities. A Total Mobility Scheme has been designed to provide disabled people with access to appropriate transport, including subsidised door-to-door transport services

Many people with albinism in New Zealand meet the criteria[7] to be members of the Royal New Zealand Foundation of the Blind (the Blind Foundation) (Blind Foundation, 2015). the Blind Foundation is a non-profit organisation and the main provider of vision-related services to the blind and those with low vision (Blind Foundation, 2015). According to the Blind Foundation 2014 annual report, the Blind Foundation has 11,774 registered members, 188 were identified as people with albinism. The organisation is governed by

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[7] For an individual adult become a member, she/he has to have a visual acuity not exceeding 6/24 in the better eye with corrective lenses, or serious limitations in the field of vision, generally not greater than 20 degrees in the widest diameter in the better eye. On the other hand, children who are currently registered with BLENNZ whatever their degree of vision is, can become a member of RNZFB.

its members and offers a wide range of services that suit all age groups and all ethnicities. These services include:

a- Services that support members with everyday life and activities such as adaptive commination and technology, recreation, counselling, financial supports, employment, and equipment services.

b- Services that help members to move around such as guide dog services

c- Services that enhance accessing information such as library, accessible format production, and telephone information services.

In 2007, New Zealand Albinism Trust was established as a charity that aims to foster and promote personal and public understanding of human albinism (New Zealand Albinism Trust, 2015). Moreover, the Trust tries to support, encourage, educate and inform parents, siblings, family, and friends about human albinism (New Zealand Albinism Trust, 2015). During the last eight years, the Trust has organised six regional seminars. These seminars were held in Palmerston North, Dunedin, Wellington, Auckland, Hamilton, and Christchurch, and were hosted by the Blind Foundation. Also, an informal online audio forum takes place on the last Monday of each month to provide peer support and discuss issues related to albinism. For the same reason, a non-public Facebook Group is administrated by the Trust.

In collaboration with the Blind Foundation, the Trust published in 2011 a booklet named "Eyes Rights" to introduce living with albinism in New Zealand. Based on this booklet, the two organisations produced and audio CD called "Living with Albinism" in 2014.

Recently, the Trust has submitted a report to the Health Select Committee[8] in order to provide an accessible, comprehensive low vision rehabilitation services for the growing number of New Zealanders disabled with vision loss or conditions - such as albinism. Especially, for those who do not qualify for membership or benefit from the Blind Foundation because their visual acuity is not considered low enough (New Zealand Parliament, 2014).

1.7 Conclusion

Indeed, by going through all definitions of disability, and considering their vision limitation and skin disorder, people with albinism can be very much classified as a

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[8] Health Select Committee is a parliamentary committee that considers matters relating to health.

disabled sup-group. Therefore, they may directly benefit from implementing both the New Zealand Disability strategy and the United Nation Convention on the Rights of Persons with Disabilities. There is no source of data that includes information about people with albinism in New Zealand except the database of the Blind Foundation. According to their visual acuity, people with albinism are eligible to become members of the Blind Foundation that give them access to a variety of services from the government and the Blind Foundation.

Chapter Two: Literature review

How do social scientists understand and explain disability? How did they investigate albinism as a kind of disability? This chapter tries to answer those two questions providing an academic background of what is known about people with albinism from a social science perspective. First it begins with a theoretical review to explore approaches to disablism as a social problem from different perspectives, paradigms, and on different level of analyses. After that a review of social studies about people with albinism will be presented before I conclude.

2.1 Disability: Theoretical Explanations

Historically, three main patterns regarding disability can be traced in western culture (Kristiansen, Vehmas, & Shakespeare, 2009). The first is the moral model of disability, familiar from the Bible and Medieval Christianity whereby impairment was seen as a sin and a creation of God. This belief-based model was contradicted by medical practitioners (Barnes, Mercer, & Shakespeare, 1999). By the eighteenth century, and as a result of industrialisation, there was a significant rise in the scientific medical profession (Barnes et al., 1999). The success in medicalising illness and impairment led to radical shifts in the treatment of disabled people (Barnes et al., 1999). The expression medical model of disability became common at this time and disability became a personal tragedy that results from individual's physiological defects and disorders (Kristiansen et al., 2009). In the 1970s and 1980s disabled people and their organisations voiced increasing criticism of the medical model of disability (Barnes et al., 1999). These critiques led to the rise of the expression the social model of disability. This model sees disability as a social problem that need to be dealt with social intervention by focusing on the social and environmental barriers (Barnes & Mercer, 2003).

Focusing on the recent social scientific engagement within social sciences and humanities, scholars attempt to theorise disability by looking at different factors such as body, subjectivity, culture, and society (Goodley, Hughes, & Davis, 2012). However, Goodley (2011) emphasised that understanding the sociological debates around structure-agency, subjectivity-objectivity, and consensus-conflict can help clarify the theoretical developments of disability (Goodley, 2011). Therefore a helpful place to start a theoretical review is with sociology.

Using a sociological level of analysis, Goodley (2011) distinguished between different theoretical views of disability within sociology (Goodley, 2011). These ranged from a view of disability as the product of an individual's mental functioning and behaviour (functionalism) to the suggestion of engagement with the structures and institutions of society that disable (radical structuralism). Along the way, researchers have illuminated the primacy of experiences of disabled people to an understanding of their social world (interpretivism), while others have contested ideologies of disablism (radical humanism) (Goodley, 2011). These paradigm distinctions among sociologists generated some sociological approaches of disability.

One of the most significant views of disability was Talcott Parsons' sick role theory. Before Parsons has published his work 'The Social System' in 1951, the medical model of disability was not deemed an appropriate subject for sociological enquiry (Barnes et al., 1999). Parsons argued that all members of society must play their appropriate social role in order to have a properly functioning society (Barnes et al., 1999). Under this analysis, disabled people are not able to play their social role because of their impairments, and this leads to the establishment of the 'Sick Role' that grants temporary and conditional legitimacy to the sick person (Barnes & Mercer, 2003). Moreover, Parsons continued that individual must obtain medical confirmation of their condition and follow the recommended treatment, while agreeing the importance of leaving the sick role behind as soon as possible (Barnes & Mercer, 2003). The consensual underpinnings of this theory focus on the ways in which disabled people are managed in order to maintain the social order, even if this involves their being therapeutically treated (controlled) by professionals allied to medicine, such as social workers (Goodley, 2011), this was the central critique by C. Wright Mills of Parsons' theory of sick role, disagreeing with how Parsons started and ended with the individual and the maintenance of social order (Goodley, 2011).

Another prominent view was Goffman's theory of stigma. This theory explores how interaction within societies can categorise people (Barnes et al., 1999) . It focuses on responses to stigma, or a spoiled identity, including abominations of the body, the various physical deformities, blemishes of individual character, and the tribal stigma of race, nation, and religion (Barnes et al., 1999). Goffman was interested in 'undesired differentness', and how individuals manage their 'spoiled identity' in everyday social interaction. The theory goes on to explain how 'normal' people provide the basis for the stigma while interacting with disabled (Barnes et al., 1999), and in response how disabled

people have strategies to avoid embarrassment and social sanctions such as hiding their impairment or reducing its significance (Barnes & Mercer, 2003). Otherwise, the stigmatised people are more likely to withdraw from social interaction. Goffman's theory of stigma has been criticised because of his consensual position which leads to more interest in the status quo than wider structural inequalities, because the theory belongs to social psychology rather than sociology (Goodley, 2011). However Goodley (2011) emphasised that these critics fail to recognise the radical application of Goffman's work and his work on stigma which allowed many scholars to reposition disability as a sociological problem (Goodley, 2011).

By shifting to a conflict perspective, studies of social construction of disability took their cue from C. Wright Mills (Barnes & Mercer, 2003). He argued that sociologists should examine two key concepts: 'private troubles' of individuals that occur in our relationships with others (often when our own values are threatened) and 'public issues' of organisations and institutions (that often arise as a crisis of institutional arrangements) (Goodley, 2011). Under this analysis, social problems must be located within wider material and political contexts, including the power relation and conflicts between dominant and subordinate classes (Barnes & Mercer, 2003). The argument of C. Wright Mills has given disability a new dimension as a socio-political problem, and to some extent it can explain the deviance and social oppression associated with disability.

Feminists also have their own view of disability, emerging from the theories of radical humanism and the cultural politics of disability. Both ideas concentrate on the culture system and the ideological aspects of disablism. Feminist disability studies noted that disabled women occupy different kinds of social positions from disabled men, because more than one system of oppression exists (Barnes, Oliver, & Barton, 2002). On a deeper level, radical humanists interested in the politics of appearance, the cultural *dis*-location of desire, the ma(r)kings of normalcy, the socio-cultural production of bodies, the fiction of an idealised body politic, ideological representations of dis/ability, and disability as a site for the reproduction for social ideologies of perversion, victimisation and fetish (Goodley, 2011). For radical humanists, disability in general is understood as an ideological construction or a creation of culture, politics, and society.

Likewise, radical structuralism – specifically historical materialism – offers another radical explanation of disability. Materialist analyses view the categories of disability/impairment as essential to a capitalist system's exclusion of certain social

groups from participating in economic activity (Goodley, 2011). Mike Oliver explained this view further, when he argued that as wage-labour relations became increasingly bound up with large-scale industry from the late eighteen century in Britain, people with impairment began to be systematically excluded from direct involvement in economic activity (Barnes et al., 2002). By contrast, late capitalism gave rise to knowledge economy that might include some disabled people, for example through the use of enabling technologies (Goodley, 2011). From a materialistic point of view this knowledge economy is unable to include all categories of disabled (Goodley, 2011). However, radical structuralism studied disability from a macro-sociological focus on the social system.

In the context of social policy in western counties including New Zealand, the debates over welfare philosophy are conducted between two modern theoretical approaches (a neo-liberal and social democratic approach (third way)) (Beatson, 2004). The neoliberals argued that the main responsibility of welfare lies with the family and civil society (Beatson, 2004). According to some writers in this approach, goods and services are to be purchased from the open market out of household income or civil society's funds (Beatson, 2004; King & Ross, 2010). The ideas of the neo-liberal approach originated from the works of Friedrich Von Hayek and his follower Milton Friedman, and their arguments against the welfare state and Keynesianism (King & Ross, 2010). On the other hand, the social democratic alternative requires government to play an active role in promoting the well-being of disabled citizens (Beatson, 2004). Also family and civil society have their part to play.

2.2 Albinism: A Social Research Issue

People with albinism have been a social research issue since the last decade of the twentieth century. Social researchers investigated albinism from different disciplines' perspectives. In this section I present a disciplinary review in which albinism has been investigated from psychological, educational, and sociological point of view as well as albinism as a social policy topic.

To begin with, the psychological aspects of albinism attracted researchers in the United States of America and Australia. Quantitative research was done by Moniqueka E. Gold (1998) to explore the effects of physical features associated with albinism on the self-esteem of African-American youth (Gold, 1998). Thirty African-American students between the ages of 14 to 19 participated in this study. Participants were selected from a sample of those available in the participating school systems. The participants were

divided into three groups (students with albinism, students with visual impairment and 'normal' students) of 10 subjects each. Gold used three measures in this study (a) the Tennessee self-concept scale 2, (b) the Self-Perception Inventory, and (c) two open-ended questions about the participants' physical appearance. Three hypotheses were developed, to be examined based on group assignment:

1- There will be no difference in the total score on the Tennessee self-concept scale
2- There will be no difference in the total self-esteem score on the Self-Perception Inventory.
3- There will be no difference in the frequency of responses related to the physical attributes provided by the participants in response to the open-ended questions.

The research findings indicated that there was no statistical significance among groups on the Tennessee self-concept scale 2 and the Self-Perception Inventory. The open-ended questions revealed a difference in the frequency of responses of each question. Additionally, the chi-square tests conducted revealed a significant difference with the descriptor 'hair length' among group on the open-ended questions.

Another study by Carolyn Palmer in 2007 investigated the self-esteem of a small group of students with albinism (Palmer, 2007). Ten case studies were conducted and data collected using a widely recognized psychological instrument called 'the coopersmith Self-Esteem Inventories'. The research question of the study was whether albinism affected children's rates of self-esteem. The findings indicated that the self-esteem of the participants in this study was generally high.

In one further way researchers have investigated albinism, educational studies have also been used to reveal some features of albinism. In Africa, Gareth Dart, Tiroyaone Nkanotsang, Ose Chizwe and Lily Kowa conducted a double case study research in 2010 to investigate the educational experience of two particular pupils with albinism in junior secondary schools in Botswana (Dart, Nkanotsang, Chizwe, & Kowa, 2010). Case studies were carried out by student teachers on teaching practice. The findings of this research indicated that the pupils were shown to be struggling at school partly as a result of the difficulties caused by their albinism but also because the attitudes of those around them, and the social context in which they find themselves.

In 2011 a quantitative research (demographic survey) by Jillian Watson-Hulum examined whether demographic factors had a direct relationship with educational attainment in

individuals with albinism (Watson-Hulum, 2011). The research sample consisted of 161 individuals with albinism (49 men and 112 women) who are members of albinism online community of the United States National Organization for Albinism and Hypopigmentation (NOAH). The study used a multiple regression analysis of three predictor variables (ethnicity, socioeconomic status, and visual acuity) and one outcome variable (educational attainment). The findings of this research analysis revealed a significant relationship between visual acuity and educational attainment. No significant relationship was found between socioeconomic status, ethnicity and educational attainment. Future studies should evaluate other variables that may predict educational attainment in individuals with albinism.

Sociologists have also investigated albinism and its social aspects. Qualitative research was done by Nathalie Wan in 2002 to determine the social aspects of people with albinism from their perspective (Wan-Kee-Cheung, 2002). Twelve people (from Canada, United States, and Australia), seven women and five men, participated in this study. The sampling design was conducted in a snowball fashion, whereby each interviewee was asked if he or she knew someone else with albinism who would be interested to participate. The participants ranged in age from 17 to 51 years. Data was collected using open-ended, semi-structured interviews. The study was framed around Erving Goffman's theory of stigma and spoiled identity. The results identified eight principal methods of reaction and response to the discrimination against people with albinism. These include:

a) The Defiant (those who are quick to respond to insults and are forthright in asserting their rights).

b) The Activists (those who are involved in heightening public awareness about albinism in a positive light).

c) The Serenes (those who patiently explain their condition to others).

d) The Internalisers (those who resent mistreatment but 32 internalise and assimilate their pain).

e) The Talkers (those who discuss their adversities with family and friends).

f) The Hiders (those who hide their disability to escape prejudice).

g) The Flamboyants (those who display themselves and publicly reveal their uniqueness).

h) The Positivists (those who have learned to accept albinism as a part of their identity).

On the other hand, quantitative research by Victoria S. Young in 2012 also investigated the social stigma on the basis of physical appearance by focusing on people with albinism in the United States (Young, 2012). A non-probability sample of 154 subjects was selected from those who have oculocutaneous albinism. NOAH assisted the researcher to recruit the research subjects by sending out e-mail and postcard announcements in two waves to its members. Moreover a link to the questionnaire was posted on NOAH's website and its printed magazine. Also the researcher shared the questionnaire link on Facebook's two albinism pages. The questionnaire was designed to gather the data around self-esteem, concealment, group affiliation, salience, endorsement of stereotypes, and experience of prejudice and discrimination. Statistical analyses such as correlation analysis and multiple regression analysis assisted in the survey's outcomes. The findings indicated that people with albinism are stigmatised, with negative stereotypes being the strongest contributor to felt stigma. In addition, people with albinism are frequently experience prejudice and discrimination that might lead to physical threat and social isolation. However, the study shows that people with albinism have a strong sense of self, as well as a desire to educate the public about their condition to reduce negative stereotyping and misinformation about albinism. Also the study discovered that the more people with albinism think about their condition, the less likely they feel stigmatised.

People with albinism and their condition were also investigated by social policy researchers. In the African context, and as a health issue, Patricia M. Lund and Retha Gaigher in 2002 examined a health intervention programme for children with albinism at a special school in South Africa (Lund & Gaigher, 2002). The intervention was based on the assumption that any attempt to address both the health and social problems should be of a holistic, interactionist nature, and be based on the values and belief systems of the local community. In order to address the physical problems, the programme focused on sensible sun protection habits from a young age and the active participation of the children. A questionnaire was given to 38 pupils (age range 11-16 years old, 18 male and 20 female). The questionnaire covered socio-demographic, education, and health information as well as protective measures adopted to manage their condition. The findings indicated that alleviating the social problems a team (interactionist) approach including children, teachers, parents, health officials and the wider community is recommended. Another research finding reiterates the need for increased awareness of and public health interventions for albinism in order to better address the medical,

psychological and social needs of this vulnerable population in Africa (Hong, Zeeb, & Repacholi, 2006).

In 2005 Tal Harmati conducted a cross-sectional study to examine the support systems available to children with albinism and whether those systems are enabling them to fulfill their potential as learners in the education system (Harmati, 2005). With support of The United States National Organization for Albinism and Hypopigmentation (NOAH) a sample of 330 subjects participated. The sample combined individuals of different ages, different occupations, and different educational and income levels. In the beginning stages of the research, a pilot survey was sent to ten people with albinism containing several open and closed questions. One thousand responses came back. The reason for this was that the people who received the survey sent it to other people they knew. This study was conducted to ensure the survey was relevant to the population. The study used the survey to gather the data about the experiences of students during three periods of their education (infant to preschool, preschool, and elementary school). The findings of this research indicated that the family doctor is the main source of information about albinism. Also the majority of parents consulted the preschool teacher regarding their child's needs. Also more than %90 of the research participants enrolled their child in a regular school and most of them were assigned to a regular classroom. Some classroom adaptations are made to student with albinism such as seated close to the board and seated with their backs to the windows. A few students were provided with additional protection from sunlight through the windows. A magnifying glass was the most common aid children had received in school.

Another qualitative study in 2007 aimed to explore and describe the life experiences of people with oculocutaneous albinism in South Africa (Mmuso, 2012). The study conducted in-depth individual phenomenological interviews to gather the data. A purposive sample of 15 people with oculocutaneous albinism participated in the study, including 12 females and three males aged between 18 and 48 years. The central question posed to all interview subjects was whether they would be willing to share their experience about albinism. Data from the interviews were analysed using Collaizi's qualitative data analysis method and three main themes emerged: (1) perceptions of the internal environment, for example the self; (2) experiences in the external environment, for example family and community; and (3) the need for self-development and growth based on their experiences. The findings of this research indicated that priority issues for

addressing the psychological impact of oculocutaneous albinism, especially with regard to self-concept, should be pursued in future research.

2.3 Conclusion

This review of the literature highlights that conducting a research on a probability sample is a challenge for any researcher who will study people with albinism. As a result of that researchers are not able to make generalization out of their findings. Absolutely, there are no administrative data can provide researchers with even the number of people with albinism. However, the United Nations High Commissioner for Human Rights recommends that governments need to include people with albinism in a census of the population and the mandatory registration of birth (Rights, 2013). Also as any other disability study, studying people with albinism is an ethically sensitive issue. Researchers overcome this dilemma by properly testing their data collection tools after they conduct consultations with people with albinism and their advocacy organizations for the purpose of negotiate the research topic and the best ways of gathering the data. Moreover, it became clear that there are differences between social and policy research in developed countries and developing countries in the ways people with albinism have been studied. While the research in developed countries (especially in North America) focuses on the social and psychological consequences of having albinism, in Africa albinism is a significant health issue and people with albinism are facing discrimination and violence because of their condition.

Chapter Three: Methodology

This is a multi-strategy research (research that combines quantitative and qualitative data). Based on (1) research purpose, (2) level of interaction between the quantitative and qualitative strands, (3) the point in which the two stands integrate, and (4) the priority and timing of both of them, there are variety of mixed methods research designs. This research uses ***The Convergent Parallel Design[9]*** which is the design where the researcher collects the quantitative and the qualitative data at the same phase of the research process and keeps them independent during the analysis stage and then merges them together at the final overall interpretation.

Since people with Albinism and their needs has never been investigated before in New Zealand, using a combination of quantitative and the qualitative approaches will provide more complete understanding of the topic. It was originally planned to conduct the components sequentially however, time constraints prevented this. So the convergent design become the most suitable alternative as it uses concurrent timing to gather quantitative and the qualitative data at the same stage of the research. Moreover, Creswell and Plano Clark (2011) argue that the convergent design is the most appropriate mixed method design which allows a single researcher to collect limited quantitative and qualitative data.

3.1 Sample Recruitment

In order to recruit the research sample, I relied on the Blind Foundation database which includes 188 registered members with albinism - as in February 2014. The Blind Foundation database was recommended by the New Zealand Albinism Trust as the most comprehensive database that include information about people with albinism in New Zealand at all ages and from different locations across the country..

The Blind Foundation assigned two volunteers to make contact with its members to gain consent for participating in the project. At least three attempts were made to contact each potential participant. 101 members (48 females and 53 males) gave their consent for their contact details to be passed through to me while 21 members refused and for 66 members there was no response. Out of the 101, 65 members were identified as adults

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[9] The Convergent Parallel Design is the most popular mixed method research design. Scholars from different disciplines began using this design from early 1970s. It was known as simultaneous triangulation, parallel study, convergence model, and concurrent triangulation.

Figure 1: *Flowchart of the Basic Procedures in Implementing a Convergent Design*

STEP 1	**Design the Quantitative Strand:** • State quantitative research questions and determine the quantitative approach. **Collect the Quantitative Data:** • Obtain permissions. • Identify the quantitative sample. • Collect closed-ended data with instruments.

STEP 1

Design the Quantitative Strand:
• State quantitative research questions and determine the quantitative approach.
Collect the Quantitative Data:
• Obtain permissions.
• Identify the quantitative sample.
• Collect closed-ended data with instruments.

and

Design the Qualitative Strand:
• State qualitative research questions and determine the qualitative approach.
Collect the Qualitative Data:
• Obtain permissions.
• Identify the qualitative sample.
• Collect open-ended data with protocols.

STEP 2

Analyse the Quantitative Data:
• Analyse the quantitative data using descriptive statistics, inferential statistics, and effect sizes.

and

Analyse the Qualitative Data:
• Analyse the qualitative data using procedures of theme development and those specific to the qualitative approach.

STEP 3

Use Strategies to Merge the Two Sets of Results:
• Identify content areas represented in both data sets and compare, contrast, and/or synthesize the results in a discussion or table.
• Identify differences within one set of results based on dimensions within the other set and examine the differences within a display organized by the dimensions.
• Develop procedures to transform one type of result into the other type of data (e.g., turn themes into counts). Conduct further analyses to relate the transformed data to the other data (e.g., conduct statistical analyses that include the thematic counts).

STEP 4

Interpret the Merged Results:
• Summarize and interpret the separate results
• Discuss to what extent and in what ways results from the two types of data converge, diverge, relate to each other, and/or produce a more complete understanding.

Adopted from figure 3.3, 'Designing and conducting mixed method research' (Creswell and Plano Clark, 2011: 79).

(15 years and over) and 36 members were identified as children (0-14). The figure below summarises the Blind Foundation's work.

Figure 2: *The Blind Foundation's work*

3.2 Design, procedures, and data analyses

3.2.1 The Quantitative Strand:

A nationwide survey was conducted between October 2014 and late January 2015 to gather data from adults with albinism as well as parents of children with albinism. Parents of children with albinism were invited to participate instead of the children themselves, as the study focuses on assessing the existing policies and services. Therefore, parents may provide the researcher with more adequate responses than children. The survey used two questionnaires to collect the data from the research participants[10], one for adults and one for parents. They cover different aspects of life such as health, education, employment, income, transport, housing, and respite care. Table 5 provides a summary of indicators used to develop the questionnaires. Indicators were selected based on their relevance to albinism as a type of impairment, and followed the recommended framework of the Office for Disability Issues to assess the long-term life outcomes for disabled people[11].

The questionnaire for adults with albinism has 88 questions (81 multiple choice and 7 open-ended) divided into 15 sections. The questionnaire designed for parents of children

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[10] full copy of the questionnaires are available in the appendices (see appendices 11 and 12)
[11] Full copy of the Office for Disability Issues' Framework for the 10-year review of the New Zealand Disability Strategy is available in the appendices (see appendix 15).

with albinism has 42 questions (39 multiple choice and 3 open-ended) divided into 9 sections. All the questions of the questionnaires were discussed carefully with the trustees of the New Zealand Albinism Trust.

The survey materials were made available in three different formats (online, hard copy, and audio "on request") to avoid any reading difficulties. These materials include the formal invitation, the questionnaires and the participant information sheet. Only 79 people (47 adults with albinism and 32 parents of children with albinism) out of 101 were invited to participate online by sending the survey materials - including the online survey link - to their e-mail addresses five times, whereas, 22 hardcopies of the questionnaires were posted to 18 adults with albinism and 4 parents of children with albinism. Table 4 shows that approximately 64 percent of parents participated in this study, whereas, nearly 43 percent of adults did so. Based on age, a self-selection bias occurred. Parents of children aged four years or under and adults over 65 years old are overrepresented in this study. In contrast, young adults aged between 15 and 24 years old were less likely to respond.

Table 4: *The response rate of the survey*

		Invited	Participated	Response rate
By age				
Children	0 to 4	10	10	100%
	5 to 14	26	13	50%
	Total	**36**	**23**	**64%**
Adults	15 to 24	21	5	24%
	25 to 44	15	8	53%
	45 to 64	16	5	31%
	65+	13	10	77%
	total	**65**	**28**	**43%**
By gender				
Males		53	27	51%
Females		48	24	50%
	total	**101**	**51**	**50%**

Note:

The SPSS was used to analyse the survey data. Techniques such as univariate and multivariate analysis were employed to analyse these quantitative data.

Table 5: *Summary of indicators that used in the quantitative stand*	
Purpose of the section	**Used Indicators**
1- General information	
This section aimed to collect demographic data from the participants.	Gender, age, location, and ethnicity. These indicators were recommended by the Office for Disability Issues in order to assess the long-term life outcomes for disabled people. Questions were adopted from both the New Zealand Disability Survey of 2013, the Blind Foundation Needs Assessment Main Survey of 2014.
2-Impariment Type	
This section aimed to determine the impairment type	1- Type of albinism 2- Multiple disabilities: this indicator was used in the New Zealand Disability Survey of 2013, the Blind Foundation Needs Assessment Main Survey of 2014
3- Special Devices or Equipment	
This section aimed to investigate whether people with albinism have access to special equipment or devices for seeing.	1- Access to special equipment or devices for seeing: this indicator was used in the Blind Foundation Needs Assessment Main Survey of 2014. 2- Unmet need for special equipment or devices: this indicator was used in the New Zealand Disability Survey of 2013.
4-Health	
This section aimed to assist whether people with albinism have access to appropriate health and wellbeing services.	1- Self-assessed of the health status - frequently of visiting health professional: these indicators were used in the New Zealand Disability Survey of 2013, the Blind Foundation Needs Assessment Main Survey of 2014. 2- Percentage of disabled people who perceive accessing disability supports, health and wellbeing services to be simple - Percentage of disabled people who perceive their health and wellbeing needs are timely met - Percentage of disabled people who feel they are at the centre of service and support provision: these indicators were recommended by the Office for Disability Issues in order to assess the long-term life outcomes for disabled people. 3- Level and percentage of use of needs assessment: these indicators were used in the New Zealand Disability Survey of 2013 and recommended by the Office for Disability Issues in order to assess the long-term life outcomes for disabled people.
5-Education	
this section aimed to assist whether people with albinism have access to appropriate health and wellbeing services	**First part: children with albinism** questions were developed based on the following indicators: 1- Percentage of children with albinism enrolled or receiving early childhood education – Type of schooling – Percentage of children with albinism enrolling in special school - Percentage of children with albinism enrolling in correspondence School - Percentage of children with albinism enrolling in home schooling - Percentage of children with albinism enrolling in regular school -Percentage of children with albinism attending special education classes – Unmet needs: these indicators were used in the New Zealand Disability Survey of 2013, the Blind Foundation Needs Assessment Main Survey of 2014 and some were recommended by the Office for Disability Issues in order to assess the long-term life outcomes for disabled people.. 2- percentage of children with albinism had an educational needs assessment through the Blind and Low Vision Education Network NZ (BLENNZ) - Level of awareness within education professionals

Table 5: *Summary of indicators that used in the quantitative stand*	
Purpose of the section	**Used Indicators**
	3- Availability of optical aids in the school – Types of adaptations available in the classroom: these questions were inspired from the study of Tal Harmati (2005) about Children with albinism in the educational system in the U.S.A. **Second part: Adult with albinism** Questions were developed based on the following indicators: 1- highest educational qualification – Percentage of adults with albinism currently enrolled in education or training programme – Percentage of adults with albinism studying (Primary/intermediate school - Secondary school - Tertiary institution) – Percentage of adults with albinism Studying (full time – Part time): these indicators were used in the New Zealand Disability Survey of 2013, the Blind Foundation Needs Assessment Main Survey of 2014 and some were recommended by the Office for Disability Issues in order to assess the long-term life outcomes for disabled people.. 2- Percentage of adults with albinism received academic accommodations or supports such as information in alternative formats: - academic performance: these indicators were used in the Blind Foundation Needs Assessment Main Survey of 2014.
6-Employment	
This section aimed to assist whether people with albinism meaningful employment of their choice.	1- Percentage of working age people with albinism in paid job – satisfaction with current job – Percentage of working age people with albinism would like to work if job is available: these indicators were used in the New Zealand Disability Survey of 2013 and some were recommended by the Office for Disability Issues in order to assess the long-term life outcomes for disabled people.. 2- Nature of employment – Number working of hours per week – satisfaction within workplace – the received and needed accommodations in the work place: these indicators were used in the Blind Foundation Needs Assessment Main Survey of 2014.
7-Income	
This section aimed to assist whether people with albinism income support their independence and their choices.	1- Source of Income – total personal income in the last 12 months – total house hold income in the last 12 months: these indicators were used in the Blind Foundation Needs Assessment Main Survey of 2014. 2- Percentage of disabled people who manage their finances - Percentage of disabled people who perceive their income is adequate to support their independence: were recommended by the Office for Disability Issues in order to assess the long-term life outcomes for disabled people.
8-Transport	
This section aimed to assist whether people with albinism have available, accessible, and affordable transport.	Percentage of people with albinism who are able to drive a private motor vehicle – Percentage of people with albinism who travel as a passenger in a private motor vehicle – Percentage of people with albinism who use public transport to travel short distances – Percentage of people with albinism having difficulties while using public transport to travel short distances – sort of difficulties while using public transport – frequent of using taxis to travel short distances – Percentage of people with albinism using total mobility scheme: these indicators were used in the New Zealand Disability Survey of 2013, the Blind Foundation Needs Assessment Main Survey of 2014 and some were recommended by the Office for Disability Issues in order to assess the long-term life outcomes for disabled people..
9- Accessing Information	

Table 5: *Summary of indicators that used in the quantitative stand*	
Purpose of the section	**Used Indicators**
This section aimed to determine how people with albinism access information.	Preferred formats of accessing information - Frequency and purpose of reading - The importance of (internet, TV, newspaper, radio, and people) as a source of information – Using the internet – Location of using the internet – Devices used to access the internet – Purpose of using the internet: these indicators were used in the Blind Foundation Needs Assessment Main Survey of 2014.
10-Housing	
This section aimed to investigate whether people with albinism have a secure, accessible, affordable, quality home in the community.	1- Percentage of people with albinism who live in different types of housing – Length of stay: these indicators were used in the Blind Foundation Needs Assessment Main Survey of 2014 and were recommended by the Office for Disability Issues in order to assess the long-term life outcomes for disabled people. 2- The last question about people with albinism satisfaction of the security, accessibility, affordability, and quality of home was developed directly from the section question.
11- Discrimination	
This section aimed to investigate whether people with albinism have equal rights in their community.	1- Percentage pf people with albinism who had experienced discrimination in the last 12 months – frequent of experiencing discrimination in the last 12 months: this indicator was used in the New Zealand Disability Survey of 2013. 2- Percentage of people with albinism who made complain to the human rights commission because of unlawful discrimination against you on the grounds of you disability – complains by area: these indicators were used by the Independent Monitoring Mechanism of the Convention on the Rights of Persons with Disability
12- Relationship	
This section aimed to investigate whether people with albinism are able to make and keep relationships.	Frequent of feeling lonely in the last four weeks – Percentage of people with albinism made face-to-face contact with family and friends - Level of contact with family and friends – Number of hours spend on social and recreational activities – Extent of feeling reluctant to leave home: these indicators were used in the New Zealand Disability survey of 2013.
13-Recreation	
This section aimed to investigate whether people with albinism enjoy cultural and recreation activities of their choices.	**First part: children with albinism** questions were developed based on the following indicators: Percentage of children who (had music or art lessons (outside of school), played a team sport, done physical activity such as swimming or gymnastics, participated in club activities, gone out with family or friends, visited friends, and/or gone away on a holiday) over the last 4 weeks - Percentage of people who have difficulties doing the same recreation activities: these indicators were used in the New Zealand Disability Survey of 2013, and were recommended by the Office for Disability Issues in order to assess the long-term life outcomes for disabled people. **Second part: Adult with albinism** Questions were developed based on the following indicators: Percentage of people who (done voluntary work, been to a theatre or cinema, been to a café, restaurant or pub, played sport, been a spectator at a sporting event, and/or Gone away on a holiday) over the last 4 weeks - Percentage of people who have difficulties doing the same recreation activities: these indicators were used in the New Zealand Disability Survey of 2013, and were recommended by the Office for Disability Issues in order to assess the long-term life outcomes for disabled people.
14-Quality of life	

Table 5: *Summary of indicators that used in the quantitative stand*	
Purpose of the section	**Used Indicators**
This section aimed to gain information about the overall life satisfaction	1- Self-assessment of implementing the CRPD and NZDS 2- Overall life satisfaction: this indicator was used in the New Zealand Disability Survey of 2013.

3.2.2 The Quantitative Strand (The interviews)

Five semi-structured interviews with trustees of Albinism Trust were planned in order to get in-depth information about people with albinism in New Zealand. Unfortunately, only four interview could be conducted as one of the trustees is now living overseas and could not be reached. The interviews were conducted during April 2015. An interview guide with 20 open-ended questions was designed to cover different aspects of life such as health, education, employment, income, transport, housing, discrimination, recreation, and relationship[12]. The four interviews were conducting online, recorded using computer software and were professionally transcribed. The length of each interview took approximately one hour. A thematic analysis was employed to analyse the interview data.

3.3 Methodological limitations

Securing a representative or random sample was not possible with the lack of information about people with albinism in New Zealand as well as the self-selection bias. Therefore, the conclusion of this research cannot be generalised to the larger population of people with albinism. The self-selection bias by itself mostly affected the results related to use of transport among children and results related to education and employment among adults. However, this research can be considered as exploratory research as it was the first research to target people with albinism in New Zealand.

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[12] Full copy of the interview guide is available in the appendices (see appendix 10).

Results

Chapter Four: People with albinism in New Zealand

Since the purpose of this research is discussing the needs of people with albinism and assessing how well these are being met against the objectives of the New Zealand Disability Strategy and the requirements of the United Nations Convention on the Rights of Persons with Disabilities, this study gathered survey responses from 23 parents of children with albinism, as well as 28 adults with albinism of those who are members of the Royal New Zealand Foundation of the Blind. Subsequently, four interviews with the trustees of the New Zealand Albinism Trust were conducted in order to get in-depth information about people with albinism in New Zealand and policies relating to them. Both the survey and the interviews include questions regarding the type of albinism, access to special devices or equipment, health, education, employment, Income, transport, housing, discrimination, relationship, recreation, and quality of life as described in the previous methodology chapter three. This chapter presents the findings of the research.

4.1 Characteristics of the sample:

Twenty three parents of children with albinism (21 mothers and 2 fathers) completed the survey on behalf of their children (15 males and 8 females). In contrast 28 questionnaires were completed by adults (16 females and 12 males) with albinism. In addition, four trustees (3 males and 1 female) were interviewed (see table 6).

Table 6: *Number and percentage of research participants by sex*

	Male		Female	
	Count	Percentage	Count	Percentage
1- Parents survey				
Parents	2	9%	21	91%
Children	15	65%	8	35%
Total		23		
2- Adults survey				
Adults	12	43%	16	57%
Total		28		
3- Interviews				
Trustees	3	75%	1	25%
Total		4		
Total count of participants		55		

Almost three-quarters (about 74%) of parents were between 25 and 44 years old. Also table 7 shows that more than half of children (about 56%) were between 5 to 14 years old, while 43.5 percent are 4 years or less. On the other hand, approximately 37 percent of adults were 65 years old and over, whereas, only 8 out of 28 of them (about 28%) were

between 25 and 44 years old. Also age groups such as 15 to 24 and 45 to 65 received low responses. In addition, all interviewees (the trustees) were aged 50 years and over.

Table 7: *Number and percentage of surveys' respondents by age group*

group Age		Total
1- Parents survey		
0 to 4 years old	Count	10
	% of Total	43.5%
5 to 14 years old	Count	13
	% of Total	56.5%
Total	Count	23
	% of Total	100.0%
2- Adults Survey		
15 to 24 years old	Count	5
	% of Total	17.9%
25 to 44 years old	Count	8
	% of Total	28.4%
45 to 64 years old	Count	5
	% of Total	17.9%
65 years old and over	Count	10
	% of Total	35.8%
Total	Count	28
	% of Total	100.0%

Figure 3 shows that the majority of parents (about 83%) considered their ethnic background to be New Zealand European, while a little more than two-third of the adults (about 68%) also considered their ethnic background to be New Zealand European. Also, all interviewees (the trustees) had New Zealand European ethnicity.

Figure 3: *Percentage of surveys' respondents by ethnic background*
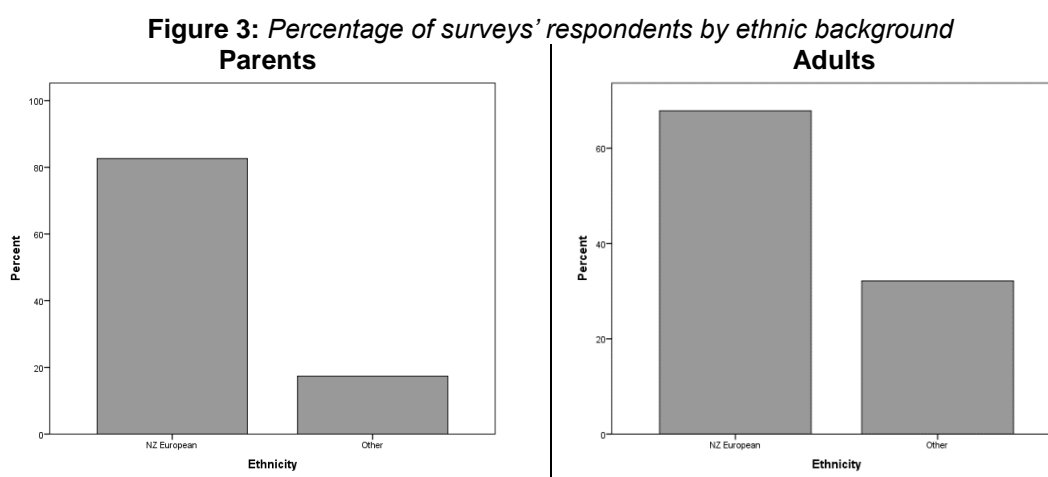
As it is shown in figure 4, more than half of children with albinism (about 52%) were living with their families in cities, while approximately 26 percent were living in towns and nearly 21 percent were living in rural and remote rural areas. On the other hand, almost 61 percent of adults with albinism were living in cities, while the rest were living in town, rural, or remote rural areas. Also, the interviewees (the trustees) were asked to

determine where they live. Two of them currently were living in cities, whereas one was living in a small town and one lives in a rural area.

Figure 4: *Percentage of surveys' respondents by location*
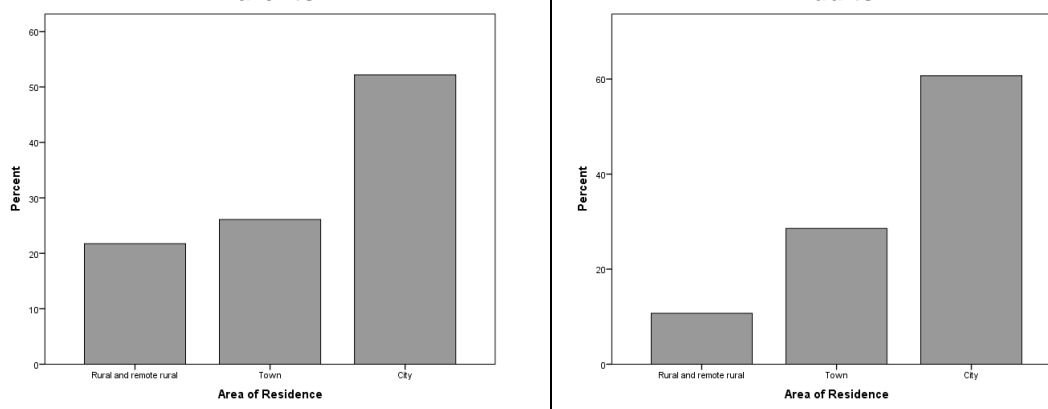
4.2 Impairment type:

Basically, there are two main types of albinism. Oculocutaneous Albinism (OCA) is the type in which the condition affects the eyes, hair and skin, whereas Ocular Albinism (OA) involves only the eye. Figure 5 shows that almost two thirds of children (about 70%) had OCA, whereas, nearly 30 percent of children had OA. On the other hand, almost all adults (about 96%) had OCA. Regarding the interviewees, three of the trustees had OCA, while only one trustee had OA.

Figure 5: *Percentage of surveys' respondents by type of albinism*
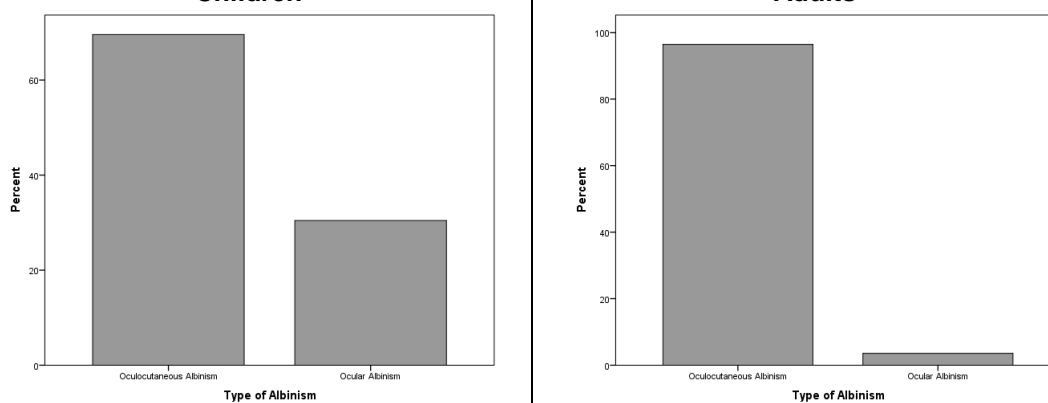
Subsequently, respondents were asked whether their child/they have any disabilities or health conditions other than albinism. Only seven out of sixteen children (about 44%) had another health condition. In comparison nearly 37% of adults had one. Alongside

albinism, Failing to Thrive[13] was the most common health condition that children had, whereas, hearing impairments was the most common health condition that adults had (see figure 6).

Figure 6: *Percentage of respondents who have other disabilities or health conditions*
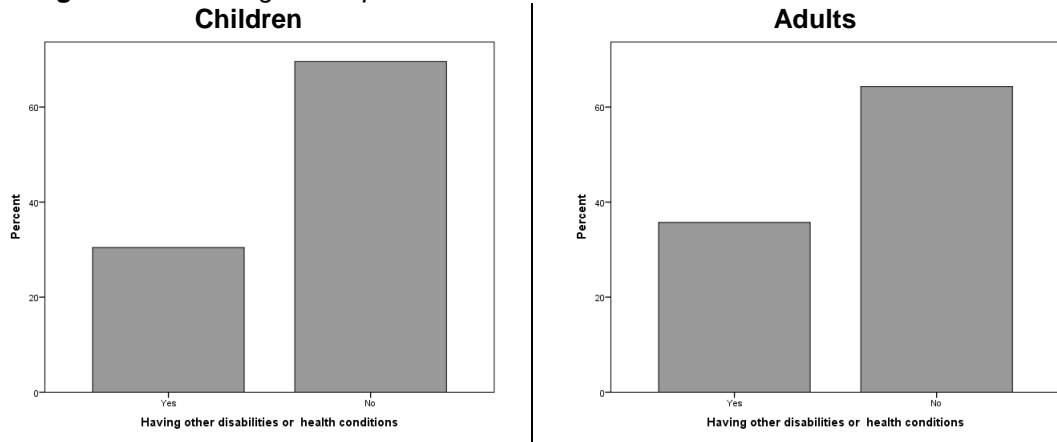
4.3 Special devices or equipment:

This section aimed to determine whether people with albinism have access to special devices or equipment for seeing. Table 8 shows that iOS devices and specialized reading or distance viewing glasses were the most common devices that children had access to. In contrast, the hand-held magnifier is the most common equipment that adults with albinism had access to, whereas, less common equipment among adults were "all in one scanning devices" and "talking or tactile medical devices". The table also shows that nearly 27 percent of parents stated that their children used other devices such as slope board, tablets, UV blocking lenses, and reading glasses. On the other hand, about 11 percent of adults indicated that they used other devices such as Short Range Moonscope, Headlamps and large computer/laptop screens.

Subsequently, respondents were asked if their children/they have an unmet need for equipment or a device. As shown in figure 7 the majority (about 87% of children and 82% of adults) answered no. Most of those who had an unmet need for equipment were not sure what best suited them at this stage.

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[13] Failing to Thrive means that child is very slow to put on weight and grow.

I'm not sure. Possibly not, but I don't know what equipment are available in order to say for sure.

- An adult survey comment -

No or few services or equipment are provided for kindergarten age - despite child directed interest in early reading.

- A parent survey comment -

Table 8: *Percentage of respondents who have access to some equipment for seeing*

Devices or equipment	% of children	% of adults
Screen Reader (e.g. JAWS, NVDA)	4.5%	-
Screen Magnifier (e.g. Zoomtext, Magic)	9.1%	14.8%
Refreshable Braille Display	-	-
Scanner (OCR software)	9.1%	-
All in one scanning device	-	3.7%
CCTV (Video Magnifier)	9.1%	11.1%
Tape Recorder/audio recording device	-	7.4%
Digital recorder	-	-
Digital Reader (e.g. Book port, Victor Reader Stream)	4.5%	11.1%
iOS Devices (e.g. iPhone, iPad)	31.8%	33.3%
Hand Held Magnifier	18.2%	77.8%
Labeller (e.g. Penfriend or dymo labeller)	-	-
Specialized reading or distance viewing glasses	27.3%	44.4%
Colour detector	-	-
Household and kitchen aids	4.5%	7.4%
Talking or tactile home maintenance equipment (e.g. tape measures, spirit levels)	-	-
Talking or tactile medical devices (e.g. talking glucometer)	-	3.7%
None	31.8%	3.7%
Other	27.3%	11.1%

Figure 7: *Percentage of respondents who have unmet need for equipment for seeing*
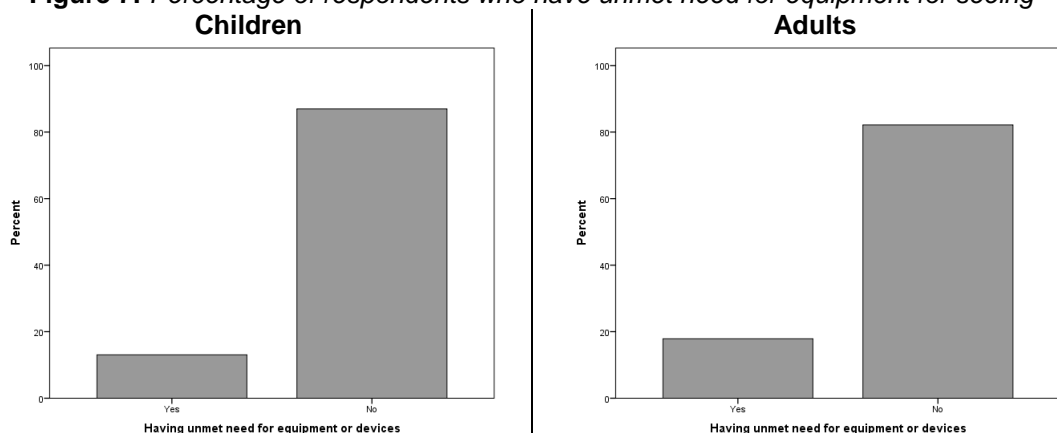
4.4 Health:

This section tries to investigate whether people with albinism have access to appropriate health and wellbeing services.

Since vision impairment is the most significant health element associated with albinism, both parents and adults were asked to assess their child/their vision. Figure 8 shows that a little over half of parents (about 52%) saw that their child's vision as fair, whereas, approximately 43 percent of adults self-assessed their vision to be poor/very bad.

Figure 8: *Parent/self-assessment of vision*
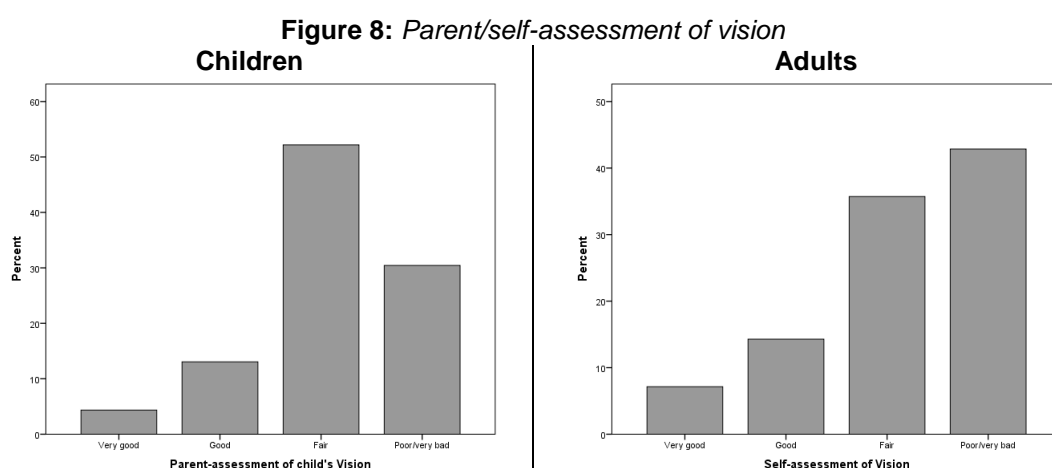
As people with albinism - especially people with OCA – were more likely to have sensitive skin. Parents and adults were asked to assess their child/their skin health. Figure 9 shows that approximately two-third of parents (about 56%) saw that their child's skin health was also fair, whereas nearly 57 percent of adults were somewhat satisfied with their skin health.

Figure 9: *Parent/self-assessment of skin health*
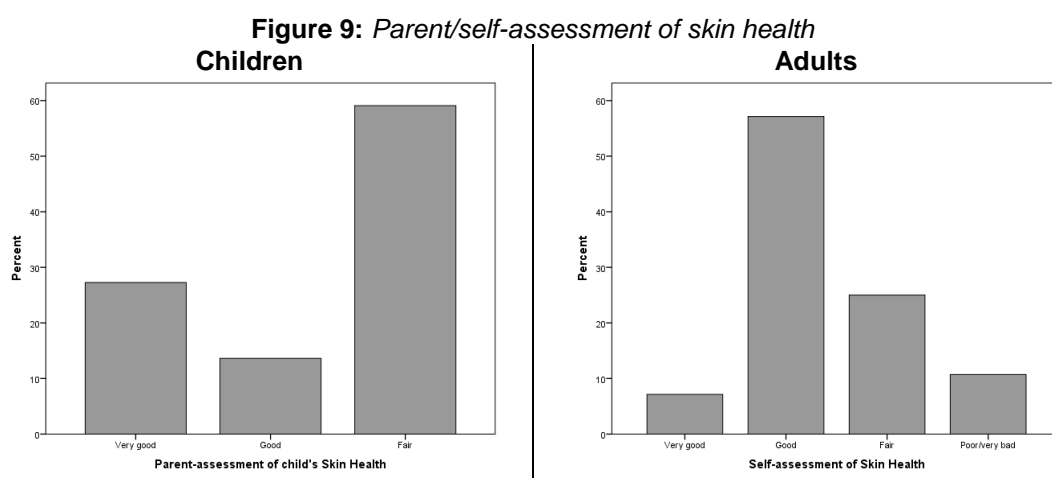
Then both parents and adults were asked to assess their child/their overall health. Figure 10 shows that overall health assessment of children with albinism tended to be very good as half of the parents (50%) answered in that way. In comparison nearly 57 percent of adults were somewhat satisfied with their overall health.

Figure 10: *Parent/self-assessment of overall health*
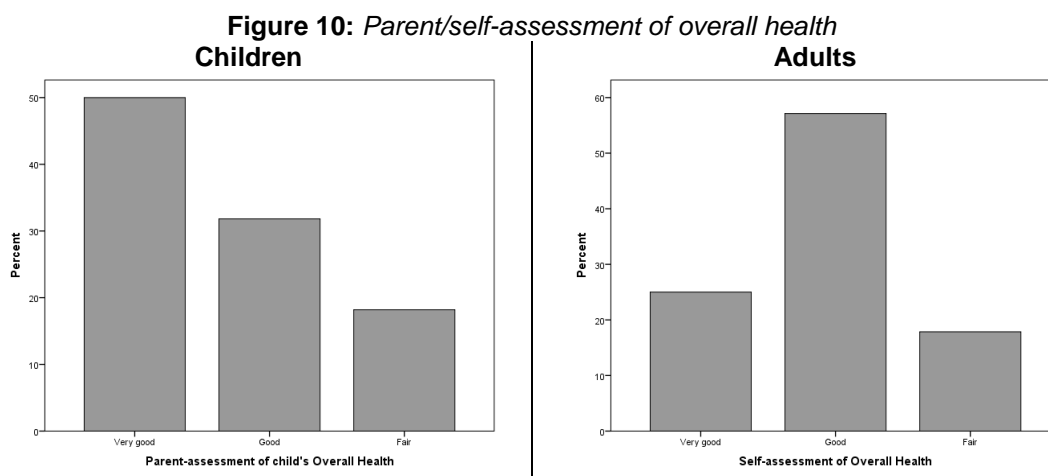
After that, respondents were asked about the frequency of visiting health professionals last year for reasons related to their child/they having albinism. Nearly 68 percent of children visited health professional less than 4 times a year. While approximately 87 percent of the adults visited a health professional less than 4 times (see figure 11).

Figure 11: *Frequency of visiting health professionals*
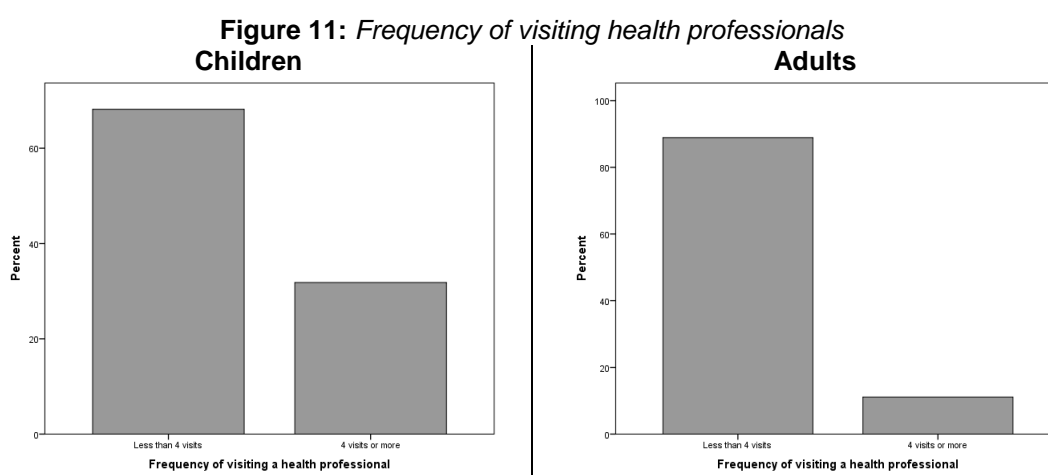
Further, respondents were asked whether they have an unmet need to visit a health professional during the same period of time. Figure 12 shows that about three-quarters of parents (about 78%) indicated that their children had no unmet need to visit a health

professional over the last year. In contrast, approximately 22 percent had an unmet need to visit a health professional, because they couldn't get a suitable appointment and/or couldn't afford to. On the other hand, most of adults (about 82%) had no unmet need to see a health professional, whereas, about 18 percent of them failed to see a health professional, because they could not afford to and/or had transport difficulties.

Figure 12: *Percentage of respondents who had unmet need to visit a health professional*
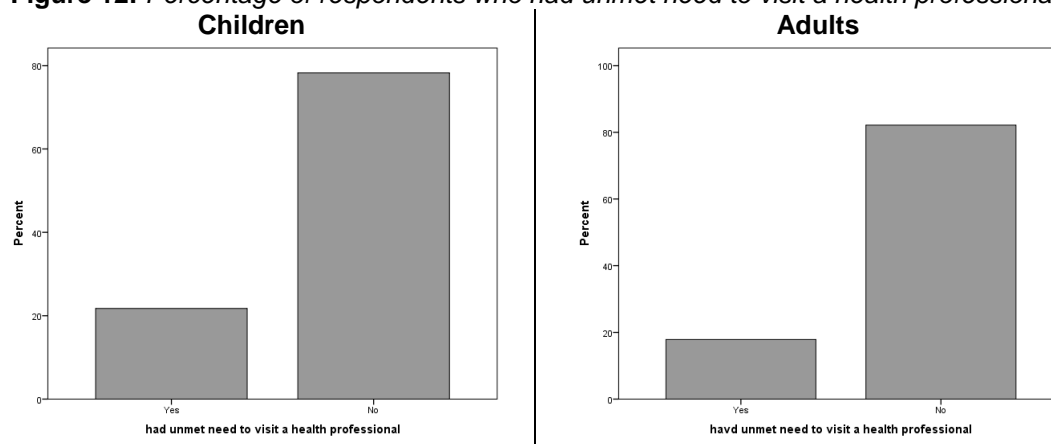
As shown in figure 13, a little over half of the parents (about 52%) as well as nearly 42 percent of adults pointed out that health professionals had a moderate understanding of albinism and how it affects quality of life of individuals.

Figure 13: *Level of understanding the effects of albinism by health professionals*
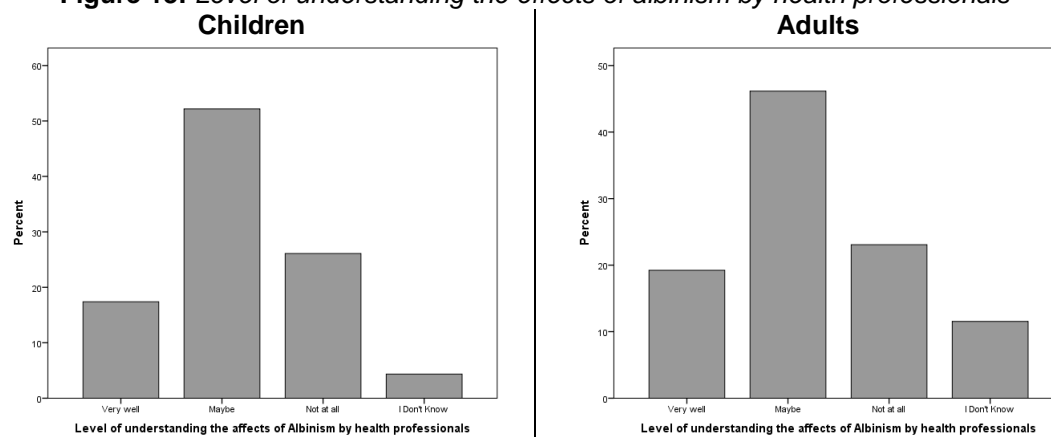
To further investigate this point, trustees were asked to describe how health professionals treat people in relation to them having albinism. All trustees agreed that health professionals do not have sufficient knowledge about albinism and tend to deal with people with albinism without giving extra attention to the requirements of albinism as a condition.

Health professionals have scant understanding of albinism, but they seem open to learn more.
- Interviewee 1 -
A lot of people are very unaware of what albinism is all about and I think even health professionals.
- Interviewee 2 -
Because there is very few of us, health professionals just treated us as the same as anybody else.
- Interviewee 3 -
My regular GP's have specific knowledge what my requirements are. But generally other doctors that I deal with don't take into any special consideration my albinism. New Zealand doctors are very allopathic. In other words, they see one symptom and they treat that symptom. They don't look at the whole person, there is no holistic medical practices in New Zealand and the general practice in the field. This is very bad. Not only for people with albinism but for the general public as well.
- Interviewee 4 -

In response to a question asking whether people with albinism had had a needs assessment[14], more than two-third of parents (about 70 %), as well as 17 out of 28 adults (about 61%) indicated that their children had their needs assessed before, whereas 17 out of 28 adults (about 61%) confirmed this (see figure 14). Unfortunately, the results showed that about 30 percent of children and 39 percent of adults had never had their needs assessed.

Figure 14: *Percentage of respondents who had needs assessment*

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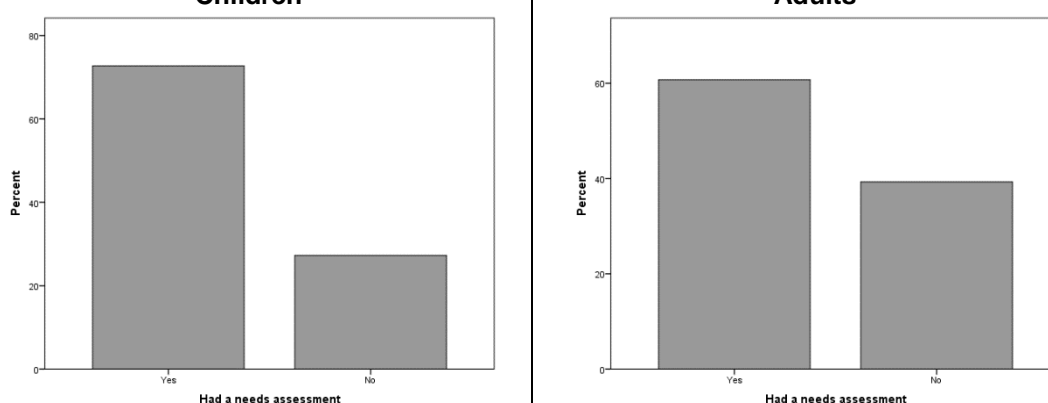
[14] According to the New Zealand Ministry of Health, Needs assessment is a systematic process that help to identify the needs of disabled people and outline what disability support services are available to them.

Furthermore, respondents were asked to determine when their last needs assessment took place. All children had their needs assessed within the last two years, whereas about three quarters of adults had one more than two years ago.

At the end of this section, respondents were asked two important questions. First, they were asked to assess whether their children/they had the ability to access health and wellbeing services. As shown in table 9 over half of the parents (about 52%) and a little under half of adults (about 46%) indicated that their access health and wellbeing services was reasonable. In contrast, approximately 9 percent of parents and 11 percent of adults saw it as difficult.

Table 9: The ability to access health and wellbeing services

	Children		Adults	
	Count	Percentage	Count	Percentage
Easy	9	39.1%	12	42.9%
Reasonable	12	52.2%	13	46.4%
Difficult	2	8.7%	3	10.7%
Total	23	100%	28	100%

Secondly, participants were required to determine how satisfied they are with services and support provision. Table 10 shows that the most commonly occurring responses among parents were "Very satisfied" and "Somewhat satisfied" with a little under half of them (about 48%) answered in that way, whereas, the most commonly occurring response among adults was "very satisfied", with about 46 of them answering in that way.

Table 10: Satisfaction with service and support provision

	Children		Adults	
	Count	Percentage	Count	Percentage
Very Satisfied	11	47.8%	13	46.4%
Somewhat satisfied	11	47.8%	11	39.3%
Somewhat dissatisfied	1	4.4%	2	7.1%
Missing (No answer)	-	-	2	7.1%
Total	23	100%	28	100%

During the interviews, trustees were asked to assess the existing health and wellbeing services. Their responses reflected how dissatisfied they were with the current situation.

> *I feel health and wellbeing services are evolving but have a long way to go. Health is the complete state of Mental, Physical and Social wellbeing not merely the presence of disease or infirmity (WHO Definition).*
> **- Interviewee 1 -**

Nobody throughout all of my life has ever told me that I have albinism. It was me who spoke to my ophthalmologist about who should I belong, you know, to the blind society because it could help with transport issues and things like that and she said oh yes you could. And she gave me the form.

- Interviewee 2 -

I didn't know much about health services. They are pretty poor actually. I have never asked for help because I actually didn't really know where to go or what to do. My parents realised at my very young age that I would need specialised optical help. So they made provision for me to have the assistance with the best optometrist they could find.

- Interviewee 3 -

In general, the health service have not catered to people like people with albinism in any positive manner. They are non-existent.

- Interviewee 4 -

4.5 Education:

This section aims to investigate whether people with albinism have equal opportunities to learn and develop their skills.

In the beginning of this section of the questionnaire, all adults were asked to identify their highest educational qualification. As shown in table 11, approximately 43 percent of respondents hold a level 7 qualification or higher, whereas nearly 36 percent of respondents had a qualification less than a level 5 diploma.

Table 11: *Adult respondents by their highest educational qualification*

	Count	Percentage
Less than level 5 Diploma	10	35.7%
Level 5 or 6 Diploma	3	10.7%
Bachelor degree or equivalent	8	28.6%
Postgraduate qualifications	4	14.3%
Missing (no answer)	3	10.7%
Total	28	100%

After that, both parents and adults were asked whether their child/they are currently enrolled in an education or training programme. Table 12 shows that approximately 70 percent of children with albinism were enrolled in or receiving educational support, whereas, nearly 30 percent of children were not. On the other hand, only four of them (about 14%) answered "Yes".

Table 12: *Respondents who are currently enrolled in education or training programme*

		Children	Adults	Total
No	Count	7	24	31
	% within Survey	30.4%	85.7%	60.8%
Yes	Count	16	4	20
	% within Survey	69.6%	14.3%	39.2%
Total	Count	23	28	51
	% within Survey	100%	100%	100%

Also the results indicated that all children (100%) were attending regular school and classrooms within the mainstream. In comparison, two of the adults were studying full time, while the other two were doing it part time. Two were enrolled in secondary schools, one was attending a tertiary level course, and one was doing a correspondence programme.

After that, parents were asked whether their child had an educational needs assessment through The Blind and Low Vision Education Network NZ (BLENNZ). As shown in the table 13 below, three quarters of those who were enrolled in or were receiving early childhood education (75%) had their needs assessed by BLENNZ.

Table 13: *Had an educational needs assessment through BLENNZ*

		Frequency	Percent	Valid Percent
	Yes	6	26.1	75.0
	No	2	8.7	25.0
	Total	8	34.8	100.0
Missing	Not applicable	15	65.2	
Total		23	100.0	

The discussion with trustees revealed that BLENNZ is providing students with albinism with significant help.

> *Generally, the ones who are getting BLENNZ support. In which case, most cases from what I can hear that are getting that extra support BLENNZ are going into the schools working with the teachers and the principals etc. ensuring that this sort of person does have the support they need.*
> **- Interviewee 4 -**

From different sorts of adaptations, parents were asked to determine what support is available for their child at school. Table 14 shows that seating close to the board and sitting with back to the window were the most common adaptations available for those queried. Adaptations and aids such as protection from sunlight from windows, teacher aide assistance, and computer access came next.

Table 14: *Adaptations and aids received at school by Children*

Adaptations	Percentage
Sitting with back to the window	57.1%
Protection from sunlight from Windows	14.3%
Seating close to the board	57.1%
Teacher aide assistance	14.3%
Computer access	14.3%

On the other hand, adults were asked to identify what kind of support they are receiving to assist them in their study. Table 15 shows that the most common assistance they received were "print materials in alternative formats" and "extra time for assignments and exams".

Table 15: *Adaptations and aids received at school by Adults*

Kind of support	Percentage
Adaptive computer equipment	50.0%
Print materials in alternative formats	75.0%
Tests and exam in alternative formats	50.0%
Extra time for assignments and exams	75.0%
Orientation and mobility support	50.0%
Readers	50.0%
Notetakers	25.0%

When asked whether their child/they have an unmet need for educational support, about 57 percent of parents indicated that their child had no unmet need for support at school, whereas, almost 43 percent confirmed that their child had so (see figure 15). Parents specified some required needs such as an orientation for the transition to school and help with the cost of medical treatment. In contrast, two out of four adults from those who were studying indicated that they had unmet needs for adoptive and computer equipment.

Figure 15: *Percentage of children who require other support at school*
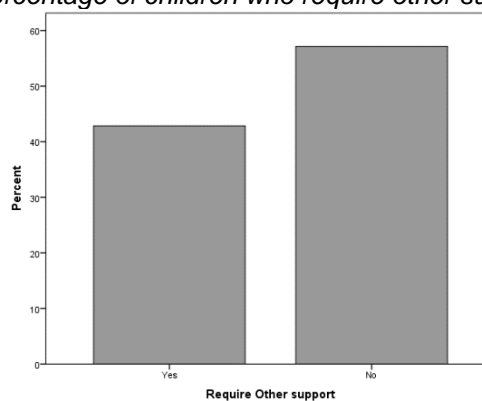
Respondents also were asked to assess whether education professionals such as teachers understand the ways in which albinism affects the quality of life. Nearly 86 percent of

parents and three out of four adults indicated that educational professionals had a moderate understanding of the condition and its impacts.

At the end of this section, adults were asked to self-assess their educational performance. Generally, participants tended to have a quite good academic performance with two out of four had a very good performance, one had a good performance, and one had a fair performance.

During the interviews, trustees were asked to assess the current education system. All responses actually emphasised that the current education system is much more compatible with the needs of disabled people including people with albinism - especially those who are members of the blind foundation as they have access to BLENNZ's services - than before.

I was educated at a time when there was little or no provision for or awareness of learning needs. At the age of fifteen I was functionally illiterate and well behind my peers. But now educational support is available from the start for children who are blind or have low vision.
- Interviewee 1 -

I think now there is more help in schools because I know people with problems can ask for assistance for example larger print or clear printing and I know that was never there years ago. I just went through the normal system so that managed my own way.
- Interviewee 2 -

My education experience was one of quiet suffering, a lot of school work was done after school, coping notes, revising just on my own. A lot of teachers back then did not really know to do with me. The education system was pretty rough. They really didn't know what to do with me. Because with this very short sight and that I couldn't even read the blackboard but I think it's recognised now. And there's more facilities for people with short-sighted and they don't treat us as something different.
- Interviewee 3 -

I came through the system as baby boomers after the Second World War. More of us then there was facilities to teach us properly. So anyone with the disability got - fell through the gaps in the system. In today's age, there is a little bit more improvement in so far as those that are entitled to services from BLENNZ.
- Interviewee 4 -

4.6 Employment:

The purpose of this section is to investigate whether adults with albinism obtain meaningful employment of their choice.

First, participants were asked whether they ever received any support to find, maintain, or/and return to work. Of those who answered, nearly 65 percent of participants never received any, while about 35 percent received some assistance. Further, participants who received assistance were asked to determine what agencies provided them with employment-related support. As shown in table 16, participants relied most on agencies that provide support specifically for disabled people. When asked whether the support of these agencies helped them to find work, about 44 percent of those who answered the question reported that these agencies helped them very much. In contrast, nearly 22 percent pointed out that the support they received did not help much. Also about the same percentage saw that the support of these agencies did not help at all (see Figure 16).

Table 16: *Source of employment related support*

Agency	Percentage
Employment services (not related to disabled people)	38.5%
Employment services for disabled people	46.2%
Career and employment services of an education provider.	23.1%
Other	23.1%

Figure 16: *The degree of help of the employment services*
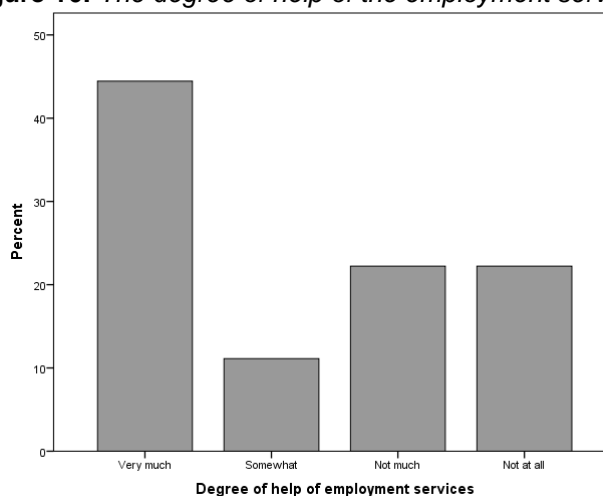
During the interviews, trustees emphasised that employment services for disabled people are theoretically good. But when it comes to practice, they need to be improved.

Government's policies regarding employment seem poorly organised and controlling.

- Interviewee 1 -

I know Workbridge, they assist people in getting work or help for anything that they might need in the workplace so that is the role which I've already

used in the recent times but I understand that they're very helpful and useful and a good place to get help, advice and support.
- Interviewee 2 -
I would say that getting support to find work is a good idea because if they don't do that, they've got to support you anyway. So you might as well do and feel as though you are a part of the community.
- Interviewee 3 -
I've had six different consultants through my employment history. Only one tried his hardest to give me some employment. But no one else. Basically they just push it back on to me. No help whatsoever as far as I was concerned.
- Interviewee 4 -

After that, participant were asked to specify the point of time when they tend to disclose their impairment to their employer/intended employer. As shown in table 17, about 44 percent of those who responded mentioned that they revealed their vision impairment at the time of an interview, while nearly 35 percent preferred to reveal it when a need arises.

Table 17: *Revelation of vision impairment*

		Percent	Valid Percent
	In my application	14.3	17.4
	At the time of an interview	35.7	43.5
	When the need arises	28.6	34.8
	I don't disclose at all	3.6	4.3
	Total	82.1	100.0
Missing	No answer	7.1	
	Not applicable	10.7	
	Total	17.9	
Total		100.0	

The discussion with the trustees revealed that disclosing the person's impairment is a decisive decision which significantly affects the individual's ability to get the job.

I never admitted that I have vision impairment. Because I always felt that would jeopardized me getting a job. So I have always muzzled my way to and pretended on the sort of normal.
- Interviewee 2 -
When I did apply for jobs that as soon as they saw you had a short blonde hair, and they said "Oh! You're blind." Now that just under one roof they didn't give you a chance or a go. I did feel it, and it's a big fight to prove that you can do it.
- Interviewee 3 -
When I reach the interview process, and they see a guy walk whose reading something up close, they think what the heck I got to provide for them now.
- Interviewee 4 -

As shown in figure 17, approximately 57 percent of the respondents had no paid work, whereas, nearly 43 percent were employed.

Figure 17: *Employment status*
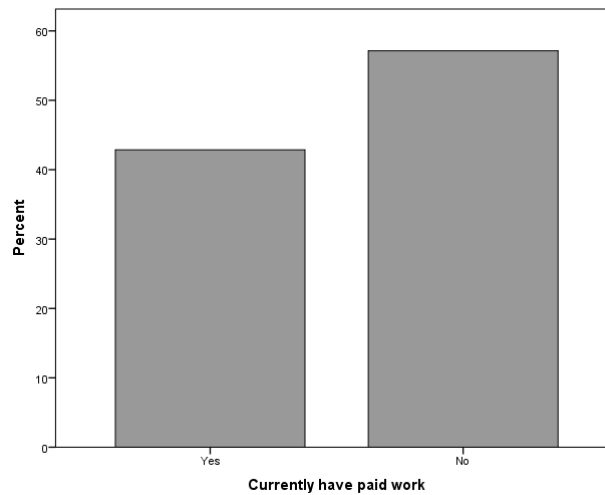
Of those who had paid work, three quarter (75%) held a permanent position. When asked how many hours they work per week, nearly 67 percent of employed respondents were working 35 hours and over (full time) (see figure 18 and figure 19). Further, participants were asked to identify their current occupation. The responses to this question showed that most of the positions they hold require quite high qualifications such as health assistant, economist, psychotherapist, teacher, social worker, technology support co-ordinator, and server admin/web developer. Some also hold talented-related positions such as musician or athlete.

Figure 18: *Nature of work*
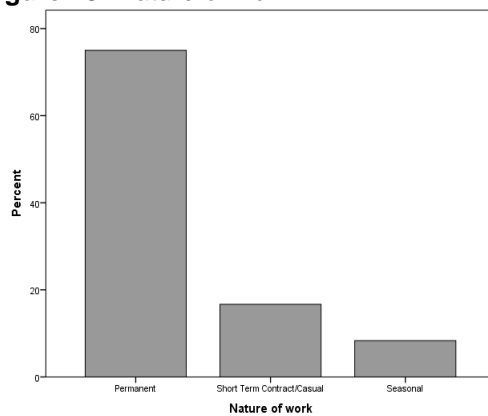
Figure 19: *Weekly working hours*

Table 18: *Number of years at current paid work*

		Percent	Valid Percent
	5 years or less	10.7	37.5
	6 to 9 years	10.7	37.5
	10 years and over	7.1	25.0
	Total	28.6	100.0
Missing	No answer	14.3	
	Not applicable	57.1	
	Total	71.4	
Total		100.0	

Subsequently, participants were asked to specify how satisfied they are with some workplace aspects. The results among respondents who answered the question were summarised in table 19. These results indicated that nearly half of the respondents were somewhat satisfied with their work environment, whereas, they tended to be very satisfied with tasks, promotion, and social opportunities within their workplace.

Table 19: *Workplace satisfaction*

	Supportive work environment	Fit with your qualifications and interests	Opportunities for advancement	Social opportunities
Very satisfied	42%	67%	50%	58%
Somewhat satisfied	50%	25%	25%	25%
Somewhat dissatisfied	8%	8%	25%	8%
Very dissatisfied	0%	0%	0%	8%

Furthermore, participants were asked to determine what accommodations are made available for them at their workplace. Table 20 shows that having adaptive or modified equipment were the most common accommodations available for those who had paid work with almost 60 percent of the respondents answered in that category. Participants were also asked whether they have unmet needs for support within their workplace. As shown in figure 20, three quarters (75%) of them said no. In contrast, there were 25 percent of participants pointed out that they required support especially with things such as adaptive technology and transportation.

Table 20: *Accommodations available at work*

Accommodations	Percentage
Adaptive or modified Equipment	60.0%
Modified Workspace	20.0%
Modified Responsibilities	20.0%

Figure 20: *Need support at work*
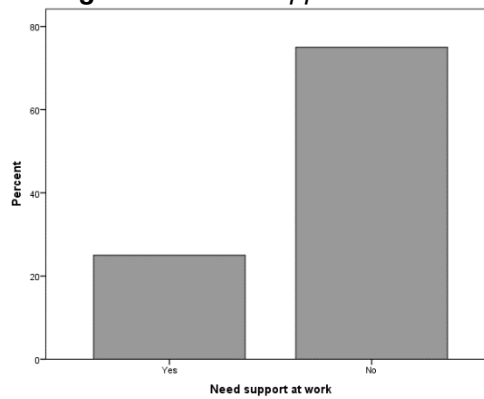
Eventually, participants who have paid work were asked to identify how satisfied they are with their current job. Figure 21 shows that participants tended to be somewhat satisfied with their occupation with half of them answering in that way.

Figure 21: *Satisfaction with current job*
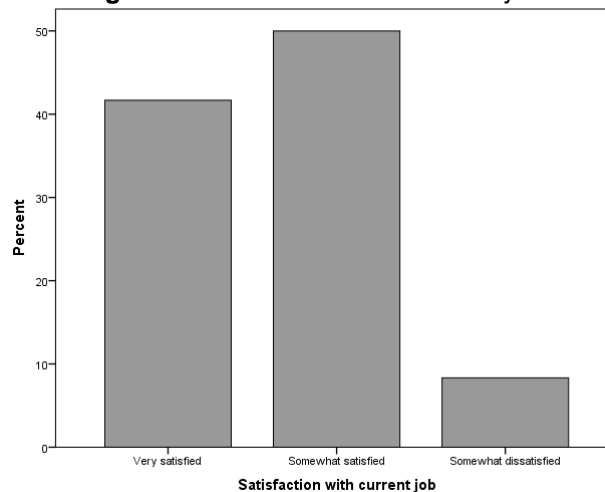
On the other hand, respondents were asked to give reasons why currently they do not have paid work. Due to age, difficulties in doing their job, or difficulties in meeting their employer expectations, nearly 44 percent of the respondents reported that retirement was the main factor of not having paid work at this stage, whereas, obstacles such as "limitation in the kind of work you could do", "limitation in the amount of paid work you could do", and "find it difficult to look for work" were the less commonly occurring responses (see table 21).

Table 21: *Reason of not having paid work*

	Frequency	Percent	Valid Percent
Retired	7	25.0	43.8
Limitation in the kind of work you could do	2	7.1	12.5
Limitation in the amount of paid work you could do	2	7.1	12.5
Find it difficult to look for work	2	7.1	12.5
Other	3	10.7	18.8
Total	16	57.1	100.0
Missing Not applicable	12	42.9	
Total	28	100.0	

During the interviews with the trustees, they were asked to clarify how albinism affects their ability to find or maintain work. The discussion with the trustees revealed that albinism - and its associated vision problems - has a significant influence on individuals' ability to find and maintain work. It also limits their ability to find the type of work that fits with their skills.

> *It has limited the options and choices I had. Since learning to read and discover the fabric of life I have selected a profession and thanks to support of the medical profession trained and qualified as a community nurse. This required solid assessment by and supervision of a low vision ophthalmologist and senior medical team who enabled me to have a go.*
> **- Interviewee 1 -**

> *It stops me taking different paths, ultimately because I sort of doubt my ability to do something because of not being able to see.*
> **- Interviewee 2 -**

> *Most employers favoured a sighted person rather than individual like myself. Thus the work that I did was really labouring, cleaning and other manual duties. "I was better than that".*
> **- Interviewee 3 -**

> *From my own personal case, majorly affects it. It affects it significantly. When I first started work, or applied for work, the general unemployment rate was less than 1%. It was almost non-existent. Those that were unemployed were those that did not want to work and found excuses not to work. I applied for 380 jobs, before I got a job. I got that job because of referral from a friend of a friend of my parents, and then from that point it was my own work ethic and my own intelligence that gave me an employment.*
> **- Interviewee 4 -**

4.7 Income:

The purpose of this section is to investigate whether adults with albinism get income support to assist their independence and their choices.

Firstly, participants were asked to determine their source of income. Table 22 shows that investments and dividends were the most common source of income among participants with 44 percent answered in that category, while income from wages and salaries came next with 36 percent. Also income from self-employment and New Zealand Superannuation were the third most common responses with 32 percent.

Table 22: *Source of Income*

Income Type	Percentage
Wages, Salary, commissions, bonuses etc. paid by employer	36%
Self-employment, or business you own and work in	32%
Interest, dividends, rent, other investments	44%
NZ Superannuation	32%
Other Superannuation, pensions, annuities	4%
Unemployment Benefit	4%
Invalid's Benefit	16%
Student Allowance	4%
Other sources of income	12%
No or Not Stated	12%

Discussion with the trustees underpinned the statistical results above. The trustees indicated that people with albinism were less likely to have access to income support initiatives for disabled people such as the invalid benefit. In the past the invalid benefit was only available for those who are members of the Blind Foundation. But nowadays only people who are totally blind can have access to such initiatives which have become means-tested.

> *Modern times have seen re-organisation of what was once referred to as 'Invalids Benefit – Blind" Some people with albinism qualified as 'Legally Blind' to have this help which was non means tested and offset the costs of their blindness.*
> **- Interviewee 1 -**
> *I can only talk from my personal experience. I have never got a benefit because of my disability. Never. The only one would have been is the - what was the old blind benefit but that got changed.*
> **- Interviewee 4 -**

After that, respondents were asked to identify their personal and household annual income. As shown in table 23, approximately 27 percent of the respondents had an annual personal income between 24 to 28 thousand dollars. In contrast, about 23 percent had a gross personal income less than 15 thousand dollars a year, whereas, 36 percent of the respondents had an annual household income of 48 thousand dollars or more.

Table 23: *Annual income*

		Personal Income		Household income	
		Percent	**Valid Percent**	**Percent**	**Valid Percent**
Gross	Less than $15,000	21.4	23.1	7.1	8
Income	$15,001 to $24,000	14.3	15.4	10.7	12
	$24,001 to $48,000	25	26.9	28.6	32
	$48,001 or more	21.4	23.1	32.1	36
	Not stated	10.7	11.5	10.7	12
	Total	92.9	100	89.3	100
Missing	No answer	7.1		10.7	
Total		100		100	

At the end of this section, participants were asked about their ability to manage their finances with their current income. Figure 22 shows that the most commonly occurring responses were "I manage very well" and "I struggle a little" with a little less than half (about 46%) of the respondents answered in those categories. In contrast, only two out of twenty four (about 8%) of the respondents confirmed that they financially struggle a lot.

Figure 22: *The ability to manage with current income*
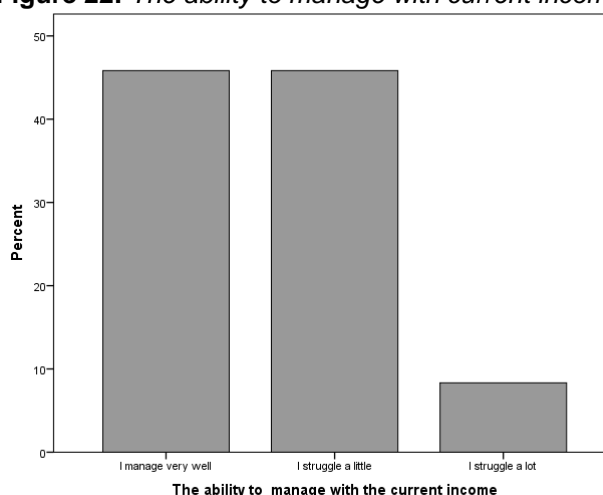
4.8 Transport:

The Section aims to investigate whether people with albinism have available, accessible, and affordable transport.

In the beginning of this section, adults were asked to clarify where they are able to drive a private motor vehicle. It was not surprising that almost all (about 96%) of them were not permitted to drive their own vehicle in New Zealand.

When asked whether their child/they rely on public transport such as trains, buses, ferries to travel short distances, a little more than third of the children (about 36%) relied on public transport to travel short distance, whereas, 14 out of 22 (about 64%) of them were not using it. In contrast, approximately 70 percent of adults depended mainly on public transport for the purpose of personal mobility (see figure 23).

Figure 23: *Percentage of respondents who used public transport*

Children — **Adults**
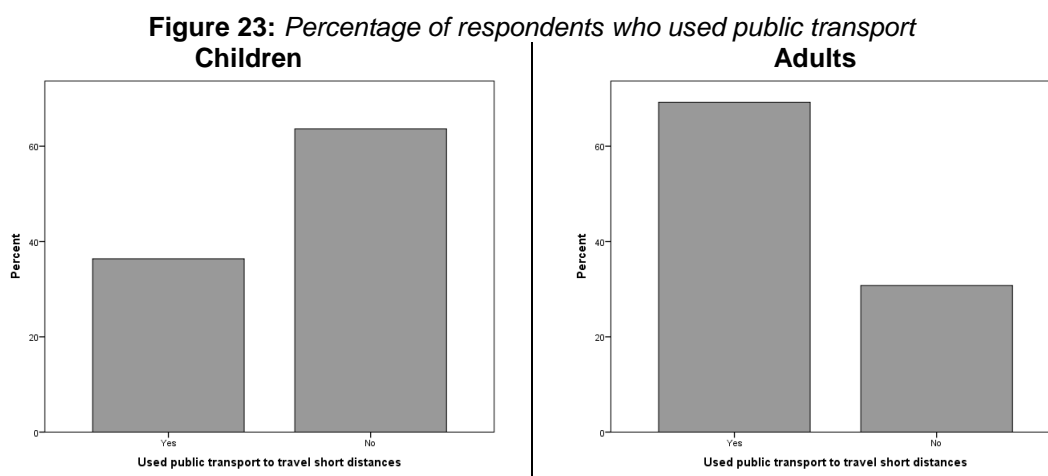
To know how albinism affects the ability to use public transport, participants were asked to determine whether they have difficulties using public transport. Figure 24 shows that nearly 63 percent of parents confirmed that their child had no difficulties, whereas, approximately 37 percent of children face some barriers. On the other hand, 64 percent of adults who answered the question reported that they also face some difficulties while using public transport because of their condition.

Figure 24: *Percentage of respondents who have difficulties using public transport*

Children — **Adults**
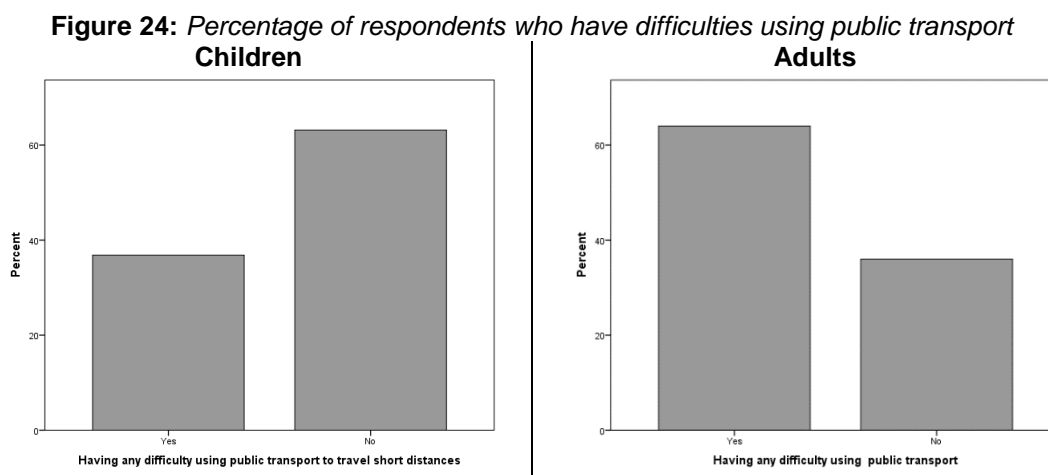
Further, respondents were asked to specify what difficulties their child/they face. Table 24 shows that "Identifying the right bus, train, tram or ferry" received the maximum response among parents (about 17%). Difficulties such as "getting to or finding the stop", "getting on or off "came next. On the other hand, the results indicated that identifying the right services was also the most commonly occurring difficulty that adults face with nearly 79 percent answered in this way, whereas, getting information about timetable and routes and dealing with staff who are not helpful came next.

Table 24: *Difficulties while using public transport*

	Children		Adults	
	Count	Percentage	Count	Percentage
Difficulty getting to or finding the stop	2	11.1%	4	16.7%
Waiting at the stop	-	-	1	4.2%
Getting on or off	2	11.1%	3	12.5%
Identifying the right bus, train, tram or ferry	3	16.7%	19	79.2%
Getting information about timetables or routes	1	5.6%	9	37.5%
Staff who are not supportive or helpful	1	5.6%	6	25%
No difficulties	5	27.8%	5	20.8%
Other	9	50%	1	4.2%
Missing (No answer)	6	33.5%	4	16.7%

Also the trustees summarised the most common difficulties that people with albinism face while using public transport. Their comments also emphasised that people with albinism rely on the staff to make sure that they use the right service.

I cannot see timetables and transport markings or destination.   When on a bus do not know where I am so depend on driver to tell me and let me off.
- Interviewee 1 -
I think identifying the service you want like reading the best sign perfectly better but on reading trains. I went to the train stations recently and I usually use the train and so I did ask somebody just to make sure I am on the right train because of that is a little harder to see. The electronic bus signs they had, I see they are changing them now for white ones which are very much clearer to see much brighter.
- Interviewee 2 -
I know the time tables on the bus stops. Boy! They are hard to see. Most bus drivers can help you, but us with albinism we really like to be in the peanut, don't we? And don't want to be and make people draw into you because you can't see.
- Interviewee 3 -
Apart from reading signs, as long as I investigate - I got to investigate beforehand to know what or which bus I'm going to catch or which train etc. Work out where or how long where I'm going to go.
- Interviewee 4 -

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Moreover, the trustees highlighted that having access to new technologies such as digital cameras, GPS, and smartphones can make individuals with albinism more independent while using public transport.

> *I use smartphone a lot. It is great. I do always check before I leave home or I always use it in the bus stop that is quite I really like it.*
> **- Interviewee 2 -**
> *I do know about cameras on the phone, they can take the photo of it and bring it a bit bigger. Just to read it.*
> **- Interviewee 3 -**
> *As long as your service provider's GPS coordinating system is working probably, it will be a bit easier.*
> **- Interviewee 4 -**

Using taxis as an alternative way to travel short distances was also been investigated with the survey participants. The research findings indicated that almost all parents (about 91%) confirmed that their child did not use taxis at all. On the other hand, about 35 percent of the adults confirmed that they did not use taxis at all, whereas, nearly the same percentage (35%) used taxis at least once a week and approximately 31 percent of them use taxis on monthly basis.

When asked to determine the primary reason why they do not use taxis, approximately 43 percent of all the respondents indicated that their child/they do not need to or cannot afford to (see table 25). Respondents also gave other reasons such as their child is too young and there is no taxi service available where they live.

Table 25: *Primary reason of not using taxis*

		Children	Adults	Total
Don't need to use taxis	Count	9	4	13
	% within Survey	42.9%	44.4%	43.3%
Too expensive	Count	11	2	13
	% within Survey	52.4%	22.2%	43.3%
Other	Count	3	3	4
	% within Survey	33.3%	33.3%	13.3%
Total	Count	21	9	30
	% within Survey	100%	100%	100%

Moreover, they were asked whether they are aware of total mobility scheme[15]. As shown in table 26, more than three quarters of parents were not aware of such initiative. In contrast, most (about 85%) of the adults were aware of it.

Table 26: *Aware of Total Mobility Scheme*

		Children	Adults	Total
Yes	Count	5	22	27
	% within Survey	22.7%	84.6%	56.3%
No	Count	17	4	21
	% within Survey	77.3%	15.4%	43.8%
Total	Count	22	26	48
	% within Survey	100.0%	100%	100%

4.9 Accessing information:

This section aims to determine how adults with albinism access information.

First of all, participants were asked to identify what formats they prefer in order to access information. As shown in table 27, respondents tended to prefer digital and large print materials with approximately three-quarters of them answered in these categories. Whereas, nearly 22 percent of those how answered the question preferred to use audio recorded materials to gather information. The responses to this question also showed that nobody of those who queried access information in Braille format.

Table 27: *Preferable formats to access information*

Format	Percentage
Large Print Materials	73.9%
Audio recorded Materials	21.7%
Digital Materials such as emails, web searches	78.3%
Other	8.7%

When asked to specify their frequency of reading, most (about 80%) of the participants read on daily basis (see figure 25). Further, participants were asked to identify their purposes of reading. As shown in table 28, "gaining information" as a purpose of reading received the most responses with 84 percent of the respondents answered in that category. Also purposes such as reading for pleasure and reading for work received high responses in comparison to reading for study purposes. Moreover, participants were asked to determine what materials they usually read. Table 29 shows that the respondents were more likely to read books with most of them (80%) answered in that category. On the

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[15] The Total Mobility Scheme provides subsidised taxi services to disabled people.

other hand, reading other materials as respondents specified such as reading work related materials received the lowest responses.

Figure 25: *Frequency of reading*
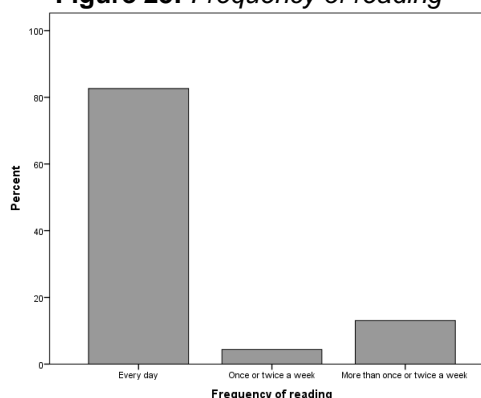
Table 28: *Purposes of reading*

Purpose	Percentage
For work	52%
For study	32%
For pleasure	72%
To gain information	84%
Other	8%

Table 29: *Reading materials*

Materials	Percentage
Newspapers	60%
Magazines	44%
Books	80%
Journals	24%
Educational materials	44%
Other	12%

Subsequently, participants were asked to indicate the level of importance of some sources of information such as the internet, television, newspaper, radio, and other people such as family and friends. As shown in table 30, the internet tended to be the most important source of information with 84 percent of the respondents indicated that. In contrast newspapers tended to be the least important source of information among the research participants.

Table 30: *Level of importance of some sources of information*

	Not important	Neutral	Important
The internet	16%	0%	84%
Television	30.8%	34.6%	34.6%
Newspapers	62.5%	12.5%	25%
Radio	34.6%	11.5%	53.9%
Family and friends	3.8%	30.8%	65.4%

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Based on the information above, it was not surprising that nearly 81 percent of the respondents used the internet. On the other hand, there are about 19 percent who were not internet users (see figure 26). However, table 31 shows that desktop computers or smartphones were the most commonly used devices to access the internet among the research participants with a little over three quarters (about 76%) of them answered in these categories. Also laptops and tablets tended to be common devices that the participants used to access the internet. In contrast, participants were less likely to access the internet using smart televisions.

Figure 26: *Percentage of adults who use internet*
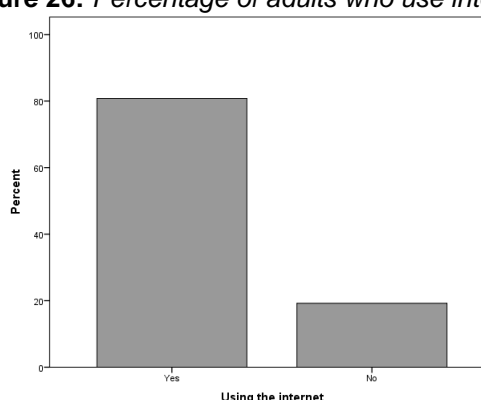
Table 31: *Internet compatible devices available at home*

Devices	Percentage
a desktop computer	76.2%
a laptop computer (or notebook)	61.9%
a smartphone	76.2%
a tablet (e.g. iPad or an Android tablet)	61.9%
a game console (Xbox, PlayStation, Wii)	19.0%
a smart television, i.e. an internet capable television	9.5%
Other	4.8%

At the end of this section respondents were asked to identify the purpose of using the internet. Almost all (about 95%) of the respondents agreed that the primary purpose of using the internet is communication and to keep in touch with other people. Gathering information was the second purpose for using the internet among participants with approximately 86 percent of the respondents answered in that category. However, table 32 summarise the responses to this question.

Table 32: *Purposes of using the internet*

Purpose	Percentage
For work	57.1%
For school/study	38.1%
To keep in touch with people	95.2%
To gather information	85.7%
For pleasure	76.2%
Other	9.5%

4.10 Housing:

This section aims to investigate whether adults with albinism have a secure, accessible, affordable, quality home in the community.

Firstly, participants were asked to determine what sort of housing they live in. Table 33 shows that about two-thirds (about 69%) of the respondents were living in their owned/rented home. Subsequently, they were asked to identify how long they have been living in their current house/apartment. The majority of the respondents (about 81%) had lived in their house for at least one year. In contrast, nearly 19 percent of them had moved to their house less than one year before.

Table 33: *Form of housing*

		Frequency	Percent	Valid Percent
	My own place (rented or owned) with or without family	18	64.3	69.2
	Renting a place with friends	5	17.9	19.2
	My parents' home	2	7.1	7.7
	A residence at school	1	3.6	3.8
	Total	26	92.9	100.0
Missing	No answer	2	7.1	
Total		28	100.0	

After that, participants were asked to assess the house where they currently live. Table 34 shows that overall respondents tended to be very satisfied with the security, accessibility, affordability, and quality of their current house.

Table 34: *Satisfaction with housing*

	Security	Accessibility	Affordability	Quality
Very satisfied	61%	65%	64%	54%
Somewhat satisfied	27%	27%	16%	23%
Somewhat dissatisfied	8%	4%	12%	15%
Very dissatisfied	4%	4%	8%	8%

During the interviews, trustees were asked to determine how albinism affects the individuals' choices of housing. Their responses focused mainly on the location of the house and how it should be close to the public transport in order to facilitate their personal

mobility. One other thing that was mentioned affordability as an issue – especially for those who financial difficulties.

> *I need to choose a place that is close to public transport and that is going to get me to and from work. That's the criteria that I always look for. Also brightness is often an issue that's why I tinted my windows to block the glare. So I always need to fix thing like that.*
> **- Interviewee 2 -**
> *It's probably one area we are no different from anyone else. From what I can establish. The big thing with housing is, can you afford it? And if you have not been able, through the education system has failed you for whatever reason, you haven't been able to get into a decent housing, with financial constraints, then yes your albinism has affected your housing - you're choices of housing.*
> **- Interviewee 4 -**

4.11 Discrimination:

This section aims to investigate whether adults with albinism have equal rights to not be discriminated against in their community.

In response to a question asking whether they experienced discrimination of any kind during the prior 12 months, about 62 percent of the respondents said no. In contrast, 10 out of 26 (about 38%) of the respondents confirmed that they had been discriminated against over the last year. 70 percent of them were discriminated against in three or less than three occasions, while 30 percent had that experience over three times (see figure 27 and figure 28).

Figure 27: *Experienced discrimination*   **Figure 28:** *Frequency of discrimination*
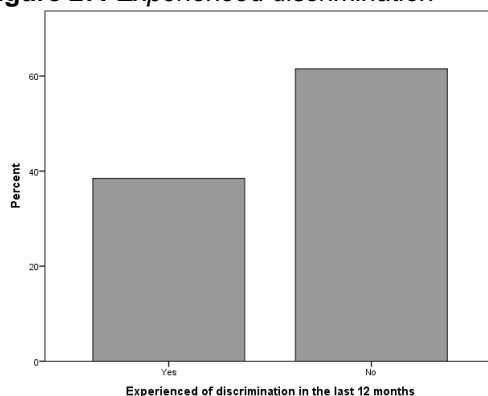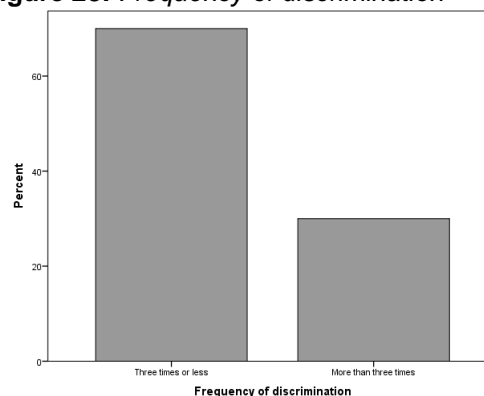
Subsequently, participants were asked to specify in which areas of interaction with others they faced some sort of discrimination. Table 35 summaries the responses to this

question. The results indicate that the respondents were more likely to be discriminated against in public palaces, vehicles, and facilities during the last year - with half of the respondents answered in that category. Also 40 percent of respondents confirmed that discrimination within employment came next. When asked whether they had ever made a complaint to the Human Rights Commission because of unlawful discrimination against them on the grounds of their disability, all respondents said no.

Table 35: *Areas in which adults with albinism experienced discrimination*

Areas	Percentage
Employment	40.0%
Education	20.0%
Government activity	20.0%
Places, vehicles, and facilities	50.0%
Goods and services	20.0%
Other	10.0%

Furthermore, the responses of the trustees confirmed the statistical results above. They are personally experienced a direct discrimination at work and school. At work some of them were prevented to get promoted, whereas, at school some of them were subject to bullying. Also some reported some indirect discrimination and negative attitudes while dealing with other.

> *I think discrimination is there indirectly but I've never had it quite so direct personally. I usually get that feeling but I do sometimes. I often think that I can't see people's expressions or whatever, I think maybe that is a good thing sometimes. Because even my children would say to me, you see that way that lady look at you, I said no I didn't notice. Also I think sometimes you are not chosen for something but was somebody else's but nobody is going to say that to you. In the paper, I read just last week that a lady not with albinism but with the visual problem who just refused to be given the discount in the bus because the driver thought she was not disabled.*
> **- Interviewee 2 -**
>
> *There is discrimination happening here. There is. Because soon as they see a blind here, and they just put you in that category. Too hard. For example when I was bowling they would say to me "What is he doing here, he's blind?*
> **- Interviewee 3 -**
>
> *There's instances where I was passed over for promotion, in my work place, knowing the person who did it had passed me over. I know it was discrimination but actually given to that and try to prove he did it that would stand up in an unemployment court was virtually impossible.*

Also I had a building at school. I was going up the stairs to the classrooms and a guy threatened me with a knife. And I lashed out very quickly with my school bag and whacked his hand with the knife into the wall and because of that, he got disoriented and actually tripped and fell down the stairs. And he reported me to the principal and I told the principal what really happened and that confirmed with what someone else had told the principal that had actually happened and from that point on I never got picked on - bullied ever.

- Interviewee 4 -

4.12 Relationships:

The purpose of this section is to investigate whether adults with albinism are able to make and keep relationships.

In the beginning, participants were asked how often they felt lonely during the last month. Table 36 shows that a little more than half (about 54%) of the respondents indicated that they sometimes felt lonely over the last month, whereas, about 39 percent of them never have that feeling within the same period of time.

Table 36: *Frequency of feeling lonely*

		Frequency	Percent	Valid Percent
	Never	11	39.3	42.3
	Occasionally	14	50.0	53.8
	Often	1	3.6	3.8
	Total	26	92.9	100.0
Missing	No answer	2	7.1	
Total		28	100.0	

Then, participants were asked whether they made face-to-face contact with family during their last month. Figure 29 shows that approximately 73 percent of the respondents contacted their families face-to-face, while nearly 27 did not. However, twelve out of twenty six (about 43%) of the respondents made about the right amount of contact with their families (see figure 30). Furthermore, participants were asked whether they were able to contact their friends on a face-to-face basis during their last month. Figure 31 shows that almost all (about 96%) of the respondents said yes. When they were asked to determine the level of contact with friends over the same period of time, half (50%) of the respondents indicated that they made about the right amount of contact with their friends (see figure 32).

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Figure 29: Face-to-face contact with family

Figure 30: *Level of face-to-face contact with family*

Figure 31: *Face-to-face contact with friends*
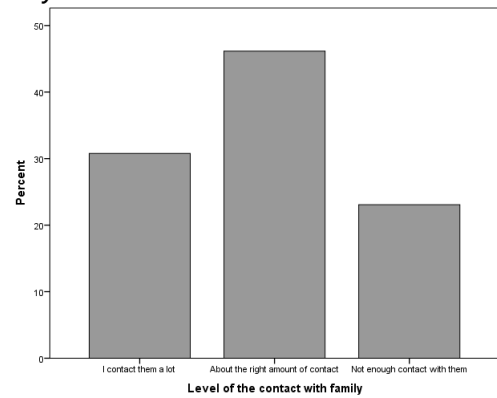
Figure 32: *Level of face-to-face contact with friends*
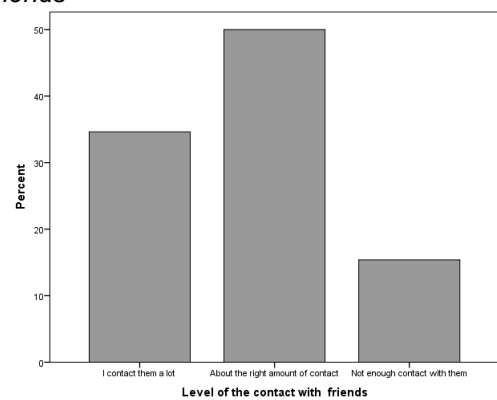
Subsequently, respondents were asked to identify the number of hours per week they spend on social and recreational activities. Table 37 shows that a little over a third (about 36%) spent a few hours (1 to 5) each week, while nearly 29 percent spent between 5 to 10 hours weekly on social and recreational activities, whereas, a quarter (25%) spent more than 10 hours a week. Also when asked whether they are reluctant to leave their home because of their albinism, nearly three-quarters (about 73%) deny that albinism had any influence on their decision to go out or stay at home (see figure 33).

Table 37: *Number of hours spends on social and recreational activities*

		Frequency	Percent	Valid Percent
	None	1	3.6	3.8
	One to 5 hours/week	10	35.7	38.5
	5 – 10 hours/week	8	28.6	30.8
	More than 10 hours/week	7	25.0	26.9
	Total	26	92.9	100.0
Missing	No answer	2	7.1	
Total		28	100.0	

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Figure 33: *The reluctance of leaving home because of albinism*
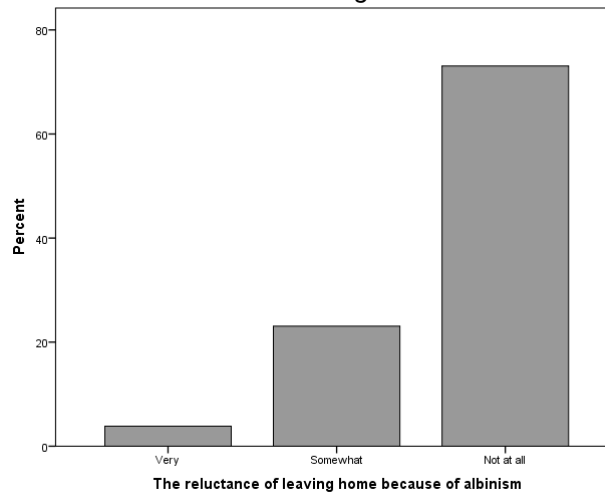
At the end of this section, participants were asked to describe how they find meeting new people and/or forming relationships. Table 38 shows that 13 out of 26 (about 46%) of the respondents found it easy to make relationships. In contrast, nearly 39 percent found it difficult to form relationships.

Table 38: Meeting new people and/or forming relationships

		Frequency	Percent	Valid Percent
	Easy	13	46.4	50.0
	Difficult	11	39.3	42.3
	Do not know	2	7.1	7.7
	Total	26	92.9	100.0
Missing	No answer	2	7.1	
Total		28	100.0	

Moreover, the trustees were asked to explain how albinism affect the ability to make and keep relationships. Their responses suggested that making relationships is slightly harder than keeping it. These difficulties in forming relationship were mostly because of vision impairment associated with albinism which may prevent them to make an eye contact with others. Also because people with albinism are more likely to get sunburn, they are not able to engage in some outdoor social activities where they can meet new friends.

To some extent albinism affects my ability to make and keep relationships. But I have a variety of very long term close and enduring relationships in spite of my Albinism. I cannot play Sport or Drive a car and get very bad sun burn so cannot share all the male pursuit's many others non albino take for granted.

- Interviewee 1 -

It's like even funnier, my brothers and sisters realised how I don't see so well. They used to make fun of me, play jokes on me when I was little, but I

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haven't been treated differently that I am aware of within my family and relatives. Also I haven't been treated differently by friends who know me either. Sometimes I find it harder to make friends. Albinism affects the ability more in the making relationship stage rather than the keeping. Because I think in starting the relationship often might experiences you have probably low self-esteem as a result of having albinism or visual disability that makes more difficult in forming the relationship or in starting the relationship or whatever. But I think when people accept me for who I am then I don't think keeping the relationship becomes an issue.

- Interviewee 2 -

As our family has children, albinism was the norm. I had myself and three sisters who have albinism. And one brother who was normally pigmented. So, the rest and my mother's, all my uncles and aunts and cousins just accepted us. That we were, there is nothing there. Friends, I've had some friends that have used my visual acuity - my lack or visual acuity to try and pour something over me. They are not my friends very long when they do that. The true friends are the ones that have been long term friends and they're still long term friends. Making new friends is difficult because when recognizing them, because people who pass on their car, oh didn't you see us cause you didn't wave out. I can't see who's in the car. It's almost impossible for me to tell who was actually in the motor vehicle. I can't see them. I know there is somebody in there but I can't see them.
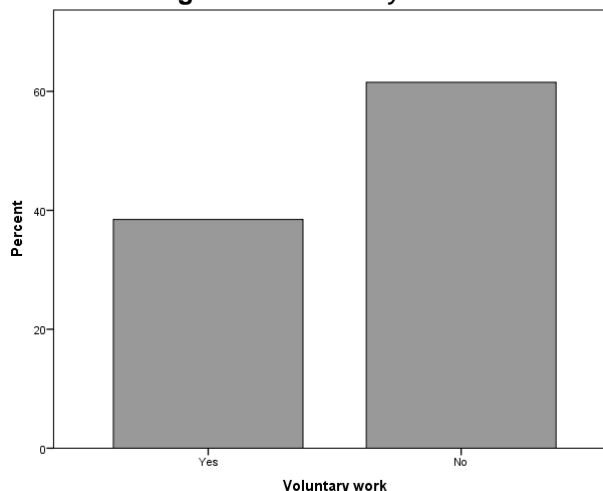
- Interviewee 4 -

4.13 Recreation:

This section aims to investigate whether people with albinism enjoy social, cultural and recreation activities of their choice.

Of adults queried, approximately 40 percent of participants were involved in voluntary work during their last four weeks, while nearly 60 percent did not (see figure 34).

Figure 34: *Voluntary work*

Then respondents were asked to choose what social and recreation activities their child/they enjoyed during the last month. Table 39 shows that all children went out with family or friends, while 18 out of 23 (about 82%) visited friends within the last four weeks, whereas, activities such as "played a team sport", "had music or art lessons (outside of school)", and "participated in club activities" were the less likely occurring responses among children with albinism. On the other hand, table 40 shows that the majority (about 92%) of the adults have been to a café, restaurant or pub. In contrast, adults were less likely to be a spectator at a sporting event.

Table 39: *Percentage of children who involve in some recreation activities*

Activities	Percentage
Had music or art lessons (outside of school)	18.2%
Played a team sport	31.8%
Done physical activity such as swimming or gymnastics	63.6%
Participated in club activities	18.2%
Gone out with family or friends	100.0%
Visited friends	81.8%
Gone away on a holiday	72.7%

Table 40: *Percentage of adults who involve in some recreation activities*

Activities	Percentage
Been to a theatre or cinema	25.0%
Been to a café, restaurant or pub	91.7%
Played sport	25.0%
Been a spectator at a sporting event	8.3%
Gone away on a holiday	29.2%

Subsequently, respondents were asked to identify what activities their child/they have difficulties to enjoy. As shown in table 41, half of the parents (50%) confirmed that their child face some difficulties that prevent their ability to play sport, whereas, playing with other children was the second commonly occurring response (about 45%). Also about 41 percent of parents indicated that the child has no difficulties. On the other hand, the majority (about 88%) of the adults confirmed that they do not have any difficulties in being engaged with such activities.

Table 41: *Frequencies of having difficulties to enjoy some leisure activates*

Activities	Percentage	Count
Playing with other children	45.5%	10
Playing sport	50.0%	11
Going away on a holiday	9.1%	2
Not applicable – no difficulties	40.9%	9

The interviews with the trustees provide additional information on how albinism affects the individuals' ability to enjoy recreation and cultural activities. Their responses suggested that albinism and its associated disorders limit the opportunities of individuals to be engaged in sports that require visual acuity. They have also stated that people with albinism tend to play singular sports than team sports. Other than this, people with albinism enjoy cultural and recreation activities as anyone else.

> *Albinism constrains and limits my ability to play sports but I have developed a wide variety of more passive leisure activities.*
> **- Interviewee 1 -**
> *My experience with sports at school was terrible because of my visual disability. But I have done sports. I used to do gymnastics and swimming. But I don't like swimming outdoors much because of the glare and really gets high to cope with. When I was a kid I use to screw up my face and go swimming, you know and go to the pool and go swimming. I also do a lot of walking, and things like I never found a bit of problem. Ball sports is more the issue. Also you know I don't really like team sporting and what sports I have done they tend to be more singular. I quite like music, shows and movies.*
> **- Interviewee 2 -**
> *I have always done individual sport. Like barefoot skiing, snow skiing, walking. I've always gave it a go but as far as team sports, you move back out on that one a bit.*
> **- Interviewee 3 -**
> *Sport is a big one. It's very almost impossible to see a cricket ball coming at you until it's too late to react. And that was actually one form of bullying at school. We had to play cricket, we had to play the rugby, we do athletics in high school and the first few years of high school we had to do it, it was a part of the compulsory education system. So sport, I did running as a sport. Moderately okay, nothing spectacular. But my recreation was music. I played guitar and semi-professional band since I left school.*
> **- Interviewee 4 -**

4.14 Quality of life:

Within this section, participants were directly asked to assess how the implementation of New Zealand Disability Strategy (NZDS) and United Nations Convention on the Rights of Persons with Disability (CRPD) were reflected in their child's/their life. Table 42 shows that nearly three quarters (about 77%) of parents did not know what the influence of both NZDS and CRPD was on their child's life, whereas, approximately 18 percent of them observed some improvement. On the other hand, nearly 61 percent of adults saw

that both initiatives have no influence and their life remained the same, whereas, about 21 percent of them observed some improvement.

Table 42: *The influence of NZDS and CRPD on quality of life for people with albinism*

		Children	Adults	Total
Improved	Count	4	6	10
	Percentage	18.2%	25%	21.7%
remained the same	Count	1	17	18
	Percentage	4.5%	70.8%	39.1%
Declined	Count	-	1	1
	Percentage	-	4.2%	2.2%
Do not know	Count	17	-	17
	Percentage	77.3%	-	37.0%
Total	Count	22	24	46
	Percentage	100%	100%	100%

By the end of the survey, respondents were asked to use their own words to express their feeling about their child's/their life overall. For the purpose of running some statistical analysis on this qualitative data, data were grouped and coded into three different categories (positive, neutral, and negative). However, figure 35 shows that respondents tended to have positive feelings about their child's/their overall life with slightly more than half of the parents and a little under three quarters of the adults answered in that category.

Figure 35: *Overall life satisfaction*
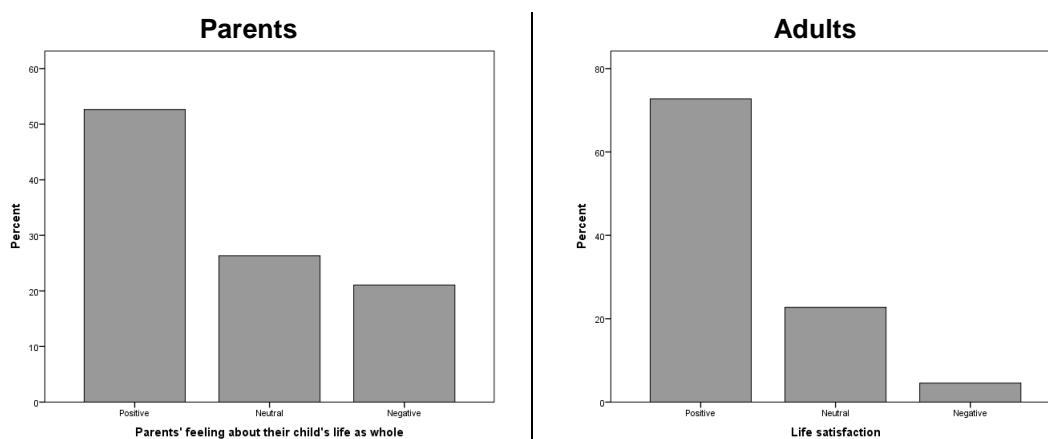
Table 43: *Parents feelings about their child's life*

Positive	Very rounded, happy and full. He has a go at everything from BMX, soccer to horse-riding and climbing trees and has tremendous support at school which has helped him to be in the top groups in his class and well-liked by his friends.
	Does well considering Albinism. Does some sport & mixes well with peers. In top tier in his yr 9 class for maths & science
	Great - very general question mind!
	He is a happy and energetic little boy who does not let his low vision stop him being involved in activities at pre-school. He is sociable and loves playing with his twin brother. His albinism has not prevented him doing anything so far. He does struggle with depth perception and changes in heights of surfaces if they are the same colour. I feel his life is no different from his brothers. At his age is difficult to know how he will be affected in the future but technology has advance significantly that I do not see there being any challenge that cannot be overcome for him.
	I think she is very lucky to be so well supported by so many different organisations. She leads a very normal life.
	nice happy , healthy boy
	Our 2 year old is leading a very normal life. BLENNZ has been of significant help in educating teachers at preschool about Albinism and low vision. We get good support from the Blind Foundation on orientation and mobility with visits. Preschool have been instrumental in getting our wee girl to enjoy playing outside-she loves music and they simply played music outside to entice her to play outside. She now loves playing outside.
	She has a very happy life in my view.
	Very upbeat, positive. Keen to participate in everything. Feels frustrated though about how best to explain her condition, but is very popular amongst her peers and makes friends easily.
	We have two children with albinism. This survey has been completed for the one who has good eye sight. As such, she doesn't need any support. The only thing we get regular checks on is her skin. She is very sociable, has a good group of friends, achieves well academically and plays top level hockey for her school. She is a well-rounded individual, and although it's obvious from her appearance that she has albinism this doesn't seem to cause her any grief socially. I will complete another survey for our other child who has the bad eye sight with her albinism
Neutral	Confused - on the one hand there is no reason why she should feel she has any issues, but on the other - she needlessly struggles because elements of her life are dictated by the personalities of what specialists happen to live in our area/closest to her.
	I wish there was more support for parents with young children, so they could better support their children more readily available.
	Some limitations but manages quite well
	Tale is surrounded by family and friends that allow him to be who he is without fear or discrimination of albinism. There is a social stigma attached to albinism driven by lack of knowledge about it. This leads to others thinking. This reasons restricting some of tale's recreation activities from our experience.
	Well supported so far - heading into College as a parent my concern is around the lack of friendships and her loneliness.
Negative	I do feel about my child's life with albinism how it's affected her medically, physically. Also how its cost for living and her life to be happy and enjoy life as she knows, feels already the pressure of it being an albinism child.
	I find it sad that there is still ignorance around Albinism and lack of education in the education department and teaching colleges about children with Albinisms needs. I do feel sad in some instances for both my sons who both have it, but overall am happy with the support and help we receive when needed
	I struggle with it more than he does. I get very frustrated where as he seems to take his low vision in his stride.
	I worry about how he will cope when he is older and more independent. He relies on his family; myself, his dad and brother, especially when in unknown environments.

Table 44: *Adults feelings about their life*

Positive	Generally I feel happy with my life. I have a partner that is really supportive and does push the boundaries sometimes for me to move forward. I enjoy the fact that I am able to use a camera.
	Good do not let it get me down.
	Good, although there is a lack of awareness about my disabilities that is challenging
	Good, free, and enjoyable.
	Great
	I am doing well and manage impairments. When I need help I ask even if I don't like asking. I am very independent. Life is pretty good and of course like everyone more money would make it better.
	I have had a normal life, married at 23 and have children, none of my children have inherited my disability. Have been able to do most activity but I was not good at sport and have not been able to drive a car because of poor eyesight. No other health problems.
	I love life as a whole. I can struggle with depression from time to time but that is related to PCOS. Despite the frustrations that come with albinism, I am a very determined person and don't let anything stand in the way of achieving my goals. For lack of a better word, I am proud to be albino as it makes me unique and links me to others that I would not have otherwise met. I am loved by my family, well-liked by friends and respected at work/study. I feel very supported and am not afraid to ask for help when I need it.
	I love my Life
	I make a pretty big effort to be independent. And not let my albinism get me down. But at the same time I'm not afraid to talk about things I struggle with. Rather than have it hold me back, I usually turn it into fun. I'm pretty happy with my life and the way I operate.
	It has been difficult to live in a society where people do not understand anything about albinism. I am very fortunate to have had very supportive and loving people in my life who have helped me to become more resilient in all aspects of my life. I was the first CEO for the Clarence Sebastian Foundation an organisation in Samoa that helps people over there with albinism. All the best with this survey and thank you for the opportunity to share.
	My life is great. My albinism has done good things for me to be honest, people are sweet as and often don't think about it after our first encounter. Every now and then you meet a real douchebag, but fuck those human beings anyway. :). Life is good.
	ok
	Personally I find life is fine, I manage well and really have very little to complain about.
	Satisfied and content
	Some days are a lot harder than others but I only get these feeling once in a while otherwise I am perfectly happy with my life
Neutral	Acceptable, but difficult living on my own at times but I have learned to live an independent life not wanting to be a burden on anyone
	I am kind of OK with my life as whole. I have an awesome family that are always there for me. A job and pretty good supportive friends. Some days are good, some are crop, some people are good, and some are crop. In general that's just the way it is.
	its ok - could be better
	OK - apart from health challenges including back pain
	Regarding albinism, the direct effects on my daily life are limited. The difficulties in my life arise from other issues.

During the interviews, trustees were asked to describe how albinism impacted on their life and how satisfied are they with their overall life. All the responses indicated that vison problems associated with albinism has a significant impact on education, employment, income, and personal mobility. However, all of them were somewhat satisfied with their life.

Albinism has in some ways impacted my life, but most issues can be managed. And I am very satisfied. Having Albinism is a fact of life. It is our attitude toward life and living which determines how we succeed or prosper. It is how we treat each other, enable and encourage others to enjoy life which determines the Quality Of Life we share.

- Interviewee 4 -

I think albinism impacted on my life in a lot of ways. If I could see normally I think that It would give me a bit of confidence in a lot more ways that I am. And also a good drive to go from A to B and be more independent in that respect. It in fact has an impact because there are things that you won't do because it is to faraway or it is too difficult to get there and back and things like that. I do feel it does low your self-esteem. However, I suppose I don't want to draw attention to my disability you know my ability not to see things the same. I am generally satisfied I mean these things is only my personal annoyance with my frustrations and cause I am not into pushing myself when I know that I need to my personal shortcomings but generally speaking okay, yea. I am that a bit satisfied.

- Interviewee 4 -

If you had better eyesight, my life would change. That's the frustrating part of the whole thing. It doesn't matter about the hair or skin or language or anything like that. The frustrating part is your eyesight. Yes sometimes it gets frustrating because you can't read something or you got to have someone else to help you along. But generally I'm very happy. I'm at this stage in life, I've been able to do what I can do now.

- Interviewee 4 -

Albinism significantly impacted on my life in so far as education is concerned. Because of the era that I was raised and the lack of education support systems. I didn't achieve as much as I could have. Which consequently limited my opportunities as far as job placement was

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concerned. Education, employment definitely, mobility because of not having a driver's license I couldn't get around; Skin cancer significant issue I don't know how many operations I've had to skin cancer now and how many times I had been blasted with dry ice. So those are the major things. People-wise, most people would get to know me like me. They take the time to get to know me. I get to know them. They never had a problem. Principally, I haven't achieved what I thought I was going to achieve. That was primarily due to loss of employment at critical points. So I haven't been out to achieve financially, put myself in a position where I was financially secure. I have four fantastic children so I am happy in that front. I still have a loving wife so happy in that point. So generally, yeah but I think I am but there are situations.

- Interviewee 4 -

The results of this research about people with albinism in New Zealand have now been presented and will be discussed in chapter five.

Chapter Five: Discussion and Conclusion

This chapter aims to develop a baseline picture of the current state of people with albinism in New Zealand. Firstly, it discusses the research findings presented previously in chapter four. Then there is a conclusion to the whole project - including recommendations for policy and further research.

5.1 Discussion

5.1.1 Count

According to objective 10 of the New Zealand Disability Strategy (NZDS), as well as Article 31 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD, the Government is obliged to collect and disaggregate appropriate information to in order to formulate and implement policies to identify and address the needs of disabled people.

The New Zealand Disability Survey of 2013 estimates that approximately 1.1 million of New Zealanders (24% of total population) were identified as disabled. Due to sensory impairments (hearing and vision loss), nearly 484,000 people (11% of total population) were limited in their everyday activities. Vision impairment by itself affected about 168,000 people (4% of total population). In addition more than 93,000 New Zealanders have vision impairments which cannot be corrected by glasses, contact lenses, medicine or surgery (LITMUS, 2015). Also there are 142,000 people (14% of total population) who have an impairment that existed at birth, such as albinism.

Depending on their vision acuity, approximately 190 New Zealanders affected by albinism are members of the Blind Foundation. A total of 11,774 people (7% of total vision impaired population) are registered as members of the Blind Foundation (Blind Foundation, 2015). However, it is estimated cite that 1 in every 17,000 New Zealanders has some form of albinism (Little, 2014). This estimation suggests that the country has between 250 and 300 individuals with albinism. Also the research findings indicate that there are more people with albinism in New Zealand than those who are members of the Blind Foundation.

> *I hope you get out to enough people through this, I know quite a few people with albinism aren't a part of the foundation of the blind. There was a meet-up of heaps of us a few years back for an international reporter, and not even half of them were members at that point.*
> **- comment by a survey respondent -**

Overall, it was clear from the literature review that the count of people with albinism is an international issue. Also sample recruitment of this study – as a process - confirmed that domestically the situation was not better off. The New Zealand's post-census disability surveys do not yet include albinism as a type of impairment. Apart from that, there is lack of administrative data on albinism. Thus, it is impossible to accurately determine the number of individuals with albinism in New Zealand. Consequently, few comparisons can be drawn between people with albinism and the general population.

5.1.2 Demographics

As shown in table 45, the respondents of the survey are approximately 53 percent males and 47 percent females. This proportion differs from its peers in total and disabled populations, as well as the proportion among the Blind Foundation members, where there are more females than males. The difference is strongly influenced by the proportion among children respondents where nearly 65 percent of them are males and 35 percent are females. However, there are no evidence within the medical literature that males are more likely to have albinism than females, or vice-versa.

Table 45: Gender

	Total population	Disabled people	People with vision impairments	Blind Foundation members	People with albinism within the survey
	Percentage				
Males	49	48	43	40	53
Females	51	52	57	60	47
Total	100	100	100	100	100

Sources: Statistics New Zealand, the 2014 Blind Foundation's annual report, People with albinism survey

Table 46 shows that nearly 45 percent of the respondents are aged under 15 years old, whereas 35 percent are between 15 and 64 years old, and 20 percent are 65 years old and over. Since albinism - as a type of impairment - existed at birth, the proportion of children is significantly higher than its counterparts in the general and disabled populations. Also it was reported that albinism is the fourth common condition among children who are members of the Blind Foundation. As a result, the percentage of children with albinism is considerably higher than the general Blind Foundation population. On the other hand,

the percentage of people with albinism over 65 years old is significantly less than percentage of those who are members of the Blind Foundation and those who identified themselves as disabled in the general population.

Table 46: Age

	Total population	Disabled people	Blind Foundation members	People with albinism within the survey
	Percentage			
0 to 14	20	8		45
15 to 44	64	26	35	25
45 to 64		29		10
65 and over	16	37	65	20
Total	100	100	100	100

Sources: Statistics New Zealand, the 2014 Blind Foundation's annual report, and people with albinism survey

Regarding ethnicity, nearly 75 percent of the survey respondents have New Zealand European ethnic background (see table 47). It is the same percentage of this ethnic group within the general population. This reflects that albinism occurs in all racial and ethnic groups in New Zealand on an equal basis (National Organization for Albinism and Hypopigmentation, 2013).

Table 47: Ethnicity

	Total population	Disabled people	Blind Foundation members	People with albinism within the survey
	Percentage			
NZ European	75	79	79	75
Other	25	21	21	25
Total	100	100	100	100

Sources: Statistics New Zealand, the 2014 Blind Foundation's annual report, and people with albinism survey

The research findings also shows that approximately 80 percent of the survey respondents live in urban areas (cities and towns), whereas, nearly 20 percent of them live in rural areas. In 2001, 71.1 percent of the census usually resident population count lived in a main urban area (population of 30,000 or more). Also the 2014 Client Needs Assessment Survey of the Blind Foundation shows that approximately 70 percent of the survey respondent live in urban areas. The percentages above suggest that the survey respondents are more likely to live in urban areas where they can be more independent and have access

to different sort of services - in comparison to the general population and the Blind Foundation members.

5.1.3 Health and wellbeing

According to Article 25 of the CRPD and Objectives 7 and 8 of the NZDS, people with albinism have access to appropriate health and wellbeing services. The government shall provide them with fair and flexible services in their communities. Especially those who live in rural areas. Also the services should be designed to minimise and prevent further disabilities. Moreover, their impairments and their needs should be early identified and addressed by high skilled health professionals.

Indeed, there are two main types of albinism. Firstly, Oculocutaneous Albinism (OCA) which involves the eyes, hair, and the skin. The majority of the survey respondents (70% of children and nearly 96% of adults) are affected by OCA. In contrast, few respondents (30% of children and 4% of adults) are affected by Ocular Albinism (OA) which involves only the eyes. This is actually underpinning the fact the OCA is more common than OA (Little, 2014).

Except those who do not have access to an adequate skin protection, people with albinism are expected to face the same types of general medical problems as the rest of the population. Table 48 shows that more than two-third (67%) of the survey respondent have no health conditions or disabilities that add to the burden of their albinism, whereas 53 percent of the total disabled population and 55 percent of the blind foundation members are affected by multiple impairments. This is - to some extent – a reflection of the age structure.

Table 48: Single / multiple impairments

	Disabled people	Blind Foundation members	People with albinism within the survey
	Percentage		
Single	47	45	67
Multiple	53	55	33
Total	100	100	100

Sources: Statistics New Zealand, the 2014 Blind Foundation's Client Survey, and people with albinism survey

Furthermore, the research findings indicate that most of the children who reported multiple impairments are experiencing "Failing to Thrive" in addition to their albinism. In this context and based on the data of the 2011 New Zealand Disability Survey, the Ministry of Health confirmed that generally this condition is the third most common type

of chronic condition/health problem among children with disabilities. On the other hand, only 2 out of 7 of the adult's respondents reported that they experience hearing impairments in addition to their albinism.

Since low vision is the most significant health problem associated with all types of albinism, the respondents' assessment of vision was fair (43%) or worse (37%). Considering that all children and adults are members of the Blind Foundation, these proportions can be accepted.

Medically, lack of skin protection can lead to developing skin cancer. Therefore, skin health is another challenge associated with albinism – especially OCA. The research findings shows that most of the parents (56%) assess their child's health skin to be fair, whereas, (57%) of adults assess their health as good.

Apart from vision and skin impairments, people with albinism of those who participated in the survey tend to have very good or better overall health status. It is also noteworthy that nobody reported bad/poor overall health status. This may indicate that albinism is a kind of stable disability where people learn how to live with it. However table 49 shows that respondents have better overall health in comparison to the mainstream population and the members of the Blind Foundation.

Table 49: Overall health status

	Total population	Blind Foundation members	People with albinism within the survey
	Percentage		
Excellent	22	24	36
Very good	39	40	46
Fair	26	30	18
Poor	13	6	-
Total	100	100	100

Sources: Statistics New Zealand, the 2014 Blind Foundations annual report, and people with albinism survey

As any other sort of disability, people with albinism definitely need some medical attention - especially when it is related to eye and/or skin care. The research findings suggest that albinism does not require high medical involvement, since almost 80 percent of the respondents visit a health professional less than 4 times during the last year for a reason related to albinism. Moreover, few of the respondents (20%) indicate that they have unmet needs to do so due to reasons related to accessibility, affordability and

transportation. In this context, Albinism Trust emphasis that person with albinism is an individual who requires a 'normal' everyday medical attention. But this does not change the fact that individuals with albinism still need to have long-term relationships with health professionals who understand albinism in order to enable living, enhance options and choices which everyone has. As well as providing the necessary medical care to prevent any expected threats such as skin cancer. However almost half of the survey respondents (parents and adults) and the interviewees confirm that unfortunately health professionals in New Zealand have scant understanding of albinism and how it affects the individuals' daily activities (see table 50). Seemingly, it is a general problem within the health and disability sector as it was confirmed cite that there is no overall intuitive to train health professionals on the rights and specific needs of disabled people.

Table 50: Level of understanding the effects of albinism by health professionals

	Count	Percentage
Very well	9	18%
Maybe	24	47%
Not at all	12	23%
I do not know	4	8%
Missing (no answer)	2	4%
Total	51	100%

Needs assessment is a process in which the needs of people with albinism are identified by a needs assessor, in order to outline what disability support services are available for them. The study findings show that about 67 percent of the respondents had their needs assessed at some time compared to a general disabled population average of 15 percent. Also it is noteworthy that all children had their assessment during the previous 24 months, whereas, the majority of adults had it more than two years ago. On the other hand, nearly 33 percent of the respondents have never had a needs assessment - most of these were adults.

Furthermore, ninety percent of the survey respondents indicate that they have a reasonable or easier access to health and wellbeing services. This included 47 percent and 43 percent who are satisfied or somewhat satisfied with service and support provision, respectively. In contrast, the interviewees' responses emphasised that health and wellbeing services need to be improved to meet the needs of people with albinism. Their responses are somewhat consistent with what have published by the Ministry of Health in 2015 which confirms that some people with low vision – especially those who live in rural areas – do

not have access to adequate services. Also it was reported that disabled people with uncommon/rare impairments – this may include albinism – do not have adequate services and health professionals have observed lack of knowledge about such conditions.

Overall, it seems that practically there are good health and wellbeing services for people with albinism in New Zealand. Certainly there are issues that need more attention and improvement - especially those related to the awareness of albinism and its needs among health professionals.

5.1.4 Educational challenges

According to Article 24 of the CRPD and Objective 3 of the NZDS, people with albinism receive the best possible education at all levels and stages on an equal basis with others in the communities in which they live. The government shall make sure that people with albinism have fair access to reasonable accommodation and receive the required support to facilitate their effective education. Also appropriate measures should be taken to ensure that teachers and educators understand the learning needs of people with albinism.

According to Carolyn Palmer (2005), albinism impacts on students in many ways. Physically, they share the same problems people with serious vision impairment have, including their sensitivity to bright light and glare.

Table 51 shows that people with albinism tend to have impressive academic achievements more the national average. For adult respondents, a little under half (48%) had bachelor degree or higher versus 20 percent of the national population. On the other hand, only 4 percent of respondents have no qualification versus 21 percent of the national population.

Table 51: Highest educational qualification

	Total population	People with albinism within the survey
	Percentage	
No qualification	21	4
Less than level 5 Diploma	46	36
Level 5 or 6 Diploma	13	12
Bachelor degree or equivalent	11	32
Postgraduate qualifications	9	16
Total	100	100

Sources: Statistics New Zealand and people with albinism survey

As shown in table 52, approximately 39 percent of the respondents are currently studying versus 24 percent of the national population and about 7 percent of the Blind Foundation members. Moreover, the study findings confirm that all students with albinism are receiving their education within the mainstream system.

The Albinism Trust emphases that educational support is available right from the start for students with albinism through the Blind and Low Vision Education Network NZ (BLENNZ) as long as they are members of the Blind Foundation. The most common educational support available for students with albinism include:

1- Seating with back to the windows to avoid glare from sun.
2- Seating close to the board.
3- Print materials in alternative formats.
4- Extra time for assignments and exams.
5- Adaptive computer equipment.

The study findings show that approximately three quarter (75%) of students with albinism had their educational needs assessed by a Resource Teachers Vision (RTV)[16], whereas nearly 25 percent of students did not receive such support. In this context, some of the parents was full of praise for the work of BLENNZ and Blind Foundation - especially within preschool stage. However, getting support from BLENNZ is still conditioned by being a member of the Blind Foundation. This does not change the fact that BLENNZ is working hard to remove the educational barriers for students who are blind or visually impaired. Consequently, work is underway to develop a similar intervention for Deaf children in order to meet their educational needs.

Table 52: Currently studying

	Total population	Blind Foundation members	People with albinism within the survey
		Percentage	
Yes	24	7	39
No	76	93	61
Total	100	100	100

Sources: Statistics New Zealand, the 2014 Blind Foundations Client NA Survey, and people with albinism survey

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[16] Resource Teachers Vision (RTVs) are trained in a course run by Massey University. They are employed by BLENNZ and work in several vision resource centres (VRCs) located in mainstream schools throughout the country.

Our 2 year old is leading a very normal life. BLENNZ has been of significant help in educating teachers at preschool about Albinism and low vision. We get good support from the Blind Foundation on orientation and mobility with visits. Preschool have been instrumental in getting our wee girl to enjoy playing outside-she loves music and they simply played music outside to entice her to play outside. She now loves playing outside.

- Comment by a parent respondent -

I came through the system as baby boomers after the Second World War. More of us then there was facilities to teach us properly. So anyone with the disability got - fell through the gaps in the system. In today's age, there is a little bit more improvement in so far as those that are entitled to services from BLENNZ.

- Interviewee 4 -

While the New Zealand Government spends nearly half a billion dollars on special education – excluding tertiary education expenditure, still about 43 percent of the respondents indicate that they have unmet need for support mostly related to adaptive and computer equipment, transition to school orientations, and cost of medical treatment. In this instance, having educational professionals who understand the needs of students with albinism becomes crucial. The study findings indicate that nearly 90% of the respondents feel that educational professionals tend to have a scant understanding of the condition and its impacts. Practically, a number of professional development opportunities are available for teachers to meet the diverse needs of their students. But unfortunately they are not mandatory.

The study findings show that approximately 20 percent of the respondents experience discrimination while they are studying. Trying to determine sources of discrimination at school, Wan (2003) emphasised that students with albinism are subject to discrimination on the basis of their condition by other students, teachers, and in most cases the education system that does not know how to deal with people with low vision generally. In this aspect, the Albinism Trust indicate that bullying, teasing, and side-lining are the most unwanted behaviours that people with albinism might face particularly during their school time.

5.1.5 Work and income

According to Articles 26, 27, and 28 of the CRPD and Objective 4 of the NZDS, people with albinism are supposed to have the same employment opportunities and have an adequate income as anyone else. In this context, the government shall provide them with appropriate and ongoing vocational and training programmes and services that underpin their potentials and abilities in order to obtain, maintain, and return to paid work.

Generally, finding a decent job is one of most significant challenges that disabled people face in New Zealand. .As shown in table 53, adults with albinism are much less likely than non-disabled adults to be employed (43 percent compared with 72 percent). They have nearly the same employment rate of disabled adults (45%). Moreover, adults with albinism participate more in the labour force than disabled adults (71 percent compared with 50 percent). This participation rate is also higher than their peers in the Blind Foundation where approximately 55 percent of members participate in the labour force. However, a significant percentage of adults with albinism (35%) still looking for paid work. These proportions reflect how difficult it is for people with albinism to find work, even if they have better educational outcomes and achievements than the national average. Approximately 40 percent of the respondents and the Office for Disability Issues as well as the 2014 Blind Foundation Client Needs Assessment Survey emphasise that unwillingness of employers to give opportunities to disabled people because of lack of knowledge and discrimination still the main barriers that disabled people - including people with vision impairments - face when they seek work.

Table 53: Employment and labour force status

	Total population	Disabled people	People with albinism within the survey
	Percentage		
Employment rate	72	45	43
Unemployment rate	5	9	35
Labour force participation rate	76	50	71

Sources: Statistics New Zealand and people with albinism survey

Based on the previously mentioned information in chapter two, people with albinism are entitled to get employment-related support from the Ministry of Social Development and the Blind Foundation. The study findings show that nearly 65 percent of adults with albinism have never received support to find, maintain or return to work. On the other

hand, 35 percent are receiving support. A little under half of them (46%) are receiving disability related support. However, their overall assessment of employment services (whether it is related to their disability or not) vary. While 44 percent see it positive, the same percentage negatively describe it. This disparity is a result of the model of support provided by employment agencies. When the support is about moving into or returning to paid work, it is relatively passive such as skill instruction on CV writing, interview techniques and so on. Therefore, the outcomes are again depend on the employers' attitudes to give the candidate a chance. But when the support is related to maintain work, it becomes more significant. In most cases it is about providing them with required modifications within the workspace. However, the study findings shows that there are approximately 25 percent of those who are currently working still have unmet needs for modifications such as adaptive technology as well as transportation. Also as shown in table 54 the respondents do not have a high level of satisfaction with their current job in comparison to the national average of 63 percent and 55 percent among the blind foundation members.

Table 54: Satisfaction with current job

	Total population	Disabled people	People with albinism within the survey
	Percentage		
0-4.9	3	9	8
5-7.9	33	36	50
8-10	63	55	42

Note: 0 is completely dissatisfied and 10 is completely satisfied.

Sources: Statistics New Zealand and people with albinism survey

Excluding those who receive age related assistance, the study findings show that few of the respondents (about 24%) are receiving financial assistance from the government. Only 16 percent of the respondents were diagnosed as blind enough to have a permanent exemption from work expectations receive the Supported Living Payment – previously known as Invalid Benefit. In contrast, the majority are relying on dividends or investments, wage or salaries, and/or self-employment to meet their living costs.

Since the blindness or vision impairments add additional costs on individuals, the discussion only compares between the respondents and the blind foundation members. The study findings indicate that the respondents have higher personal income than their peers in the Blind Foundation. Table 55 shows that approximately 42 percent of the

respondent have an annual gross income less than 30 thousand dollars, whereas, nearly 50 percent of the Blind Foundation members have the same level of income. On the other hand, 39 percent of the respondents have a gross income that exceeds 30 thousand dollars a year compared to 10 percent among the Blind Foundation members. It is also noteworthy that 19 percent of the respondents and 40 percent of the Blind Foundation members did not declare their income. This high non-response rate has an impact on how this information can be used and gives another reason not to compare with the disabled and non-disabled population levels.

Table 55: Personal income

	Blind Foundation members	People with albinism within the survey
$15,000 or less	19	21
$15,001–$30,000	31	21
$30,001–$50,000	6	18
$50,001+	4	21
Not Stated	40	19
Total	100	100

Sources: The 2014 Blind Foundation Client Needs assessment Survey, and people with albinism survey

According to the Cost of Disability research (2006), people with vision impairments have additional weekly cost between approximately $352 and $720. The additional costs differ based on the individuals' vision acuity that determine their *level* of needs. In this context, the study findings show that a little under half of the respondents (about 46%) financially struggle a little and about 8 percent struggle a lot. This reflects that a considerable percent of the respondents do not have the gross income that supports their independence and choices. Furthermore, some of the respondents (about 20 percent) tend to be dissatisfied with the affordability of housing.

> *It's probably one area we are no different from anyone else. From what I can establish. The big thing with housing is, can you afford it? And if you have not been able, through the education system has failed you for whatever reason, you haven't been able to get into a decent housing, with financial constraints, then yes your albinism has affected your housing - you're choices of housing.*

- Interviewee 4 -

5.1.6 Transportation and housing needs

According to Articles 9 and 20 of the CRPD and Objectives 7 and 8 of the NZDS, people with albinism supposed to have the right for personal mobility with the greatest possible independence. In this context, the government shall ensure that they have access to high quality public transport at affordable cost.

Transport is one of the most significant challenges that disabled people– including people with albinism - face. . It impacts on all aspects of life. Being able to move safely and independently. Transport provides individuals with full access to education, health services, employment, recreation, goods etc.

> *"The biggest trouble I have with work and everyday life is transport. Transport is my single biggest obstacle in anything I do as I cannot drive and public transport can be restricting and difficult"*
>
> **- Comment by a survey's respondent -**

Almost all the survey respondent belong to the 48 percent of those people with vision impairments who are not able to drive motor vehicles in New Zealand. As a result, it is not surprising that approximately 51 percent of the respondents rely on public transport for the purpose of personal mobility, whereas, the rest (49%) very much depend on others, particularly family members. Figure 36 shows that the adult respondents are very much more likely to use public transport than the total vision impaired population and disabled people in general. In contrast, children with albinism are slightly less likely to use it. As nearly 44 percent of the children included in this study are aged 4 years or less, so this proportion is pretty much reflective of age structure.

Figure 36: The use of public transport
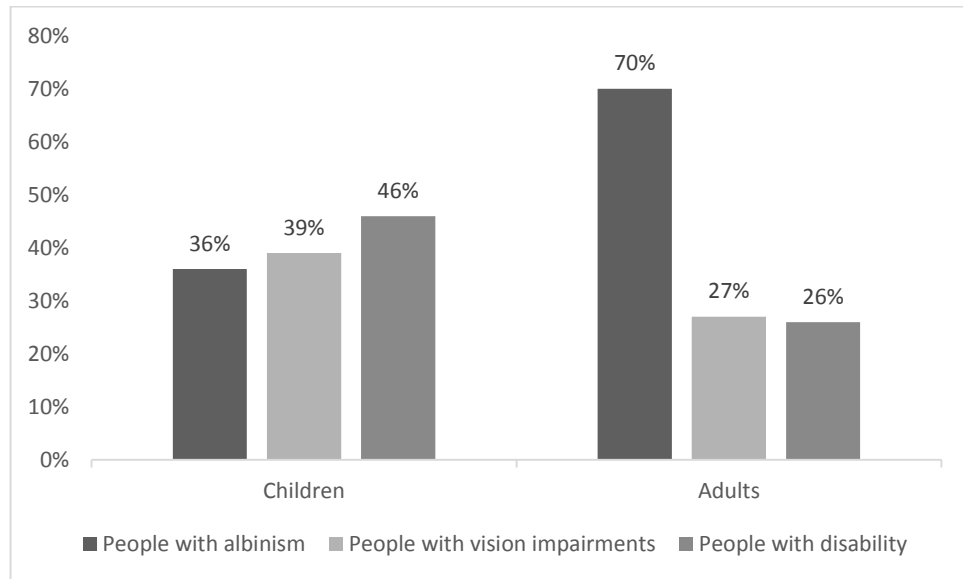
A large minority (about 45%) of the respondents found using public transport an issue of concern because of their vision. As adults use public transport more than children, they are much more likely to face problems (64 % of adults versus 37% of children). However, identify the right service, getting information about timetables, and not supportive stuff are the most commonly occurring difficulties that people with albinism face respectively. Some of these difficulties can be diminished with the spread of using new technologies and assistive devices – as the trustees confirmed (Crossland, Silva, & Macedo, 2014).

The study findings also show that nearly 66 percent adult respondents use taxis to travel short distance in comparison to 67 percent of adults with disabilities. On the other hand, children respondents are less likely to use taxis than children with disabilities in general (9 percent compared to 15 percent of disabled children). Since only 23 percent of parents are aware of Total Mobility Scheme, the high cost was the primary barrier that prevents children with albinism to use taxis – as their parents stated. Moreover, a large minority (43 percent of children and 44 percent of adult) of the respondents emphasised that they do not need to use taxis at all.

Depending on the vision acuity which determine the level of needs, people with vision impaired – including people with albinism -   spend approximately between $52 and $172 dollars per week on transportation. As presented previously in chapter two, holding the Blind Foundation Identification card or being a customer of the Total Mobility Scheme may reduce these costs.

The study findings also indicate that the availability of public transport has a significant influence on individuals with albinism's choice of housing.

> *I need to choose a place that is close to public transport and that is going to get me to and from work. That's the criteria that I always look for. Also brightness is often an issue that's why I tinted my windows to block the glare. So I always need to fix thing like that.*

- Interviewee 2 -

5.1.7 Accessing Information and assistive devices

According to Articles 9, 21, 26, 28 of the CRPD and Objectives 3, 4, 7 and 8 of the NZDS, people with albinism supposed to have access to assistive devices and technologies in order to habilitate them to fully and independently participate in their communities and be able to access information as anyone else.

The study findings indicate that adult respondents have adequate vision to read, and they prefer to access information in digital materials such as emails or web searches as well as large print formats (78% and 74% respectively). However, it is self-evident that most people with vision impairments – including people with albinism – would prefer digital materials which do not require much effort and time to read. But if - for any reasons - digital materials are not available or they do not have access to computer, large print needs be available.

Due to their limited vision, people with albinism are not able to read 'normal' printed materials without assistive devices. The study findings show that the classic Hand Held Magnifier and specialised reading glasses are the most common devices among both children and adult respondents. Few have access to technologies such as video and screen magnifiers or digital readers. This is probably because of the high cost of such devices. The 2014 client needs assessment survey of the Blind Foundation confirms that nearly 48 percent of their clients – including people with albinism – pay for these assistive devices themselves, whereas, only 15 percent of them have funding through Workbridge[17].

Purposes of reading vary among adults with albinism, but most of them (84%) read on daily bases for the purpose of gaining information, pleasure and/or social contact.

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[17] Workbridge provides professional employment services for people with low vision. Also it is contracted to administer some support funds on behalf of the Ministry of Social Development.

therefore, the internet is the most important source of data among adult respondents, since nearly 84 percent of them confirm so. This proportion is slightly higher than national average of 80 percent, and significantly less than the percentage of 42 percent among members of the Blind Foundation. However, Adults with albinism use a variety of devices to access the internet. As shown in figure 37, adult respondents generally use all the selected devices more often than their peers within the total population. While laptops are the most popular devices that New Zealanders use, adult respondents prefer desktop computers and internet-enabled mobile phones. It is also noteworthy that the respondents use tablets or handheld computers considerably higher than the rest of New Zealanders. Due to its multiple benefits such as accessibility features, smartphones and tablets become essential devices for people with vision impaired – including people with albinism. However, the only barriers for these devices to be used are the cost and lack of awareness of how useful these devices could be for people with vision impairments.

*Figure 37: Devices individuals use to access the Internet*
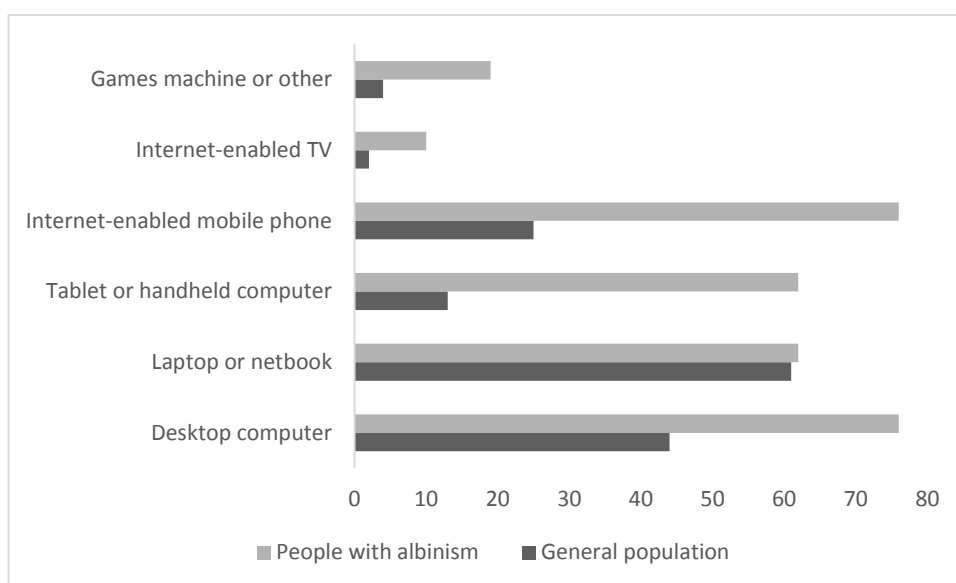
5.1.8 Recreational and social engagement

According to articles 23 and 30 of the CRPD and objectives 9 and 15 of the NZDS, people with albinism supposed to have access to cultural and recreation activities where they can make and keep relationships and enjoy their social lives as anyone else.

While adult respondents are slightly less likely to have face-to-face or direct contact with their families than the national average and compared to their disabled peers, they tend to be significantly superiors in terms of the amount of contact. By contrast, almost all of the adult respondents (96%) are keen to meet their friends much more than non-disabled and

disabled peers (see figure 38, figure 39, and figure 40). Furthermore, adult respondents spend between 1 and 10 hours a week in social and recreation activities.

Figure 38: Face-to-face contact
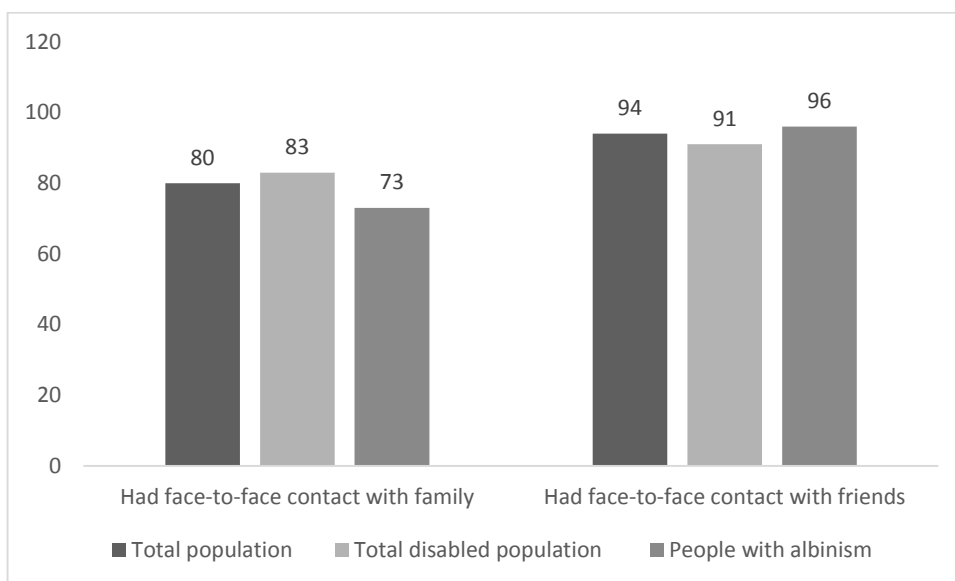
Figure 39: Amount of contact with family
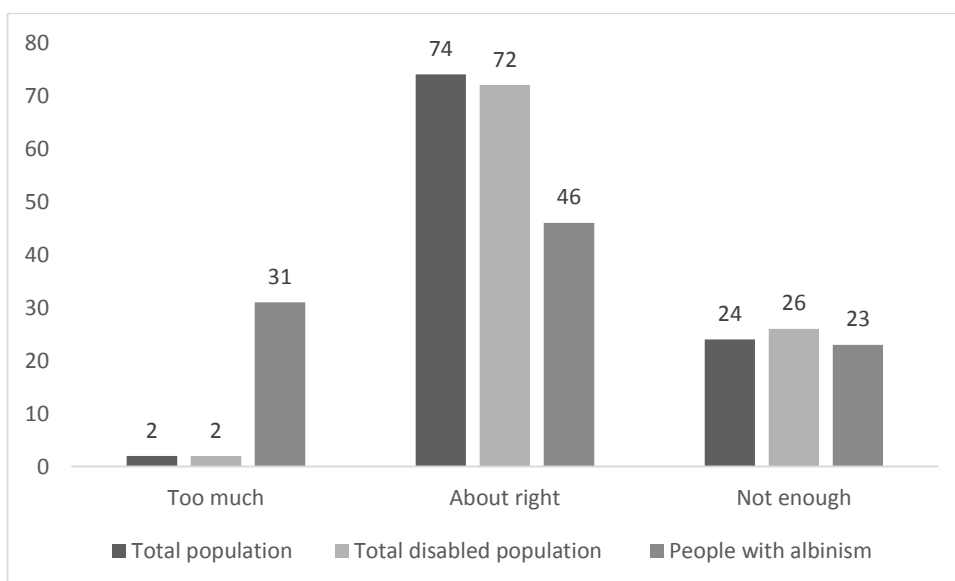
Figure 40: Amount of contact with friends

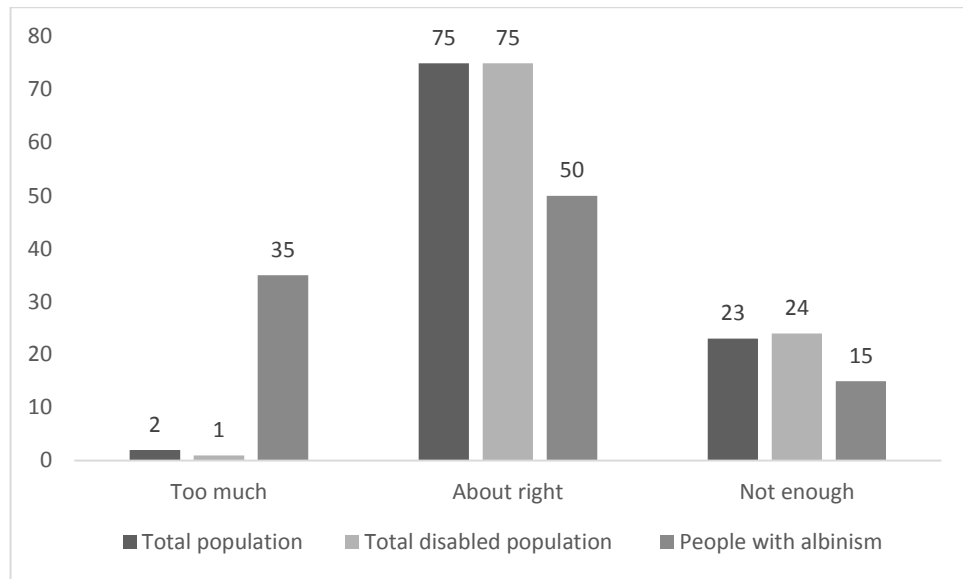In despite of the positive results regarding social contact, the study findings show that a little more than half adults with albinism occasionally tend to feel lonely in comparison to other New Zealanders - whether they have disability or not (see figure 41). In addition, approximately 43 percent of the respondents see it as difficult to meet new people and form relationships as a result of having albinism. 'These difficulties are relatively arise from attitudes and misunderstanding of others toward albinism, the low self-esteem that albinism may cause, and lack of participation in recreation activities where people with albinism can socially engage with others and have high chances to meet new people and form relationships' as the trustees justified.

Figure 41: Feelings of loneliness
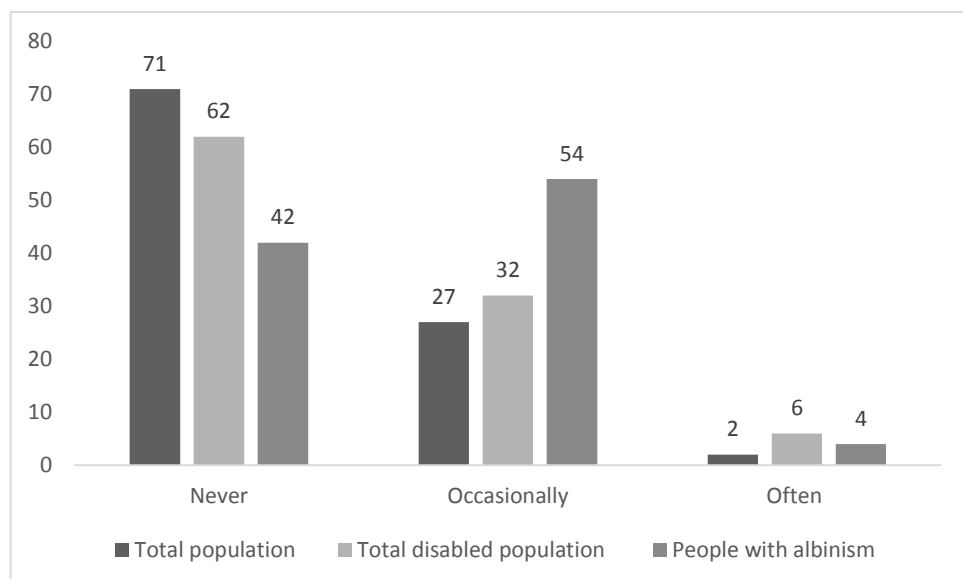
The current literature on albinism emphases that people with albinism - including children - are more likely to be stigmatised and stereotyped as a result of their condition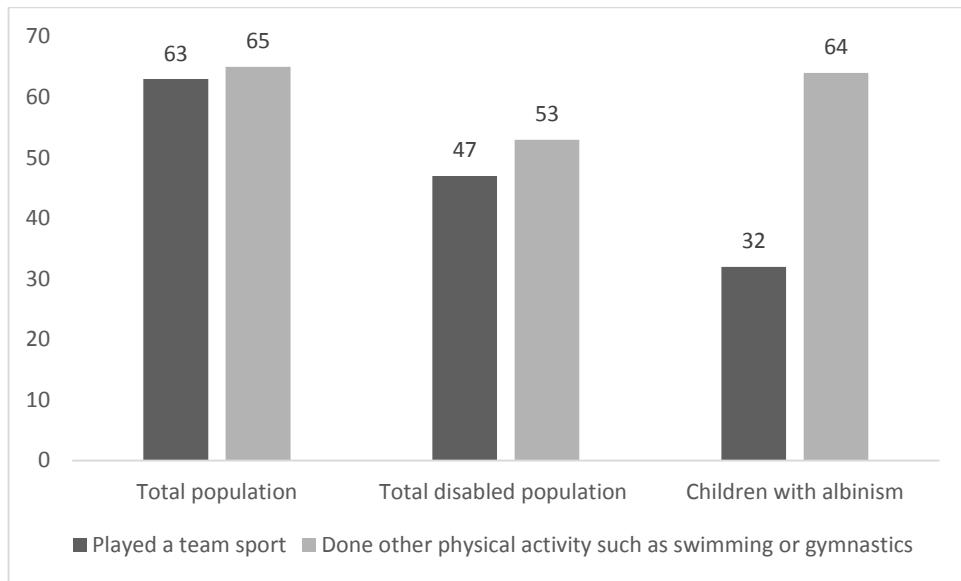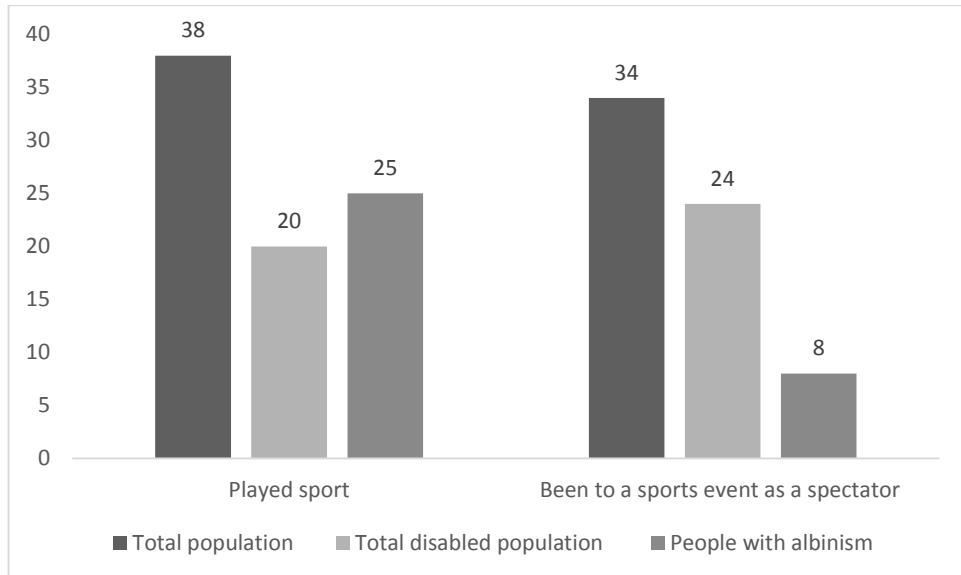. In addition, they may experience prejudice and discrimination on a frequent basis. But they have a strong sense of self and physical features associated with albinism do not directly have negative effects on their self-esteem. However, the interviews with the trustees suggest that the physical features of albinism – especially vision impairment – have a significant influence on the individuals' abilities to exercise in some 43 of sports, particularly team sports. In this context the survey findings show that children respondents exercise in singular sports such as swimming approximately as same as the national average and slightly better than their disabled peers. In contrast, there is a considerable decline in the percentage of children respondents who are involved in team sports than disabled and non-disabled New Zealanders (see figure 42). Regarding adults and as shown in figure 43, respondents are more likely to play sports than the disabled average. Due to their vision acuity, it is not surprising that the adult respondents are not likely to attend sport events the same as others.

Regardless of sport, the trustees suggest that albinism has little adverse effects on the individuals' abilities to enjoy cultural recreational activities. The survey findings show that children respondents visit their friends, go out with their families even more than the national average. Also adult respondents have the highest participation rate in voluntary work compared to all New Zealanders. Additionally, they are more likely to be places such as café, restaurant, or pub than others.

Figure 42: Children involvement with sport

Legend: ■ Played a team sport   ■ Done other physical activity such as swimming or gymnastics

Categories: Total population (63, 65), Total disabled population (47, 53), Children with albinism (32, 64)

Figure 43: Adults involvement with sport

Legend: ■ Total population   ■ Total disabled population   ■ People with albinism

Played sport (38, 20, 25), Been to a sports event as a spectator (34, 24, 8)

Regardless of sport, the trustees suggest that albinism has little adverse effects on the individuals' abilities to enjoy cultural recreational activities. The survey findings show that 82 percent of the children respondents visited their friends compared to 92 percent of the total population. Also all of them went out with their families even more than the

national average of 97 percent. Also adult respondents have the highest participation rate in voluntary work (39%) compared to (36%) of all New Zealanders. Additionally, they are more likely to go to public places such as café, restaurant, or pub than others. Even if nearly 20 percent of them experience discrimination in such places. Some repetition in this para

Overall, people with albinism are at risk of social stigmatisation because their condition is sometimes misunderstood. As a result, some of them may find it difficult to form relationships with others. Despite, they have adequate social competence to keep social relationships. On the other hand, the physical features associated with albinism limit their abilities to enjoy sports.

5.1.9 Quality of life

The majority of the respondents commented positively on the overall life satisfaction open-ended question. Most parents emphasised that their child tended to have a 'normal' life so far. Some of parents also appreciate the support they receive from BLENNZ and the Blind Foundation. Others, believe that technology will even advance their child's ability to be independent in the future. On the other hand, adults have learned how to cope with their condition and most of them are surrounded by supportive social relationships.

He is a happy and energetic little boy who does not let his low vision stop him being involved in activities at pre-school. He is sociable and loves playing with his twin brother. His albinism has not prevented him doing anything so far. He does struggle with depth perception and changes in heights of surfaces if they are the same colour. I feel his life is no different from his brothers. At his age is difficult to know how he will be affected in the future but technology has advance significantly that I do not see there being any challenge that cannot be overcome for him.

- Comment by a parent respondent -

I am very fortunate to have had very supportive and loving people in my life who have helped me to become more resilient in all aspects of my life.
- Comment by an adult respondent -

In contrast, neutral and negative impressions about overall life emanate mainly from lack of awareness associated with albinism. The lack which makes parents more worried about

their child's right to enjoy social and recreation activities now and in the future. However, article 8 of the COPD and action (2-2) of the second objective of the NZDS provide the guiding principles to educate the public about albinism. But when it comes to practice, there is a need for greater understanding of uncommon conditions and impairments - including albinism.

> *He is surrounded by family and friends that allow him to be who he is without fear or discrimination of albinism. There is a social stigma attached to albinism driven by lack of knowledge about it. This leads to others thinking. This reasons restricting some of tale's recreation activities from our experience.*

> **- Comment by a parent respondent -**

> *It has been difficult to live in a society where people do not understand anything about albinism. I am very fortunate to have had very supportive and loving people in my life who have helped me to become more resilient in all aspects of my life.*

> **- Comment by an adult respondent -**

Since the NZDS and the United Nations' CRPD were developed to achieve long-term life outcomes for disabled people, a large minority 39 percent (almost all of them are adults with albinism) confirm that both do not contribute enough to the improvement of their quality of life so far. Also it is not surprising that approximately 77 percent of parents do not know how the implementation of the NZDS and the United Nations' CRPD influence on their children's quality **of** life.

5.2 Conclusion

Albinism - as a type of disability – has significant impacts on the individuals' lives overall. Healthily, people with albinism usually find themselves in front of a health professionals who do not know much about their condition and how it affect their daily life. Educationally, the situation has evolved over time. New Zealanders with albinism now receive much better education than it used to be. But they still have to face the consequences of being visually impaired and how hard it is to achieve academically. Also having an uncommon condition makes attitudes of others (student and teachers) decisive when it comes to their appearance. Economically, albinism affect the individuals' ability

to find work. This is one area they are no different from other disabled people where employers do not hire them on basis of the physical features associated with albinism. As a result, the adequate income that support their independence and choices is not sometimes guaranteed. Transportation is also a significant challenge that people with albinism face. It does not only impact on their ability to move around, but also determine where they live. Being able to drive a car remain a dream that most of New Zealanders with albinism wish to occur. Socially, people with albinism in New Zealand have impressive social competences to keep a long-term relationship. But meeting new people or/and forming new relationships are areas where albinism has its influence. With the exception of not being able to exercise some sports because of albinism, New Zealanders with albinism enjoy a variety of cultural and recreation activities of their choice.

5.2.1 Recommendations for policy

1- As recommended by Office of the United Nations High Commissioner for Human Rights in 2013:

a) The Ministry of Health needs to establish a mandatory registration of birth and death of New Zealanders with albinism.

b) The Ministry of Health needs to ensure that people with albinism have their needs evaluated and addressed on regular basis.

c) Statistics New Zealand shall include albinism as a type of impairment through the post-census disability survey.

2- The Ministry of Health needs to develop a code of practice to assist health professionals while they deal with clients with albinism.

3- The Ministry of Education needs to encourage teachers to take advantage of the available opportunities that assist them with responding to the diverse needs of students including students with vision impairments.

4- As recommended by the Independent Monitoring Mechanism of the Convention on the Rights of Persons with Disabilities in late 2012 and office for Disability Issues in 2011, the Ministry of Education needs to actively implement anti-bullying programmes that ensure that schools are safe places for disabled students - including students with albinism.

5- The Ministry of Education needs to ensure that reasonable accommodation are always available for students with albinism - including large print and digital materials.

6- The Ministry of Social Development needs to invest more to innovate new measures that promote employment outcomes for people with albinism. This may include give more opportunities within the public sector for those who have higher educational qualifications.

7- The Ministry of Transport needs to invest on research to evaluate whether people with albinism able to drive their motor vehicles the same as their peers in the United States.

8- The Government shall support the New Zealand Albinism Trust in any possible way to raise awareness about albinism that will help to reduce discrimination against people with albinism.

5.2.2 Recommendations for Further research

Since this study is the first attempt to investigate human albinism in New Zealand, it is recommended that further research to be done focusing on specific groups that were absent in this study such as Maori and women with albinism. Also it is recommended to give children with albinism the opportunity to be heard. Areas such as employment, education, and transport also require more investigation.

Bibliography

Accident Compensation Corporation. (2015). *Serious injury and disability*. Retrieved January, 2015, from http://www.acc.co.nz/disability/

Babbie, E. R. (2013). *Adventures in social research: data analysis using IBM SPSS statistics*. Los Angeles: Sage.

Barnes, C., & Mercer, G. (2003). *Disability*. Cambridge, UK: Polity Press.

Barnes, C., Mercer, G., & Shakespeare, T. (1999). *Exploring disability: a sociological introduction*. Malden, Mass: Polity Press.

Barnes, C., Oliver, M., & Barton, L. (2002). *Disability studies today*. Cambridge, UK: Polity Press in association with Blackwell Publishers.

Beatson, P. (2004). *The disability revolution in New Zealand: a social model*. Palmerston North, N.Z.: Sociology Programme, School of Sociology, Social Policy and Social Work, Massey University.

Becker, S., & Bryman, A. (2004). *Understanding research for social policy and practice: themes, methods and approaches*. Bristol: Policy Press.

Blind Foundation. (2015). *Statistics*. Retrieved May, 2105, from http://blindfoundation.org.nz/about/news-and-information/statistics

Cheyne, C., O'Brien, M., & Belgrave, M. (2005). *Social policy in Aotearoa New Zealand: a critical introduction*. South Melbourne, Vic: Oxford University Press.

Creswell, J. W., & Plano Clark, V. L. (2011). *Designing and conducting mixed methods research*. Los Angeles: Sage.

Crossland, M., Silva, R., & Macedo, A. (2014). Smartphone, tablet computer and e-reader use by people with vision impairment. *Ophthalmic and Physiological Optics, 34*(5), 552-557. doi:10.1111/opo.12136

Dart, G., Nkanotsang, T., Chizwe, O., & Kowa, L. (2010). Albinism in Botswana junior secondary schools a double case study. *British Journal of Special Education, 37*(2), 77-77. doi:10.1111/j.1467-8578.2010.00465.x

Demeter, S. L., & Andersson, G. (2003). *Disability evaluation*. St. Louis, Mo: Mosby.

Devlin, R. F., & Pothier, D. (2006). *Critical disability theory: essays in philosophy, politics, policy, and law*. Vancouver: UBC Press.

Disability Resource Centre. (2010). *The Cost of Disability* Retrieved from drc@disabilityresource.org.nz

Emerson, E. (2012). The world report on disability. *Journal of applied research in intellectual disabilities : JARID, 25*(6), 495-496. doi:10.1111/j.1468-3148.2012.00693.x

Fawcett, B. P. D. (2000). *Feminist perspectives on disability*. New York: Prentice Hall.

Flynn, E. (2011). *From rhetoric to action: implementing the UN Convention on the Rights of Persons with Disabilities*. New York: Cambridge University Press.

Foundation, Blind. (2014). *Client Needs Assessment Survey*: Blind Foundation.

Gold, M. E. (1998). *The effects of the physical features associated with albinism on the self-esteem of African-American youth with albinism*. ProQuest, UMI Dissertations Publishing.

Goodley, D. (2011). *Disability studies: an interdisciplinary introduction*. London: SAGE.

Goodley, D., Hughes, B., & Davis, L. J. (2012). *Disability and social theory: new developments and directions*. New York: Palgrave Macmillan.

Gravitas Research and Strategy Ltd & Market Economics Ltd. (2006). *The Costs of Blindness in New Zealand*. Retrieved from http://blindfoundation.org.nz

Greasley, P. (2008). *Quantitative data analysis using SPSS: an introduction for health & social science*. Maidenhead: Open University Press.

Harmati, T. (2005). *Children with albinism in the educational system in the United States of America*. ProQuest, UMI Dissertations Publishing.

Harris, J., & Roulstone, A. (2011). *Disability, policy and professional practice*. London: SAGE.

Herschel, K. (2014). *Introductory statistics using SPSS*. Thousand Oaks, California: SAGE.

Hilary Stace. (2010). Social justice, the social model and disability policy in Aotearoa New Zealand. *Social Work Now: The Practice Journal of Child, Youth and Family, 46*.

Hong, E., Zeeb, H., & Repacholi, M. (2006). Albinism in Africa as a public health issue. *BMC Public Health, 6*(1), 212-212. doi:10.1186/1471-2458-6-212

Hughes, B., & Paterson, K. (1997). The Social Model of Disability and the Disappearing Body: Towards a sociology of impairment. *Disability & Society, 12*(3), 325-340. doi:10.1080/09687599727209

Independent Monitoring Mechanism of the Disability Convention. (2012). *Making disability rights real: Annual report of the Independent Monitoring Mechanism of the Convention on the Rights of Persons with Disabilities 1 July 2011 – 30 June 2012*. Retrieved from http://www.hrc.co.nz/wp-content/uploads/2012/12/Making-disability-rights-real-Print.pdf

Jan Webster, & Richard T Watson. (2002). Analyzing the past to prepare for the future: Writing a literature review. *MIS Quarterly, 26*(2), R13.

Judy McGregor, Sylvia Bell, & Margaret Wilson. (2015). *Fault Lines: Human Rights in New Zealand*: New Zealand Law Foundation Retrieved from http://www.aut.ac.nz/__data/assets/pdf_file/0010/536572/NO-watermark-Fault-lines-Human-rights-in-New-Zealand.pdf

Kendrick, J. R. (2005). *Social statistics: an introduction using SPSS for Windows*. Boston: Pearson/Allyn and Bacon.

King, & Ross. (2010). *"Critics and Beyond" Chapter 4 from The oxford Handbook of Welfare State*. New York: Oxford University Press Inc.

Kristiansen, K., Vehmas, S., & Shakespeare, T. (2009). *Arguing about disability: philosophical perspectives*. London: Routledge.

La Grow, S., Alpass, F., & Stephens, C. (2009). Economic Standing, Health Status and Social Isolation among Visually Impaired Persons Aged 55 to 70 in New Zealand. *Journal of Optometry, 2*(3), 155-158. doi:10.3921/joptom.2009.155

LITMUS. (2008). *New Zealand Disability Strategy Implementation Review 2001-2007*. Wellington: New Zealand. Retrieved from http://www.odi.govt.nz/nzds/progress-review/index.html

LITMUS. (2015). *Stocktake and Needs Analysis of Low Vision Services in New Zealand*: Ministry of Health Retrieved from https://www.health.govt.nz/system/files/documents/publications/stocktake-needs-analysis-low-vision-services-in-new-zealand-mar15_1.pdf

Little, A. (2014). *Eyes rights: an introduction to living with albinism in New Zealand* (Second ed.): New Zealand Albinism Trust & Blind Foundation. Retrieved from http://www.albinism.org.nz/wp-content/uploads/2014/11/Eyes-Right-Albinism-Trust-2014.pdf

Lund, P. M., & Gaigher, R. (2002). A health intervention programme for children with albinism at a special school in South Africa. *Health education research, 17*(3), 365-372. doi:10.1093/her/17.3.365

Ministry of Education. (2015). *Services and support*. Retrieved January, 2015, from http://www.minedu.govt.nz/NZEducation/EducationPolicies/SpecialEducation/ServicesAndSupport.aspx

Ministry of Health. (2001). *The New Zealand Disability Strategy: making a world of difference = Whakanui oranga* (0478243588, 9780478243581, 0478243596, 9780478243598). Wellington, N.Z: Ministry of Health.

Ministry of Health. (2015). *Disability services*. Retrieved January, 2015, from http://www.health.govt.nz/our-work/disability-services?mega=Our%20work&title=Disability

Ministry of Health. (2015). *Vision loss*. Retrieved January, 2015, from http://www.health.govt.nz/your-health/conditions-and-treatments/disabilities/vision-loss

Ministry of Social Development. (2010). *How Government helps with the cost of disability*. Retrieved January, 2015, from https://www.msd.govt.nz/about-msd-and-our-work/publications-resources/literature-reviews/cost-of-disability/

Mmuso, B. J. P.-M., Thandisizwe, R. Mavundla, & Arnold, L. Christianson,. (2012). The experience of people with oculocutaneous albinism. *Health S A, 17*(1), 1E-8.

National Organization for Albinism and Hypopigmentation. (2011). *Raising a child with albinism*: National Organization for Albinism and Hypopigmentation.

National Organization for Albinism and Hypopigmentation. (2013). *What Albinism is?* Retrieved August, 2013, from http://www.albinism.org/

Neuman, W. L. (2014). *Social research methods: qualitative and quantitative approaches*. Harlow, Essex: Pearson.

New Zealand Albinism Trust. (2013). *NZ Albinism Trust*. Retrieved August 2013, from http://www.albinism.org.nz/home.html

New Zealand Parliament. (2014). *In support of Petition 2011/71 of Dr Lynley Hood and Associate Professor Gordon Sanderson on behalf of the Visual Impairment Charitable Trust Aotearoa New Zealand (VICTA) and 1,321 others*. Retrieved January, 2015, from http://www.parliament.nz/resource/en-nz/50SCHE_EVI_50DBHOH_PET3165_1_A387699/2306075ca234f4a3d7645724329b8b21ed560c23

Odom, S. L., Horner, R. H., Snell, M. E., & Blacher, J. (2007). *Handbook of Developmental Disabilities*. New York: The Guilford Press.

Oetting, W. S. (1999). Albinism. *Current opinion in pediatrics, 11*(6), 565.

Office for Disability Iissues. (2005). *Including a disability perspective: Key concepts*. Retrieved August, 2014, from http://webcache.googleusercontent.com/search?q=cache:4r_1EjZKP1oJ:www.odi.govt.nz/documents/disability-perspective/key-concepts.doc+&cd=1&hl=en&ct=clnk&gl=nz

Office for Disability Iissues. (2014). *Disability in New Zealand: A changing perspective*. Retrieved August, 2014, from http://www.odi.govt.nz/resources/guides-and-toolkits/disability-perspective/disability-nz.html

Office for Disability Issues. (2011). *First New Zealand Report on Implementing the United Nations Convention on the Rights of Persons with Disabilities* Retrieved February, 2014, from http://www.odi.govt.nz/what-we-do/un-convention/monitoring-implementation/2010-report.html

Office for Disability Issues. (2014). *Resources*. Retrieved January, 2014, from http://www.odi.govt.nz/resources/index.html

Office for Disability Issues and Statistics New Zealand. (2009). *Disability and travel and transport in New Zealand in 2006: Results from the New Zealand Disability Survey*. Wellington: Statistics New Zealand.

Oliver, M. (2009). *Understanding disability: from theory to practice*. New York: Palgrave Macmillan.

Palmer, C. (2005). The social competence of children with albinism. *International Congress Series, 1282*, 917-921. doi:10.1016/j.ics.2005.05.084

Palmer, C. (2007). Myths, Stereotypes and Self-Perception: The Impact of Albinism on Self-Esteem. *British Journal of Visual Impairment, 25*(2), 144-154. doi:10.1177/0264619607075998

Pardeck, J. T., & Murphy, J. W. (2005). *Disability issues for social workers and human services professionals in the twenty-first century*. Binghamton, NY: Haworth Social Work Practice Press.

Penny Taylor, & Katie Mapp. (2010). *Clear Focus — The economic impact of vision loss in New Zealand in 2009* Retrieved from http://blindfoundation.org.nz/learn/blindness/clear-focus

Prince, M. J. (2009). *Absent citizens: disability politics and policy in Canada*. Buffalo: University of Toronto Press.

Racino, J. A. (1999). *Policy, program evaluation, and research in disability: community support for all*. New York: Haworth Press.

Statistics New Zealand. (2007). *Disability Stocktake*. Wellington: Statistics New Zealand. Retrieved from http://www.stats.govt.nz/browse_for_stats/health/disabilities/disability-stocktake.aspx

Statistics New Zealand. (2013). *Household Use of Information and Communication Technology: 2012*. Wellington: Statistics New Zealand.

Statistics New Zealand. (2014). *Social and economic outcomes for disabled people: Findings from the 2013 Disability Survey*. Wellington: Statistics New Zealand.

Stevenson, D. (1966). Albinism. *The British Medical Journal, 2*(5529), 1593-1594.

The Welfare Working Group. (2011). *Reducing Long-Term Benefit Dependency: Recommendations*. Wellington. Retrieved from http://ips.ac.nz/WelfareWorkingGroup/Index.html

Thomas, C. (2012). Theorising disability and chronic illness: Where next for perspectives in medical sociology? *Social Theory & Health, 10*(3), 209. doi:10.1057/sth.2012.7

United Nations' General Assembly. (2006). *Convention on the Rights of Persons with Disabilities*. Retrieved February 2014, from http://www.un.org/esa/socdev/enable/rights/convtexte.htm

United Nations High Commissioner for Human Rights. (2013). *Persons with albinism* Retrieved from http://www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session24/Pages/ListReports.aspx

Walter, M. (2010). *Social research methods*. South Melbourne, Vic: Oxford University Press.

Wan-Kee-Cheung, N. (2002). *The voices of albinism*. ProQuest, UMI Dissertations Publishing.

Watson-Hulum, J. (2011). *Demographic Factors that Predict Educational Attainment in Individuals with Albinism*. ProQuest, UMI Dissertations Publishing.

World Health Organization, & World Bank. (2011). *World report on disability*. Geneva, Switzerland World Health Organization.

Young, V. S. (2012). *People with Albinism and their Experience of Felt Stigma: Results of a Nationwide Survey*. ProQuest, UMI Dissertations Publishing.

Appendices

Appendix 1: Ethics Approval

AUT UNIVERSITY
TE WĀNANGA ARONUI O TĀMAKI MAKAU RAU

AUTEC
SECRETARIAT

3 September 2014

Charles Crothers
Faculty of Culture and Society

Dear Charles

Re Ethics Application: **14/205 People with Albinism in New Zealand.**

Thank you for providing evidence as requested, which satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC).

Your ethics application has been approved for three years until 3 September 2017.

As part of the ethics approval process, you are required to submit the following to AUTEC:

- A brief annual progress report using form EA2, which is available online through http://www.aut.ac.nz/researchethics. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 3 September 2017;

- A brief report on the status of the project using form EA3, which is available online through http://www.aut.ac.nz/researchethics. This report is to be submitted either when the approval expires on 3 September 2017 or on completion of the project.

It is a condition of approval that AUTEC is notified of any adverse events or if the research does not commence. AUTEC approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

AUTEC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this. If your research is undertaken within a jurisdiction outside New Zealand, you will need to make the arrangements necessary to meet the legal and ethical requirements that apply there.

To enable us to provide you with efficient service, please use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at ethics@aut.ac.nz.

All the very best with your research,

Kate O'Connor
Executive Secretary
Auckland University of Technology Ethics Committee

Cc: Hazem Ahmed Adb Elkader fzd5703@aut.ac.nz

Auckland University of Technology Ethics Committee
WA505F Level 5 WA Building City Campus
Private Bag 92006 Auckland 1142   Ph: +64-9-921-9999 ext 8316 email ethics@aut.ac.nz

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Albinism Trust
www.albinism.org.nz
7 Earl Street
Levin 5510

24th February 2014

AUT Ethics Committee
C/o   Hazem Abd Elkader
Unit O / 3 Mountain Road
Mount Wellington
Auckland 1072

People with Albinism in New Zealand Research proposal By Hazem Abd Elkader

This letter confirms that **Mr Abd Elkader** has the support of our organisation for his proposed research. He has consulted with the 'Albinism Trust' and duly considered our suggestions which are reflected in his chosen question.

Mr Abd Elkader research will investigate whether the implementation of the New Zealand Disability Strategy of 2001 provides people with albinism with the support they need. The research is significant because it will be the first project to target People with Albinism and their needs in New Zealand.

We believe the research to be undertaken has the potential to benefit New Zealanders with Albinism and urge its approval.

Albinism Trust commend Mr Abd Elkader for the energy and imagination he has shown advancing this important topic for consideration. Our Trustees will be pleased to do whatever is required to help with this research. In particular it would be my pleasure to collaborate with anyone it might concern to ensure the ultimate success of Mr Abd Elkader in pursuing his academic objective. I am personally happy to remain available to answer questions or give elaboration as or if required and can be contacted 24/7 on phone (06) 367-5900 or Mobile (021) 02533330

We wish Hazem well in his research efforts and commend him to whomever for most favourable consideration.

Yours faithfully,

Allen J Little QSM,JP
National Organiser

Appendix 3: Second letter of support from Albinism Trust

Albinism Trust
www.albinism.org.nz
Registered Charity CC22352

7 Earl Street,
Levin 5510
Phone 06 367-5900

31st August 2014

TO WHOM IT MAY CONCERN

Whereas **Mr Hazem Abd Elkader** a Postgraduate Student at AUT (Student ID 1127485) is desirous of perusing his academic education, we are pleased to write this letter of support confirming that Mr Abd Elkader has the support of our organisation for his proposed research. He has consulted with the 'Albinism Trust' and duly considered our suggestions which are reflected in his chosen question. Mr Abd Elkader's research will investigate whether the implementation of the New Zealand Disability Strategy of 2001 provides people with albinism with the support they need. The research is significant because it will be the first project to target People with Albinism and their needs in New Zealand.

We believe the research to be undertaken has the potential to benefit New Zealanders with Albinism and urge its approval. Albinism Trust commend Mr Abd Elkader for the energy and imagination he has shown advancing this important topic for consideration. Our Trustees will be pleased to do whatever is required to help with this research. In particular it would be my pleasure to collaborate with anyone it might concern to ensure the ultimate success of Mr Abd Elkader in pursuing his academic objective. I am personally happy to remain available to answer questions or give elaboration as or if required and can be contacted 24/7 on phone (06) 367-5900 or Mobile (021) 02533330

We wish Hazem well in his research efforts and commend him to whomever for most favourable consideration.

Yours faithfully,

Allen Little

National Organiser

Appendix 4: First letter of support from the Blind Foundation

Beyond vision loss

19 June 2014

Mr Hazem Abd Elkader
5D/8 Scotia Place
Auckland CBD
Auckland 1010

Dear Hazem,

Thank you for your request for assistance in hosting the interviews for your research.

The Blind Foundation is very happy to provide office space for you to undertake the 12 interviews with our members for your albinism study. Please let me know closer to the time the locations of the interviews and I will arrange things with the local offices.

Wishing you all the best with your research.

Yours sincerely

Catherine Rae
Quality Improvement Manager
Blind Foundation
Corner of Hillside Road & Law Street, Dunedin 9012
P: 03 466 4240 x4240
M: 0276883186

Appendix 5: Second letter of support from the Blind Foundation

Beyond vision loss

31/07/2014

To whom it may concern

The Blind Foundation offers free counselling services to Blind Foundation members throughout New Zealand with issues specifically related to their vision loss.

I am aware of the research being undertaken by Hazem Abd Elkader, and if any issues arise with Blind Foundation members and they may require counselling support following being involved in this research, they can contact their nearest Blind Foundation Office.

Kind regards
Gary Alcock
Service Manager : Upper North

Blind Foundation
P: 09 355 6903 x6903
M: 0274662597

Email: galcock@blindfoundation.org.nz

Blindfoundation.org.nz

Appendix 6: Confidentiality agreement

Confidentiality Agreement

AUT
UNIVERSITY
TE WĀNANGA ARONUI O TAMAKI MAKAU RAU

Project title: *People with Albinism in New Zealand*

Project Supervisor: **Professor Charles Crothers**

Researcher: **Hazem Abd Elkader**

☒ I understand that all the material I will be asked to transcribe is confidential.

☒ I understand that the contents of the tapes or recordings can only be discussed with the researchers.

☒ I will not keep any copies of the transcripts nor allow third parties access to them.

Transcriber's *Geraldine Muncal*   signature: *David Gee*

Transcriber's   name:

Transcriber's Contact Details (if appropriate):

info@notetakingexpress.com

Date: *May 12, 2015*

Project Supervisor's Contact Details (if appropriate):

Daniel Goerz - Note Taking Express
PO Box 995 Lethbridge, AB Canada T1J-4A2
www.notetakingexpress.com
1-888-763-2966

Approved by the Auckland University of Technology Ethics Committee on 3 September 2014, AUTEC Reference number 14/205.

Appendix 7: Consent form

Consent Form

AUT
UNIVERSITY
TE WĀNANGA ARONUI O TAMAKI MAKAU RAU

Project title:	**People with Albinism in New Zealand**
Project Supervisor:	**Professor Charles Crothers**
Researcher:	**Hazem Abd Elkader**

O   I have read and understood the information provided about this research project in the Information Sheet dated 29/08/2014.

O   I have had an opportunity to ask questions and to have them answered.

O   I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.

O   I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.

O   If I withdraw, I understand that all relevant information including tapes and transcripts, or parts thereof, will be destroyed.

O   I agree to take part in this research.

O   I wish to receive a copy of the report from the research (please tick one): YesO   NoO

Participant's   signature:
    ....…………………………………………………

Participant's   name:
    ....…………………………………………………

Participant's Contact Details (if appropriate):

…………………………………………………………………………………..

………………………………………………………………………………….

………………………………………………………………………………….

Date:

Participant Information Sheet

AUT
UNIVERSITY
TE WĀNANGA ARONUI O TĀMAKI MAKAU RAU

Date Information Sheet Produced:

29/08/2014

Project Title

People with Albinism in New Zealand

An Invitation

The researcher (Hazem Abd Elkader) is a postgraduate student at Auckland University of Technology (AUT). The researcher would like to invite you to participate in his study about people with albinism in New Zealand. This study will contribute to the completion of researcher's master degree. If you agree to participate, you will need to know that the participation is voluntary and you may withdraw at any time prior to the completion of data collection.

What is the purpose of this research?

This thesis aims to determine the needs of people with albinism in New Zealand and assess how well these are being met against the objectives of the New Zealand Disability Strategy of 2001 and the requirements of the United Nations Convention on the Rights of People with Disabilities of 2006. The findings of the research will be disseminated in different formats:

1- A summary to be sent to the people who took part of the study on request.

2- A copy of the full thesis on the New Zealand Albinism Trust website.

3- A presentation at the October 2015 Conference of Albinism Fellowship of Australia (AFA) at the Rugby Institute, Massey University, Palmerston North.

4- An article about the research to be published through one of the academic journals.

How was I identified and why am I being invited to participate in this research?

You are invited to participate in this research because you are a person with albinism or raising a child with albinism and you are a member of the Royal New Zealand Foundation of the Blind.

What will happen in this research?

The data collection process of this research will take two steps. First, if you are a person with albinism or have a child with albinism you will be asked to fill in a questionnaire about people with albinism in New Zealand and their health, education, employment, income, transport, housing, and respite care. Also you will be asked give consent to the researcher to contact you for a face-to-face interview. Secondly, using the demographic data the researcher will make contact with up to 12 of those who give consent to be interviewed for an interview. During the interview you will be asked to provide information related to citizenship, recreation, relationships and value of people with albinism in New Zealand.

Note: all the information will only be used for the purpose of the research.

Approved by the Auckland University of Technology Ethics Committee on 3 September 2014, AUTEC Reference number 14/205.

What are the discomforts and risks?

There are no risks will result from participating in this research. Participants may feel uncomfortable to answer questions about relationships.

How will these discomforts and risks be alleviated?

The researcher will keep consulting the trustees of the New Zealand Albinism Trust to alleviate any discomforts and to avoid any culture differences and to correct the language that should be employed while designing the instrument of the next steps. Also, the participant will have the right not to answer any question and may withdrawal at any time during the data collection process.

What are the benefits?

This study will contribute to the completion of researcher's master degree.

How will my privacy be protected?

The researcher will be responsible to: (1) keep any information about you private and confidential, (2) use the collected information for the research purposes, and (3) destroy all relevant information including tapes and transcripts after he finish his research.

What are the costs of participating in this research?

The interview will take approximately 45 minutes. Answering the survey questions will require 30 to 45 minutes.

What opportunity do I have to consider this invitation?

After you read this information sheet carefully you will have one week to decide whether you are willing to participate.

How do I agree to participate in this research?

For the purpose of the interviews, you will be asked to sign the attached consent form. Otherwise, you will only need to complete the survey.

Will I receive feedback on the results of this research?

A summary of the research findings will be sent to the participants on request. Also the full thesis will be available on the New Zealand Albinism Trust website www.albinism.org.nz .

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, *Professor Charles Crothers, charles.crothers@aut.ac.nz, 9219999 ext 8468.*

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEC, Kate O'Connor, *ethics@aut.ac.nz*, 921 9999 ext 6038.

Whom do I contact for further information about this research?

Researcher Contact Details:

Hazem Abd Elkader, fzd5703@aut.ac.nz.

Project Supervisor Contact Details:

Professor Charles Crothers, charles.crothers@aut.ac.nz, 9219999 ext 8468.

Michael Fletcher, mfletche@aut.ac.nz

Approved by the Auckland University of Technology Ethics Committee on 3 September 2014, AUTEC Reference number 14/205.

Appendix 9: The invitation

Invitation

AUT
UNIVERSITY
TE WĀNANGA ARONUI O TAMAKI MAKAU RAU

Project title: **People with Albinism in New Zealand**
Project Supervisor: **Professor Charles Crothers**
Researcher: **Hazem Abd Elkader**

Dear ....

My name is Hazem Abd Elkader. I am a postgraduate student in the school of social science and public policy at the Auckland University of Technology. I am conducting a research study as part of the requirements of my master's degree in social science, and I would like to invite you to participate in a research project entitled people with albinism in New Zealand.

The purpose of this research project is to determine the needs of people with albinism in New Zealand and assess how well these are being met against the objectives of the New Zealand Disability Strategy of 2001 and the requirements of the United Nations Convention on the Rights of People with Disabilities of 2006. Should you choose to participate, you will be asked to complete the online/attached survey. Completing the survey should take approximately between 30 to 45 minutes.

The research should benefit all New Zealanders with albinism by providing the first ever academic investigation about their needs, and we hope that will contribute to improve the support services in the future.

For more information about this research project please read the attached information sheet.

We will be happy to answer any questions you have about the study. You may contact me at (0275055809, fzd5703@aut.ac.nz) or my supervisors, (Professor Charles Crothers, 09 921 9999 ext 8468., charles.crothers@aut.ac.nz) if you have study related questions or problems. If you have any questions about your rights as a research participant, you may contact the Executive Secretary of the Auckland University of Technology Ethics Committee, (Kate O'Connor, 09 921 9999 ext 6038, ethics@aut.ac.nz).

If you would like to participate, please (click on the link below/open the attached survey packet and begin completing the study materials.

Start the online survey

When you are done, please return the study materials using the prepaid envelop.

Thank you

Hazem Abd Elkader
Phone number: 0275055809
E-mail: fzd5703@aut.ac.nz

Approved by the Auckland University of Technology Ethics Committee on 3 September 2014, AUTEC Reference number 14/205.

Interview Guide

Draft

AUT
UNIVERSITY
TE WĀNANGA ARONUI O TAMAKI MAKAU RAU

Project title: *People with Albinism in New Zealand*

Project Supervisor: **Professor Charles Crothers**

Researcher: **Hazem Abd Elkader**

INTRODUCTION

I would like to thank you for agreeing to be interviewed. My name is Hazem Abd Elkader. I am a postgraduate student at Auckland University of Technology (AUT). This research is part of my study for my master's degree in social science.

This research aims to investigate whether the implementation of the New Zealand Disability Strategy of 2001 and the United Nations Convention on the Rights of Persons with Disabilities of 2006 provide people with albinism (PWA) with the support they need.

The purpose of conducting this interview is to gain an in-depth understanding of the needs of people with albinism and how these needs can be met.

I would like also to gain your consent to record our discussion today. The reason for recording is so that I do not miss anything that is said. Also I want you to make sure that our discussion will remain completely confidential. The information will only be used for the research project and the recording will be securely stored so that it will be only accessible to my supervisors and I. Is it OK with you to record this discussion? (Check consent to recording). This discussion will probably last about 90 Minutes. Are there any questions before we start?

GENERAL QUESTIONS

Number of interview:

Type of albinism

Ethnicity

Gender

Age

Urban or rural residence

Approved by the Auckland University of Technology Ethics Committee on 3 September 2014, AUTEC Reference number 14/205.

OPENING QUESTION

What does albinism mean to you?

KEY QUESTIONS

1- Health

From a point of view of a person with albinism, how would you describe the existing health and wellbeing services?

How did/do people in the medical profession (doctors and/or nurses) treat you in relation to you having albinism?

2- Education

Tell me about your experiences at school, how students and teachers treated you or reacted to your condition?

3- Employment

How has albinism affected your ability to find or maintain work?

The Ministry of Social Development provides support for people with disability in order to move into paid work. From your experiences, how do you describe these interventions?

4- Income

How do you feel about the existing income support provisions including (benefits and transition to work and training programmes)?

To what extent do these services support your independence and choices?

5- Transport

According to their visual condition, most of people with albinism rely on public transport for the purpose of personal mobility. Can you tell me about your experiences with public transport?

Because of your albinism, what kind of difficulties do you face while using public transport?

6- Housing

Thinking about you housing, are there any ways that albinism has affected your choice of housing?

Did/do you receive any housing assistance form the government? How do you describe the available assistance?

7- Discrimination

Have you ever experienced discrimination? Please discuss some of your experiences.

8- Relationship
Approved by the Auckland University of Technology Ethics Committee on 3 September 2014, AUTEC Reference number 14/205.

How did/do your (family, relatives, and friends) react to your condition?

How has albinism affected your ability to make and keep relationships?

9- Recreation

To what extent does albinism affect your ability to play sports or to be involved in cultural or recreation activities?

CLOSING QUESTIONS

How has having albinism impacted on your life?

How satisfied with your life are you?

What are your hopes for the future?

Are there any comments you would like to add before we finish?

Appendix 11: Parents' questionnaire

People with Albinism in New Zealand – Parents

INTRODUCTION

The researcher (Hazem Abd Elkader) is a postgraduate student at Auckland University of Technology (AUT). The researcher would like to invite you to participate in his study about people with albinism in New Zealand. This study will contribute to the completion of researcher's master degree. If you agree to participate, you will need to know that the participation is voluntary and you may withdraw at any time prior to the completion of data collection.

This thesis aims to determine the needs of people with albinism in New Zealand and assess how well these are being met against the objectives of the New Zealand Disability Strategy of 2001 and the requirements of the United Nations Convention on the Rights of People with Disabilities of 2006.

The findings of the research will be disseminated in different formats:
1- A summary to be sent to the people who took part of the study on request.
2- A copy of the full thesis will be released on the New Zealand Albinism Trust website.
3- A presentation at the October 2015 Conference of Albinism Fellowship of Australia (AFA).
4- An article about the research to be published through on an academic journal.

You are invited to participate in this research because you are a person with albinism and a member of the Royal New Zealand Foundation of the Blind.

The data collection process of this research will take two steps. First, if you are a person with albinism or have a child with albinism you will be asked to fill in an online questionnaire about people with albinism in New Zealand and their health, education, employment, income, transport, housing, and respite care. Also you will be asked give consent to the researcher to contact you for a face-to-face interview. Secondly, using the demographic data the researcher will make contact with up to 12 of those who give consent to be interviewed for an interview. During the interview you will be asked to provide information related to citizenship, recreation, relationships and value of people with albinism in New Zealand.

The researcher will be responsible to: (1) keep any information about you private and confidential, (2) use the collected information for the research purposes and (3) destroy all relevant information including tapes and transcripts after he finish his research.

Your information is confidential. Study information will be kept in a secure location at the Auckland University of Technology. You need to know that taking part in the study is your decision, and you may withdraw at any time prior to the completion of data collection. Your identity will not be revealed.

Completing this survey may take approximately between 30 to 45 minutes. If you would like to participate please press next.

SECTION A: GENERAL INFORMATION

This section aims to collect demographic data from the participants. The section includes questions about gender, age, location, and ethnicity.

1. Are you?

◯ Male

◯ Female

2. Is your child?

◯ Male

◯ Female

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3. Which age group do you belong to?

○ 15-24

○ 25-44

○ 45-64

○ 65 years and over

4. How old is your child?

[   ]

5. What best describes the area in which you live?

○ Remote rural

○ Rural

○ Town

○ City

6. What would you consider your ethnic background to be? (please check all that apply)

☐ NZ European

☐ Maori

☐ Pacific

☐ Asian

☐ Middle Eastern/Latin American/African

Other (please specify)

[   ]

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7. What is your highest educational qualification?

○ Level 1 Certificate gained at school

○ Level 2 Certificate gained at school

○ Level 3 or 4 Certificate gained at school

○ Overseas Secondary School Qualification

○ Level 1 Certificate gained post-school

○ Level 2 Certificate gained post-school

○ Level 3 Certificate gained post-school

○ Level 4 Certificate gained post-school

○ Level 5 Diploma

○ Level 6 Diploma

○ Bachelor Degree and Level 7 qualifications

○ Postgraduate and Honours Degree

○ Master's Degree

○ Doctorate Degree

Other (please specify)

[   ]

8. From all sources of income, what is your annual household income before tax?

○ Loss

○ Zero income

○ $1-$5,000

○ $5,001-$10,000

○ $10,001-$15,000

○ $15,001-$20,000

○ $20,001-$25,000

○ $25,001-$30,000

○ $30,001-$35,000

○ $35,001-$40,000

○ $40,001-$50,000

○ $50,001-$60,000

○ $60,001-$70,000

○ $70,001-$100,000

○ $100,001-$150,000

○ $150,001 or More

○ Not stated

SECTION B: IMPAIRMENT TYPE

This section aims to determine the impairment type of your child

9. What type of albinism does your child have?

○ Oculocutaneous Albinism (affected skin, hair, and eyes)

○ Ocular Albinism (affected eyes)

10. Does your child have any disabilities or any other health conditions other than albinism that affect her/his daily life?

○ Yes

○ No

If yes (please specify)

[   ]

SECTION C: SPECIAL DEVICES OR EQUIPMENT

This section aims to investigate whether children with albinism have access to special equipment or devices for

seeing.

11. Which equipment or devices does your child use? (Please select all that you use)

☐ Screen Reader (e.g. JAWS, NVDA)

☐ Screen Magnifier (e.g. Zoomtext, Magic)

☐ Refreshable Braille Display

☐ Scanner (OCR software)

☐ All in one scanning device

☐ CCTV (Video Magnifier)

☐ Tape Recorder/audio recording device

☐ Digital recorder

☐ Digital Reader (e.g. Book port, Victor Reader Stream)

☐ iOS Devices (e.g. iPhone, iPad)

☐ Hand Held Magnifier

☐ Labeller (e.g. Penfriend or dymo labeller)

☐ Specialized reading or distance viewing glasses

☐ Colour detector

☐ Household and kitchen aids

☐ Talking or tactile home maintenance equipment (e.g. tape measures, spirit levels)

☐ Talking or tactile medical devices (e.g. talking glucometer)

☐ None

Other (please specify)

[ ]

12. Does your child has unmet need for equipment or devices?

○ Yes

○ No

If yes (please specify)

[ ]

SECTION D: HEALTH

This section aims to investigate whether children with albinism have access to appropriate health and wellbeing services.

13. How would you describe your child;

	Very good	Good	Fair	Poor/very bad
Vision	◯	◯	◯	◯
Skin Health	◯	◯	◯	◯
Overall Health	◯	◯	◯	◯

14. How often does your child visit a health professional such as a GP or specialist for a reason related to albinism at the last 12 months?

◯ Less than 4 visits

◯ 4 visits

◯ More than 4 visits

✱15. Still thinking within the last 12 months, does your child have unmet need to visit a health professional for a reason related to albinism?

◯ Yes

◯ No

SECTION D: HEALTH

16. if yes, Why?

☐ Couldn't afford to

☐ Couldn't get a suitable appointment

☐ Transport difficulties

☐ No appropriate service available

Other (please specify)

[   ]

17. Do you feel health professionals understand the ways in which your child albinism affects her/his quality of life?

◯ Very well

◯ Maybe

◯ Not at all

◯ I Don't Know

18. How would you describe your child's ability to access health and wellbeing services?

◯ Easy

◯ Reasonable

◯ Difficult

＊19. Has your child ever had a needs assessment?

◯ Yes

◯ No

SECTION D: HEALTH

20. How long ago did your child last needs assessment take place?

◯ Less than one year

◯ Less than 2 years

◯ Two or more years ago

21. How satisfied are you with service and support provision?

◯ Very Satisfied

◯ Somewhat satisfied

◯ Somewhat dissatisfied

◯ Very dissatisfied

SECTION E: EDUCATION

This section aims investigate whether children with albinism have equal opportunities to learn and develop their skills.

＊22. Is your child enrolled in or receiving early childhood education?

◯ Yes

◯ No

SECTION E: EDUCATION

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23. To which type of school did your child enroll?

◯ Regular school

◯ Special school

◯ Correspondence School

◯ Other (please specify)

[   ]

24. If your child enrolled in a regular school, does she/he attend special education classes?

◯ Yes

◯ No

25. Has your child ever had an educational needs assessment through the Blind and Low Vision Education Network NZ (BLENNZ)?

◯ Yes

◯ No

26. Which of the following adaptations did you or your child's school make in the classroom?

☐ Sitting with back to the window

☐ Protection from sunlight from Windows

☐ Seating close to the board

☐ Teacher aide assistance

☐ Other (please specify)

[   ]

27. Which of the following aids did your child receive in school?

☐ Magnified texts

☐ Magnified books

☐ Audio tapes

☐ Computer access

☐ Magnifying glass

☐ Other (please specify)

[   ]

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28. Are there supports that you felt your child needed that she/he does not receive?

◯ Yes

◯ No

If yes (please specify)

[   ]

29. To what extent do you feel education professionals such as Teachers, teacher aides, education support workers and others involved in the education of the child or young person understand the ways in which albinism affects the quality of life?

◯ Very well

◯ Maybe

◯ Not at all

◯ I Don't Know

SECTION F: TRANSPORT

This Section aims to investigate whether children with albinism have available, accessible, and affordable transport.

30. Public transport includes buses, trains, trams and ferries. In the last 12 months, has your child used public transport to travel short distances?

◯ Yes

◯ No

31. Because of your child's albinism, does she/he has any difficulty using any of those kinds of public transport to travel short distances?

◯ Yes

◯ No

32. In the last 12 months, what difficulties has your child had that are due to her/his albinism? (please check all that apply)

☐ Difficulty getting to or finding the stop

☐ Waiting at the stop

☐ Getting on or off

☐ Identifying the right bus, train, tram or ferry

☐ Getting information about timetables or routes

☐ Staff who are not supportive or helpful

☐ No difficulties

☐ Other (please specify)

[   ]

✱33. Over the last 12 months, how often has your child used a taxi to travel short distances (around your local town/city)?

○ Not at all

○ Almost every day

○ Once a week or more

○ Once a month or more

SECTION F: TRANSPORT

34. Is there any reason why your child has not used taxis either at all, or more often, over the last 12 months? Please indicate your primary reason

○ Don't need to use taxis

○ Too expensive

○ Need to book in advance

○ There is nothing limiting my use of taxis

○ Not applicable - my child is too young

○ Other (please specify)

[   ]

35. Have you heard of the Total Mobility Scheme? The Scheme gives people who have a disability including children, taxi vouchers which entitle them to a discount on their taxi fares

○ Yes

○ No

SECTION G: RECREATION

This section aims to investigate whether children with albinism enjoy cultural and recreation activities of their choices.

36. During the last four weeks, has your child? (please check all that apply)

☐ Had music or art lessons (outside of school)

☐ Played a team sport

☐ Done physical activity such as swimming or gymnastics

☐ Participated in club activities

☐ Gone out with family or friends

☐ Visited friends

☐ Gone away on a holiday

37. During the last four weeks, has your Child had difficulty? (please check all that apply)

☐ Playing with other children

☐ Playing sport

☐ Going away on a holiday

☐ Not applicable – no difficulties

SECTION H: QUALITY OF LIFE

38. After New Zealand has established its disability strategy in 2001 and has ratified on the UN convention on the rights of people with disability in 2008, Do you think quality of life for children with albinism has?

○ improved

○ remained the same

○ declined

○ I do not know

39. How do you feel about your child's life as a whole?

[text box]

SECTION I: COMMENTS AND CONSENT FOR FURTHER CONTACT

40. If you have any comments about this survey. Please specify:

41. For a few of the participants, face-to-face interviews will be conducted in order to gain an in depth understanding of the situation of children with albinism in New Zealand. Would you be interested in participating in these follow up interviews should you be selected?

○ Yes

○ No

If yes, please provide your full name and contact detail

42. Would you like a summary of the findings to be sent to your e-mail address?

○ Yes

○ No

E-mail (please specify)

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Appendix 12: Adults' questionnaire

People with Albinism in New Zealand - Adults

INTRODUCTION

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SECTION A: GENERAL INFORMATION

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1. Are you?

◯ Male

◯ Female

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People with Albinism in New Zealand - Adults

2. Which age group do you belong to?

- ◯ 15-24
- ◯ 25-44
- ◯ 45-64
- ◯ 65 years and over

3. What best describes the area in which you live?

- ◯ Remote rural
- ◯ Rural
- ◯ Town
- ◯ City

4. What would you consider your ethnic background to be? (please check all that apply)

- ☐ NZ European
- ☐ Maori
- ☐ Pacific
- ☐ Asian
- ☐ Middle Eastern/Latin American/African

Other (please specify)

[   ]

SECTION B: IMPAIRMENT TYPE

This section aims to determine your impairment type

5. What type of albinism do you have?

- ◯ Oculocutaneous Albinism (affected skin, hair, and eyes)
- ◯ Ocular Albinism (affected eyes)

6. Do you any disabilities or any other health conditions other than albinism that affect your daily life?

- ◯ Yes
- ◯ No

If yes (please specify)

[   ]

SECTION C: SPECIAL DEVICES OR EQUIPMENT

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People with Albinism in New Zealand - Adults

This section aims to investigate whether people with albinism have access to special equipment or devices for seeing.

7. Which equipment or devices do you use? (Please select all that you use)

- [ ] Screen Reader (e.g. JAWS, NVDA)
- [ ] Screen Magnifier (e.g. Zoomtext, Magic)
- [ ] Refreshable Braille Display
- [ ] Scanner (OCR software)
- [ ] All in one scanning device
- [ ] CCTV (Video Magnifier)
- [ ] Tape Recorder/audio recording device
- [ ] Digital recorder
- [ ] Digital Reader (e.g. Book port, Victor Reader Stream)
- [ ] iOS Devices (e.g. iPhone, iPad)
- [ ] Hand Held Magnifier
- [ ] Labeller (e.g. Penfriend or dymo labeller)
- [ ] Specialized reading or distance viewing glasses
- [ ] Colour detector
- [ ] Household and kitchen aids
- [ ] Talking or tactile home maintenance equipment (e.g. tape measures, spirit levels)
- [ ] Talking or tactile medical devices (e.g. talking glucometer)
- [ ] None

Other (please specify)

[   ]

8. Do you have unmet need for equipment or devices?

- ( ) Yes
- ( ) No

If yes (please specify)

[   ]

SECTION D: HEALTH

This section aims to investigate whether people with albinism have access to appropriate health and wellbeing services.

9. How would you describe you;

	Very good	Good	Fair	Poor/very bad
Vision	◯	◯	◯	◯
Skin Health	◯	◯	◯	◯
Overall Health	◯	◯	◯	◯

10. How often do you visit a health professional such as a GP or specialist for a reason related to albinism at the last 12 months?

◯ Less than 4 visits

◯ 4 visits

◯ More than 4 visits

*11. Still thinking within the last 12 months, do you have unmet need to visit a health professional for a reason related to albinism?

◯ Yes

◯ No

SECTION D: HEALTH

12. if yes, Why?

☐ Couldn't afford to

☐ Couldn't get a suitable appointment

☐ Transport difficulties

☐ No appropriate service available

Other (please specify)

[   ]

13. Do you feel health professionals understand the ways in which your albinism affects the quality of life?

◯ Very well

◯ Maybe

◯ Not at all

◯ I Don't Know

14. How would you describe your ability to access health and wellbeing services?

◯ Easy

◯ Reasonable

◯ Difficult

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＊15. Have you ever had a needs assessment?

◯ Yes

◯ No

SECTION D: HEALTH

16. How long ago did your last needs assessment take place?

◯ Less than one year

◯ Less than 2 years

◯ Two or more years ago

17. How satisfied are you with service and support provision?

◯ Very Satisfied

◯ Somewhat satisfied

◯ Somewhat dissatisfied

◯ Very dissatisfied

SECTION E: EDUCATION

This section aims investigate whether people with albinism have equal opportunities to learn and develop their skills.

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18. What is your highest educational qualification?

◯ Level 1 Certificate gained at school

◯ Level 2 Certificate gained at school

◯ Level 3 or 4 Certificate gained at school

◯ Overseas Secondary School Qualification

◯ Level 1 Certificate gained post-school

◯ Level 2 Certificate gained post-school

◯ Level 3 Certificate gained post-school

◯ Level 4 Certificate gained post-school

◯ Level 5 Diploma

◯ Level 6 Diploma

◯ Bachelor Degree and Level 7 qualifications

◯ Postgraduate and Honours Degree

◯ Master's Degree

◯ Doctorate Degree

Other (please specify)

[   ]

✱19. Are you currently enrolled in education or training programme?

◯ Yes

◯ No

SECTION E: EDUCATION

20. Where are you studying?

◯ Secondary school

◯ Tertiary institution

◯ Other (please specify)

[   ]

21. Are you studying?

◯ Part time

◯ Full time

22. What kind of support are you receiving to assist you in your study?

☐ Adaptive computer equipment

☐ Print materials in alternative formats

☐ Tests and exam in alternative formats

☐ Extra time for assignments and exams

☐ Orientation and mobility support

☐ Reduced course load

☐ Readers

☐ Notetakers

☐ Transportation

☐ Intervenors

☐ Other (please specify)

_____

23. Are there supports that you feel would help you academically that you are not receiving?

◯ Yes

◯ No

If yes (please specify)

_____

24. To what extent do you feel education professionals such as Teachers, teacher aides, education support workers and others involved in the education of the child or young person understand the ways in which albinism affects the quality of life?

◯ Very well

◯ Maybe

◯ Not at all

◯ I Don't Know

25. How would you rate your academic performance?

◯ Very good (A)

◯ Good (B)

◯ Fair (C)

◯ Poor (D to F)

SECTION F: EMPLOYMENT

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This section aims to investigate whether people with albinism obtain meaningful employment of their choice.

26. Have you ever received any support to find, maintain, or/and return to work?

◯ Yes

◯ No

27. If you have received employment related supports, what agencies provided them? (Please check all that apply)

☐ Employment services (not related to disabled persons)

☐ Employment services for people with a vision impairment

☐ Career and employment services of an education provider.

☐ Other (please specify)

[   ]

28. To what degree did the employment services you received help you find a job?

◯ Very much

◯ Somewhat

◯ Not much

◯ Not at all

29. At what point in searching for employment do you tend to disclose that you have a vision impairment? (please check all that apply)

◯ In my application

◯ At the time that I am offered an interview

◯ At the time of an interview

◯ At the time that a job is offered

◯ After accepting a job offer

◯ When the need arises

◯ I don't disclose at all

◯ Not applicable

Other (please specify)

[   ]

✱30. Do you currently have paid work?

◯ Yes

◯ No

SECTION F: EMPLOYMENT

31. Is your work?

○ Permanent

○ Short Term Contract/Casual

○ Seasonal

32. Approximately, how many hours do you work each week?

[ ]

33. What is your occupation?

[ ]

34. for how long have you been working?

[ ]

35. How satisfied are you with each of the following in your workplace?

	Very satisfied	Somewhat satisfied	Somewhat dissatisfied	Very dissatisfied
Supportive work environment	○	○	○	○
Fit with your qualifications and interests	○	○	○	○
Opportunities for advancement	○	○	○	○
Social opportunities	○	○	○	○

36. Which of the following accomodations do you receive in your current job?

☐ Adaptive or modified Equipment

☐ Job Redesign

☐ Modified hours or days

☐ Modified Workspace

☐ Modified Responsibilities

☐ Other (please specify)

[ ]

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37. Were there supports that you felt you needed that you did not receive?

◯ Yes

◯ No

If yes (please specify)

[   ]

✱38. How satisfied are you with your current job?

◯ Very Satisfied

◯ Somewhat satisfied

◯ Somewhat dissatisfied

◯ Very dissatisfied

SECTION F: EMPLOYMENT

✱39. Why do not you have paid job? (please check all that apply)

◯ Studying

◯ Retired

◯ At home looking after children

◯ Limitation in the kind of work you could do

◯ Limitation in the amount of paid work you could do

◯ Find it difficult to look for work

◯ Would need a modified work area such as special seating to be able to work

◯ Would need special equipment to be able to work

◯ Would need building modifications at the workplace to be able to work

Other (please specify)

[   ]

SECTION F: EMPLOYMENT

40. Have you received any support to help you find work?

◯ Yes

◯ No

41. If a job was available, could you start work in the next four weeks?

◯ Yes

◯ No

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SECTION F: EMPLOYMENT

42. Is your vision impairment a factor in your decision to retire?

○ Yes

○ No

43. If yes, what is the reason?

○ I could no longer do my job

○ My employer would not accommodate my vision related needs

○ I could no longer get to work

○ My employer refused to continue my employment because of factors related to my vision impairment

○ Other

44. What was your occupation?

45. for how long have you been working?

SECTION G: INCOME

This section aims to investigate whether people with albinism income support their independence and their choices.

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46. Mark as many spaces as you need to show all the ways you received personal income in the last 12 months:

☐ Wages, Salary, commissions, bonuses etc. paid by employer

☐ Self-employment, or business you own and work in

☐ Interest, dividends, rent, other investments

☐ ACC Regular Payments

☐ NZ Superannuation

☐ Other Superannuation, pensions, annuities

☐ Unemployment Benefit

☐ Sickness Benefit

☐ Domestic Purposes Benefit

☐ Invalid's Benefit

☐ Student Allowance

☐ Other government benefits, income support payments or war pensions

☐ Other sources of income

☐ No or Not Stated

47. From all sources of income what is your total before tax in the last 12 months?

◯ Loss

◯ Zero income

◯ $1-$5,000

◯ $5,001-$10,000

◯ $10,001-$15,000

◯ $15,001-$20,000

◯ $20,001-$25,000

◯ $25,001-$30,000

◯ $30,001-$35,000

◯ $35,001-$40,000

◯ $40,001-$50,000

◯ $50,001-$60,000

◯ $60,001-$70,000

◯ $70,001-$100,000

◯ $100,001-$150,000

◯ $150,001 or More

◯ Not stated

48. From all sources of income, what is your annual household income before tax?

◯ Loss

◯ Zero income

◯ $1-$5,000

◯ $5,001-$10,000

◯ $10,001-$15,000

◯ $15,001-$20,000

◯ $20,001-$25,000

◯ $25,001-$30,000

◯ $30,001-$35,000

◯ $35,001-$40,000

◯ $40,001-$50,000

◯ $50,001-$60,000

◯ $60,001-$70,000

◯ $70,001-$100,000

◯ $100,001-$150,000

◯ $150,001 or More

◯ Not stated

49. With your current income, to what degree you can manage your finances?

◯ I manage very well

◯ I struggle a little

◯ I struggle a lot

◯ I do not cope at all

SECTION H: TRANSPORT

This Section aims to investigate whether people with albinism have available, accessible, and affordable transport.

50. Are you able drive a private motor vehicle?

◯ Yes

◯ No

51. Public transport includes buses, trains, trams and ferries. In the last 12 months, have you used public transport to travel short distances?

◯ Yes

◯ No

52. Because of your albinism, do you have any difficulty using any of those kinds of public transport to travel short distances?

◯ Yes

◯ No

53. In the last 12 months, what difficulties have you had that are due to your albinism? (please check all that apply)

☐ Difficulty getting to or finding the stop

☐ Waiting at the stop

☐ Getting on or off

☐ Identifying the right bus, train, tram or ferry

☐ Getting information about timetables or routes

☐ Staff who are not supportive or helpful

☐ No difficulties

☐ Other (please specify)

[   ]

*54. Over the last 12 months, how often have you used a taxi to travel short distances (around your local town/city)?

◯ Not at all

◯ Almost every day

◯ Once a week or more

◯ Once a month or more

SECTION H: TRANSPORT

55. Is there any reason why you have not used taxis either at all, or more often, over the last 12 months? Please indicate your primary reason

○ Don't need to use taxis

○ Too expensive

○ Need to book in advance

○ There is nothing limiting my use of taxis

○ Other (please specify)

[   ]

56. Have you heard of the Total Mobility Scheme? The Scheme gives people who have a disability, taxi vouchers which entitle them to a discount on their taxi fares

○ Yes

○ No

SECTION I: ACCESSING INFORMATION

This section aims to determine how people with albinism access information.

57. Do you use any of the following formats to access information? (Please check all that apply)

☐ Braille

☐ Large Print Materials

☐ Audio recorded Materials

☐ Digital Materials such as emails, web searches

☐ Other (please specify)

[   ]

58. How often do you read?

○ Every day

○ Once or twice a week

○ More than once or twice a week

○ Not applicable as I never read

59. For which purposes do you read? (Please check all that apply)

- [ ] For work
- [ ] For study
- [ ] For pleasure
- [ ] To gain information
- [ ] Other (please specify)

60. What do you read? (Please check all that apply)

- [ ] Newspapers
- [ ] Magazines
- [ ] Books
- [ ] Journals
- [ ] Educational materials
- [ ] Other (please specify)

61. How important is each of the following to you as a source of information in general?

	Not important	Neutral	Important
The internet (through any device and including online media)	○	○	○
Television (not online)	○	○	○
Newspapers (not online)	○	○	○
Radio (not online)	○	○	○
Other people such as family and friends	○	○	○

*62. Do you currently use the internet/email?

- ○ Yes
- ○ No

SECTION I: ACCESSING INFORMATION

63. In the past year have you connected to the internet, from any location, from

	Yes	No
a desktop computer?	○	○
a laptop?	○	○
a mobile phone?	○	○
a tablet, e.g. iPad?	○	○
any other device (e.g. TV, game console)?	○	○

64. Which of the following devices, if any, do you have access to in your household? (please check all that apply)

☐ a desktop computer

☐ a laptop computer (or notebook)

☐ a smartphone

☐ a tablet (e.g. iPad or an Android tablet)

☐ a game console (Xbox, PlayStation, Wii)

☐ a smart television, i.e. an internet capable television

☐ Other (please specify)

[   ]

65. For which of the following purposes do you use email and/or the internet (check all that apply)

☐ For work

☐ For school/study

☐ To keep in touch with people

☐ To gather information

☐ For pleasure

☐ Other (please specify)

[   ]

SECTION J: HOUSING

This section aims to investigate whether people with albinism have a secure, accessible, affordable, quality home in the community.

66. What best describes the form of housing you live in?

○ My own place (rented or owned, with or without partner and children)

○ Renting a place with friends

○ My parents' home

○ A residence at school

○ A supported living unit

○ A nursing home

○ A group home

○ A retirement home

○ A seniors' apartment building

○ Shelter or temporary housing

○ Other (please specify)

[   ]

67. How long have you lived at this house?

○ Less than one year

○ One year and over

68. Regarding housing, how satisfied are you with the following matters?

	Very satisfied	Somewhat satisfied	Somewhat dissatisfied	Very dissatisfied
Security	○	○	○	○
Accessibility	○	○	○	○
Affordability	○	○	○	○
Quality	○	○	○	○

SECTION K: DISCRIMINATION

This section aims to investigate whether people with albinism have equal rights in their community.

✱69. Have you had experience of discrimination in the last 12 months?

○ Yes

○ No

SECTION K: DISCRIMINATION

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70. How frequently have you experienced discrimination in the last 12 months?

◯ Once

◯ Two or three times

◯ More than three times

71. In which area have you experienced discrimination? (please check all that apply)

☐ Advertisements

☐ Employment

☐ Education

☐ Government activity

☐ Land, housing, accommodation

☐ Places, vehicles, and facilities

☐ Pre-employment

☐ Professional associations

☐ Goods and services

☐ Other (please specify)

[_____]

72. have you ever made a complaint to the Human Rights Commission because of unlawful discrimination against you on the grounds of you disability?

◯ Yes

◯ No

SECTION L: RELATIONSHIP

This section aims to investigate whether people with albinism are able to make and keep relationships.

73. Which best describes how frequently you feel lonely in the last four weeks/?

◯ Never

◯ Occasionally

◯ Sometimes

◯ Often

74. Have you made face-to-face contact with family in the last four weeks?

◯ Yes

◯ No

75. What best describes your contact with family?

◯ I contact them a lot

◯ About the right amount of contact

◯ Not enough contact with them

76. Have you made face-to-face contact with friends in the last four weeks?

◯ Yes

◯ No

77. What best describes your contact with friends?

◯ I contact them a lot

◯ About the right amount of contact

◯ Not enough contact with them

78. Approximately how many hours per week do you spend on social and recreational activities?

◯ None

◯ One to 5 hours/week

◯ 5 – 10 hours/week

◯ 10 – 20 hours/week

◯ More than 20 hours/week

79. Because of your albinism, would you say you are reluctant to leave your home?

◯ Very

◯ Somewhat

◯ Not at all

80. Generally, how do you find meeting new people and/or forming relationships?

◯ Easy

◯ Difficult

◯ Do not know

SECTION M: RECREATION

This section aims to investigate whether people with albinism enjoy cultural and recreation activities of their choices.

81. Have you done voluntary work in the last four weeks?

◯ Yes

◯ No

82. During the last four weeks, have you? (please check all that apply)

☐ Been to a theatre or cinema

☐ Been to a café, restaurant or pub

☐ Played sport

☐ Been a spectator at a sporting event

☐ Gone away on a holiday

83. During the last four weeks, have you had difficulty? (please check all that apply)

☐ Going to a theatre or cinema

☐ Going to a café, restaurant or pub

☐ Playing sport

☐ Being a spectator at a sporting event

☐ Going away on a holiday

☐ Not applicable – no difficulties

SECTION N: QUALITY OF LIFE

84. After New Zealand has established its disability strategy in 2001 and has ratified on the UN convention on the rights of people with disability in 2008, Do you think quality of life for people with albinism has?

◯ improved

◯ remained the same

◯ declined

85. How do you feel about your life as a whole?

[text entry box]

SECTION O: COMMENTS AND CONSENT FOR FURTHER CONTACT

86. If you have any comments about this survey. Please specify:

87. For a few of the participants, face-to-face interviews will be conducted in order to gain an in depth understanding of the situation of people with albinism in New Zealand. Would you be interested in participating in these follow up interviews should you be selected?

○ Yes

○ No

If yes, please provide your full name and contact detail

88. Would you like a summary of the findings to be sent to your e-mail address?

○ Yes

○ No

E-mail (please specify)

Appendix 13: New Zealand Disability Strategy

ALL people want all or some of these things:

- ➤ Families/Whanau
- ➤ Recreation/Leisure
- ➤ Education
- ➤ Home
- ➤ Money
- ➤ Jobs
- ➤ Holidays
- ➤ Dreams
- ➤ Relationships
- ➤ Friendships

BUT sometimes this doesn't happen.

The New Zealand Government is concerned about this
and wants to change it so:

- ▪ People are included
- ▪ People participate
- ▪ People have a lot of new opportunities in their lives

What does all this mean? What action will the Government take?

The New Zealand Disability Strategy is the Government's answer.

The Strategy has 15 objectives and actions for all of these.

Objective 1

Encourage and educate the community and society to understand, respect and support disabled people.

Actions

- Have education programmes to help people understand.
- Make sure disabled people are asked what they think and asked about their experiences.
- Make sure disabled people's achievements are recognised.
- Encourage people to talk about disability issues.

Objective 2

Ensure disabled people's rights are understood and promoted.

Actions

- Provide information for everyone on the rights of disabled people.
- Provide education so disabled people understand their rights and can be self-advocates.
- Review Human Rights laws so they help disabled people more.
- Look at how good New Zealand is at making sure disabled people get their rights.
- Look at how people can have independent advocacy.

Objective 3

Provide the best education for disabled people.

Actions

- Make sure every disabled child can go to their local school.
- Make sure disabled people have help to communicate effectively.
- Be sure teachers and educators understand the learning needs of disabled people.
- Make sure disabled people have fair access to the things they need to get the best education.
- Make sure schools meet the needs of disabled students.
- Help disabled people to have further education once school is finished.

Objective 4

Provide opportunities in employment and make sure disabled people have an adequate income.

Actions

- Provide education and training to help disabled people get jobs.
- Educate employers about the abilities of disabled people.

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- Provide information so disabled people know what help they can get.
- Make the move from school to work easier for disabled people.
- Make sure disabled people have the same employment opportunities and rights as everyone else.
- Look at what income disabled people get and make sure it is enough.

Objective 5

Strengthen the leadership of disabled people.

Actions

- Involve disabled people in decision-making as service users and in things like service management and planning.
- Help disabled people to help themselves.
- Help advocacy organisations.
- Support leadership and development training for disabled people.
- Identify disabled people who could work with the Government.
- Make sure disabled people and advocacy organisations know how to influence government planning.

Objective 6

Make sure that government organisations, and organisations that get money from the Government, know about and respond to disabled people.

Actions

- Make sure that government organisations support what the New Zealand Disability Strategy wants to have happen.
- Train people to know what the New Zealand Disability Strategy says and what disabled people expect.
- Make sure all government organisations treat disabled people the same as everyone else.
- Improve information available for disabled people, e.g. plain language.
- Make sure all buildings of government organisations are easy for disabled people to access.

Objective 7

Have services for disabled people that work for disabled people and are easy to get.

Actions

- Treat people fairly and make sure there is some flexibility in the services that support them.
- Make sure that people who run services work together, to make it simpler for disabled people to get support.
- Have good rehabilitation services.
- Identify what needs are not being met and find ways of fixing this.
- Have skilled staff and support people to work with disabled people.

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Objective 8

Support disabled people to have a good life in the community and to have the opportunity to live in their own homes.

Actions

- Help disabled people to live in the community in their own homes.
- Assist disabled people living in rural areas by improving access to services.
- Make sure disabled people can get health services in their community.
- Make public transport accessible for disabled people.
- Make it easier to get between building, public transport and public places like footpaths, streets and parks.

Objective 9

Support disabled people to have choices and help them to have access to recreation and cultural opportunities.

Actions

- Support disabled people in making choices about their relationships, sexuality and reproductive rights.
- Educate arts, recreation and sporting organisations about disability issues and inclusion.
- Support the development of arts, recreational and sports projects involving disabled people.

Objective 10

Collect information about disabled people to help with planning and understanding what disabled people want and need.

Actions

- Make sure good research is done about disability.
- Use research information to help with planning and developing services.
- Collect only useful information about disabled people.
- Make sure research information is presented in a way disabled people can understand.
- Make sure disabled people are involved with research and that it is of a high standard.

Objective 11

Promote the involvement of disabled Maori so their culture is understood and recognised.

Actions

4

- Make sure disabled Maori have a say about what they want.
- Involve Maori in planning services and in leadership roles.
- Have more services developed and provided by Maori.
- Train providers about what Maori want and need.
- Ensure information is available in a way that Maori can access.

Objective 12

Promote the involvement of disabled Pacific peoples so their cultures are understood and recognised.

Actions

- Improve services for disabled Pacific peoples, their families and communities.
- Train providers so they understand what disabled Pacific peoples want and need.
- Have more disability services provided by Pacific peoples.
- Get Pacific communities to talk and think about disability issues.
- Make sure information is available in a way that Pacific peoples can access.

Objective 13

Help disabled children and young people to have good lives that prepare them to be adults.

Actions

- Make sure government agencies know about the needs and wants of disabled children, young people and their families.
- Make sure anything happening for all New Zealand children involves disabled children and young people.
- Ask disabled children and young people what they want.
- Provide education to help people understand the needs and wants of disabled children and young people.
- Make sure services are available for disabled children and young people.
- Make transition from childhood education through to employment easier.
- Identify disabled children and young people as leaders and make sure government organisations involve them in discussions and planning.

Objective 14

Assist disabled women to improve their lives and be a part of their communities.

Actions

- Understand what rights disabled women have and make sure that they have the same opportunities as men.
- Support disabled women to live independently.
- Make sure that treatment for health and reproduction is the same as for non-disabled women.
- Make sure disabled women are involved when strategies and plans are being developed.

5

Objective 15

Recognise the importance of families, whanau and people who provide support for disable people.

- Provide education and information for families and people who support disabled people.
- Involve family/whanau in decisions where appropriate.
- Develop information to help professionals understand how to communicate with families of disabled people.
- Involve family/whanau in the planning and development of services where appropriate.

So what next …. ?

- All government departments/organisations will have to work towards making the things in the New Zealand Disability Strategy happen.
- All government departments will have to make a plan.
- Disabled people need to make sure the Government does what it says it is going to do.

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6

United Nations Convention on the Rights of Persons with Disabilities

Preamble

The States Parties to the present Convention,

(a) *Recalling* the principles proclaimed in the Charter of the United Nations which recognize the inherent dignity and worth and the equal and inalienable rights of all members of the human family as the foundation of freedom, justice and peace in the world,

(b) *Recognizing* that the United Nations, in the Universal Declaration of Human Rights and in the International Covenants on Human Rights, has proclaimed and agreed that everyone is entitled to all the rights and freedoms set forth therein, without distinction of any kind,

(c) *Reaffirming* the universality, indivisibility, interdependence and interrelatedness of all human rights and fundamental freedoms and the need for persons with disabilities to be guaranteed their full enjoyment without discrimination,

(d) *Recalling* the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights, the International Convention on the Elimination of All Forms of Racial Discrimination, the Convention on the Elimination of All Forms of Discrimination against Women, the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, the Convention on the Rights of the Child, and the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families,

(e) *Recognizing* that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others,

(f) *Recognizing* the importance of the principles and policy guidelines contained in the World Programme of Action concerning Disabled Persons and in the Standard Rules on the Equalization of Opportunities for Persons with Disabilities in influencing the promotion, formulation and evaluation of the policies, plans, programmes and actions at the national, regional and international levels to further equalize opportunities for persons with disabilities,

(g) *Emphasizing* the importance of mainstreaming disability issues as an integral part of relevant strategies of sustainable development,

(h) *Recognizing also* that discrimination against any person on the basis of disability is a violation of the inherent dignity and worth of the human person,

(i) *Recognizing further* the diversity of persons with disabilities,

(j) *Recognizing* the need to promote and protect the human rights of all persons with disabilities, including those who require more intensive support,

(k) *Concerned* that, despite these various instruments and undertakings, persons with disabilities continue to face barriers in their participation as equal members of society and violations of their human rights in all parts of the world,

(l) *Recognizing* the importance of international cooperation for improving the living conditions of persons with disabilities in every country, particularly in developing countries,

(m) *Recognizing* the valued existing and potential contributions made by persons with disabilities to the overall well-being and diversity of their communities, and that the promotion of the full enjoyment by persons with disabilities of their human rights and fundamental freedoms and of full participation by persons with disabilities will result in their enhanced sense of belonging and in significant advances in the human, social and economic development of society and the eradication of poverty,

(n) *Recognizing* the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices,

(o) *Considering* that persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them,

(p) *Concerned* about the difficult conditions faced by persons with disabilities who are subject to multiple or aggravated forms of discrimination on the basis of race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status,

(q) *Recognizing* that women and girls with disabilities are often at greater risk, both within and outside the home of violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation,

(r) *Recognizing* that children with disabilities should have full enjoyment of all human rights and fundamental freedoms on an equal basis with other children, and recalling obligations to that end undertaken by States Parties to the Convention on the Rights of the Child,

(s) *Emphasizing* the need to incorporate a gender perspective in all efforts to promote the full enjoyment of human rights and fundamental freedoms by persons with disabilities,

(t) *Highlighting* the fact that the majority of persons with disabilities live in conditions of poverty, and in this regard recognizing the critical need to address the negative impact of poverty on persons with disabilities,

(u) *Bearing in mind* that conditions of peace and security based on full respect for the purposes and principles contained in the Charter of the United Nations and observance of applicable human rights instruments are indispensable for the full protection of persons with disabilities, in particular during armed conflicts and foreign occupation,

(v) *Recognizing* the importance of accessibility to the physical, social, economic and cultural environment, to health and education and to information and communication, in enabling persons with disabilities to fully enjoy all human rights and fundamental freedoms,

(w) *Realizing* that the individual, having duties to other individuals and to the community to which he or she belongs, is under a responsibility to strive for the promotion and observance of the rights recognized in the International Bill of Human Rights,

(x) *Convinced* that the family is the natural and fundamental group unit of society and is entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities,

(y) *Convinced* that a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities will make a significant contribution to redressing the profound social disadvantage of persons with disabilities and promote their participation in the civil, political, economic, social and cultural spheres with equal opportunities, in both developing and developed countries,

Have agreed as follows:

Article 1: Purpose

The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

Persons with disabilities include 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.

Article 2: Definitions

For the purposes of the present Convention:

"Communication" includes languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology;

"Language" includes spoken and signed languages and other forms of non spoken languages;

"Discrimination on the basis of disability" means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation;

"Reasonable accommodation" means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms;

"Universal design" means the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. "Universal design" shall not exclude assistive devices for particular groups of persons with disabilities where this is needed.

Article 3: General principles

The principles of the present Convention shall be:

(a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;

(b) Non-discrimination;

(c) Full and effective participation and inclusion in society;

(d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;

(e) Equality of opportunity;

(f) Accessibility;

(g) Equality between men and women;

(h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

Article 4: General obligations

1. States Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability. To this end, States Parties undertake:

(a) To adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the present Convention;

(b) To take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities;

(c) To take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes;

(d) To refrain from engaging in any act or practice that is inconsistent with the present Convention and to ensure that public authorities and institutions act in conformity with the present Convention;

(e) To take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise;

(f) To undertake or promote research and development of universally designed goods, services, equipment and facilities, as defined in article 2 of the present Convention, which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines;

(g) To undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost;

(h) 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;

(i) To promote the training of professionals and staff working with persons with disabilities in the rights recognized in this Convention so as to better provide the assistance and services guaranteed by those rights.

2. With regard to economic, social and cultural rights, each State Party undertakes to take measures to the maximum of its available resources and, where needed, within the framework of international cooperation, with a view to achieving progressively the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately

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applicable according to international law.

3. In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

4. Nothing in the present Convention shall affect any provisions which are more conducive to the realization of the rights of persons with disabilities and which may be contained in the law of a State Party or international law in force for that State. There shall be no restriction upon or derogation from any of the human rights and fundamental freedoms recognized or existing in any State Party to the present Convention pursuant to law, conventions, regulation or custom on the pretext that the present Convention does not recognize such rights or freedoms or that it recognizes them to a lesser extent.

5. The provisions of the present Convention shall extend to all parts of federal states without any limitations or exceptions.

Article 5: Equality and non-discrimination

1. States Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.

2. 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.

3. In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.

4. Specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination under the terms of the present Convention.

Article 6: Women with disabilities

1. States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.

2. States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of

guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.

Article 7: Children with disabilities

1. States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.

2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.

3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

Article 8: Awareness-raising

1. States Parties undertake to adopt immediate, effective and appropriate measures:

(a) 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;

(b) To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life;

(c) To promote awareness of the capabilities and contributions of persons with disabilities.

2. Measures to this end include:

(a) Initiating and maintaining effective public awareness campaigns designed:

(i) To nurture receptiveness to the rights of persons with disabilities;
(ii) To promote positive perceptions and greater social awareness towards persons with disabilities;
(iii) To promote recognition of the skills, merits and abilities of persons with disabilities, and of their contributions to the workplace and the labour market;

(b) Fostering at all levels of the education system, including in all children from an early age, an attitude of respect for the rights of persons with disabilities;

(c) Encouraging all organs of the media to portray persons with disabilities in a manner consistent with the purpose of the present Convention;

(d) Promoting awareness-training programmes regarding persons with disabilities and the rights of persons with disabilities.

Article 9: Accessibility

1. To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia:

(a) Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces;

(b) Information, communications and other services, including electronic services and emergency services.

2. States Parties shall also take appropriate measures to:

(a) Develop, promulgate and monitor the implementation of minimum standards and guidelines for the accessibility of facilities and services open or provided to the public;

(b) Ensure that private entities that offer facilities and services which are open or provided to the public take into account all aspects of accessibility for persons with disabilities;

(c) Provide training for stakeholders on accessibility issues facing persons with disabilities;

(d) Provide in buildings and other facilities open to the public signage in Braille and in easy to read and understand forms;

(e) Provide forms of live assistance and intermediaries, including guides, readers and professional sign language interpreters, to facilitate accessibility to buildings and other facilities open to the public;

(f) Promote other appropriate forms of assistance and support to persons with disabilities to ensure their access to information;

(g) Promote access for persons with disabilities to new information and communications technologies and systems, including the Internet;

(h) Promote the design, development, production and distribution of accessible information and communications technologies and systems at an early stage, so that these technologies and systems become accessible at minimum cost.

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Article 10: Right to life

States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.

Article 11: Situations of risk and humanitarian emergencies

States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.

Article 12: Equal recognition before the law

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.

2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.

5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

Article 13: Access to justice

1. States Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their

effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.

2. In order to help to ensure effective access to justice for persons with disabilities, States Parties shall promote appropriate training for those working in the field of administration of justice, including police and prison staff.

Article 14: Liberty and security of the person

1. States Parties shall ensure that persons with disabilities, on an equal basis with others:

(a) Enjoy the right to liberty and security of person;

(b) Are not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty.

2. States Parties shall ensure that if persons with disabilities are deprived of their liberty through any process, they are, on an equal basis with others, entitled to guarantees in accordance with international human rights law and shall be treated in compliance with the objectives and principles of this Convention, including by provision of reasonable accommodation.

Article 15: Freedom from torture or cruel, inhuman or degrading treatment or punishment

1. No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his or her free consent to medical or scientific experimentation.

2. States Parties shall take all effective legislative, administrative, judicial or other measures to prevent persons with disabilities, on an equal basis with others, from being subjected to torture or cruel, inhuman or degrading treatment or punishment.

Article 16: Freedom from exploitation, violence and abuse

1. States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.

2. States Parties shall also take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognize and report instances

of exploitation, violence and abuse. States Parties shall ensure that protection services are age-, gender- and disability-sensitive.

3. In order to prevent the occurrence of all forms of exploitation, violence and abuse, States Parties shall ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities.

4. States Parties shall take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services. Such recovery and reintegration shall take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs.

5. States Parties shall put in place effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.

Article 17: Protecting the integrity of the person

Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.

Article 18: Liberty of movement and nationality

1. States Parties shall recognize the rights of persons with disabilities to liberty of movement, to freedom to choose their residence and to a nationality, on an equal basis with others, including by ensuring that persons with disabilities:

(a) Have the right to acquire and change a nationality and are not deprived of their nationality arbitrarily or on the basis of disability;

(b) Are not deprived, on the basis of disability, of their ability to obtain, possess and utilize documentation of their nationality or other documentation of identification, or to utilize relevant processes such as immigration proceedings, that may be needed to facilitate exercise of the right to liberty of movement;

(c) Are free to leave any country, including their own;

(d) Are not deprived, arbitrarily or on the basis of disability, of the right to enter their own country.

2. Children with disabilities shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and, as far as possible, the right to know and be cared for by their parents.

Article 19: Living independently and being included in the community

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

(a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

(b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

(c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

Article 20: Personal mobility

States Parties shall take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities, including by:

(a) Facilitating the personal mobility of persons with disabilities in the manner and at the time of their choice, and at affordable cost;

(b) 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;

(c) Providing training in mobility skills to persons with disabilities and to specialist staff working with persons with disabilities;

(d) Encouraging entities that produce mobility aids, devices and assistive technologies to take into account all aspects of mobility for persons with disabilities.

Article 21: Freedom of expression and opinion, and access to information

States Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice, as defined in article 2 of the present Convention, including by:

(a) Providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost;

(b) Accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions;

(c) Urging private entities that provide services to the general public, including through the Internet, to provide information and services in accessible and usable formats for persons with disabilities;

(d) Encouraging the mass media, including providers of information through the Internet, to make their services accessible to persons with disabilities;

(e) Recognizing and promoting the use of sign languages.

Article 22: Respect for privacy

1. No person with disabilities, regardless of place of residence or living arrangements, shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence or other types of communication or to unlawful attacks on his or her honour and reputation. Persons with disabilities have the right to the protection of the law against such interference or attacks.

2. States Parties shall protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others.

Article 23: Respect for home and the family

1. States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that:

(a) The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized;

(b) The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided;

(c) Persons with disabilities, including children, retain their fertility on an equal basis with others.

2. States Parties shall ensure the rights and responsibilities of persons with disabilities, with regard to guardianship, wardship, trusteeship, adoption of children or similar institutions, where these concepts exist in national legislation; in all cases the best interests of the child shall be paramount. States Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities.

3. States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families.

4. States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.

5. States Parties shall, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting.

Article 24: Education

1. States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and life long learning directed to:

(a) The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;

(b) The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;

(c) Enabling persons with disabilities to participate effectively in a free society.

2. In realizing this right, States Parties shall ensure that:

(a) Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;

(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.

3. States Parties shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community. To this end, States Parties shall take appropriate measures, including:

(a) Facilitating the learning of Braille, alternative script, augmentative and alternative modes, means and formats of communication and orientation and mobility skills, and facilitating peer support and mentoring;

(b) Facilitating the learning of sign language and the promotion of the linguistic identity of the deaf community;

(c) Ensuring that the education of persons, and in particular children, who are blind, deaf or deafblind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development.

4. In order to help ensure the realization of this right, States Parties shall take appropriate measures to employ teachers, including teachers with disabilities, who are qualified in sign language and/or Braille, and to train professionals and staff who work at all levels of education. Such training shall incorporate disability awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities.

5. States Parties shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others. To this end, States Parties shall ensure that reasonable accommodation is provided to persons with disabilities.

Article 25: Health

States Parties recognize 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 health services that are gender-

sensitive, including health-related rehabilitation. In particular, States 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.

Article 26: Habilitation and rehabilitation

1. States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:

(a) Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;

(b) 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.

2. States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services.

3. States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.

Article 27: Work and employment

1. States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. States Parties shall safeguard and promote the realization of the right to work, including for those who acquire a disability during the course of employment, by taking appropriate steps, including through legislation, to, inter alia:

(a) Prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions;

(b) Protect the rights of persons with disabilities, on an equal basis with others, to just and favourable conditions of work, including equal opportunities and equal remuneration for work of equal value, safe and healthy working conditions, including protection from harassment, and the redress of grievances;

(c) Ensure that persons with disabilities are able to exercise their labour and trade union rights on an equal basis with others;

(d) Enable persons with disabilities to have effective access to general technical and vocational guidance programmes, placement services and vocational and continuing training;

(e) Promote employment opportunities and career advancement for persons with disabilities in the labour market, as well as assistance in finding, obtaining, maintaining and returning to employment;

(f) Promote opportunities for self-employment, entrepreneurship, the development of cooperatives and starting one's own business;

(g) Employ persons with disabilities in the public sector;

(h) Promote the employment of persons with disabilities in the private sector through appropriate policies and measures, which may include affirmative action programmes, incentives and other measures;

(i) Ensure that reasonable accommodation is provided to persons with disabilities in the workplace;

(j) Promote the acquisition by persons with disabilities of work experience in the open labour market;

(k) Promote vocational and professional rehabilitation, job retention and return-to-work programmes for persons with disabilities.

2. States Parties shall ensure that persons with disabilities are not held in slavery or in servitude, and are protected, on an equal basis with others, from forced or compulsory labour.

Article 28: Adequate standard of living and social protection

1. States Parties recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability.

2. States Parties recognize the right of persons with disabilities to social protection and to the enjoyment of that right without discrimination on the basis of disability, and shall take appropriate steps to safeguard and promote the realization of this right, including measures:

(a) To ensure equal access by persons with disabilities to clean water services, and to ensure access to appropriate and affordable services, devices and other assistance for disability-related needs;

(b) To ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes;

(c) To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care;

(d) To ensure access by persons with disabilities to public housing programmes;

(e) To ensure equal access by persons with disabilities to retirement benefits and programmes.

Article 29: Participation in political and public life

States Parties shall guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others, and shall undertake to:

(a) Ensure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others, directly or through freely chosen representatives, including the right and opportunity for persons with disabilities to vote and be elected, inter alia, by:

(i) Ensuring that voting procedures, facilities and materials are appropriate, accessible and easy to understand and use;

(ii) Protecting the right of persons with disabilities to vote by secret ballot in elections and public referendums without intimidation, and to stand for elections, to effectively hold office and perform all public functions at all levels of government, facilitating the use of assistive and new technologies where appropriate;

(iii) Guaranteeing the free expression of the will of persons with disabilities as electors and to this end, where necessary, at their request, allowing assistance in voting by a person of their own choice;

b) Promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs, including:

(i) Participation in non-governmental organizations and associations concerned with the public and political life of the country, and in the activities and administration of political parties;

(ii) Forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels.

Article 30: Participation in cultural life, recreation, leisure and sport

1. States Parties recognize the right of persons with disabilities to take part on an equal basis with others in cultural life, and shall take all appropriate measures to ensure that persons with disabilities:

(a) Enjoy access to cultural materials in accessible formats;

(b) Enjoy access to television programmes, films, theatre and other cultural activities, in accessible formats;

(c) Enjoy access to places for cultural performances or services, such as theatres, museums, cinemas, libraries and tourism services, and, as far as possible, enjoy access to monuments and sites of national cultural importance.

2. States Parties shall take appropriate measures to enable persons with disabilities to have the opportunity to develop and utilize their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of society.

3. States Parties shall take all appropriate steps, in accordance with international law, to ensure that laws protecting intellectual property rights do not constitute an unreasonable or discriminatory barrier to access by persons with disabilities to cultural materials.

4. Persons with disabilities shall be entitled, on an equal basis with others, to recognition and support of their specific cultural and linguistic identity, including sign languages and deaf culture.

5. With a view to enabling persons with disabilities to participate on an equal basis with others in recreational, leisure and sporting activities, States Parties shall take appropriate measures:

(a) To encourage and promote the participation, to the fullest extent possible, of persons with disabilities in mainstream sporting activities at all levels;

(b) To ensure that persons with disabilities have an opportunity to organize, develop and participate in disability-specific sporting and recreational activities and, to this end, encourage the provision, on an equal basis with others, of appropriate instruction, training and resources;

(c) To ensure that persons with disabilities have access to sporting, recreational and tourism venues;

(d) To ensure that children with disabilities have equal access with other children to participation in play, recreation and leisure and sporting activities, including those activities in the school system;

(e) To ensure that persons with disabilities have access to services from those involved in the organization of recreational, tourism, leisure and sporting activities.

Article 31: Statistics and data collection

1. States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention. The process of collecting and maintaining this information shall:

(a) Comply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for the privacy of persons with disabilities;

(b) Comply with internationally accepted norms to protect human rights and fundamental freedoms and ethical principles in the collection and use of statistics.

2. The information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties' obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.

3. States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.

Article 32: International cooperation

1. States Parties recognize the importance of international cooperation and its promotion, in support of national efforts for the realization of the purpose and objectives of the present Convention, and will undertake appropriate and effective measures in this regard, between and among States and, as appropriate, in partnership with relevant international and regional organizations and civil society, in particular organizations of persons with disabilities. Such measures could include, inter alia:

(a) Ensuring that international cooperation, including international development programmes, is inclusive of and accessible to persons with disabilities;

(b) Facilitating and supporting capacity-building, including through the exchange and sharing of information, experiences, training programmes and best practices;

(c) Facilitating cooperation in research and access to scientific and technical knowledge;

(d) Providing, as appropriate, technical and economic assistance, including by facilitating access to and sharing of accessible and assistive technologies, and through the transfer of technologies.

2. The provisions of this article are without prejudice to the obligations of each State Party to fulfil its obligations under the present Convention.

Article 33: National implementation and monitoring

1. States Parties, in accordance with their system of organization, shall designate one or more focal points within government for matters relating to the implementation of the present Convention, and shall give due consideration to the establishment or designation of a coordination mechanism within government to facilitate related action in different sectors and at different levels.

2. States Parties shall, in accordance with their legal and administrative systems, maintain, strengthen, designate or establish within the State Party, a framework, including one or more independent mechanisms, as appropriate, to promote, protect and monitor implementation of the present Convention. When designating or establishing such a mechanism, States Parties shall take into account the principles relating to the status and functioning of national institutions for protection and promotion of human rights.

3. Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.

Article 34: Committee on the Rights of Persons with Disabilities

1. There shall be established a Committee on the Rights of Persons with Disabilities (hereafter referred to as "the Committee"), which shall carry out the functions hereinafter provided.

2. The Committee shall consist, at the time of entry into force of the present Convention, of twelve experts. After an additional sixty ratifications or accessions to the Convention, the membership of the Committee shall increase by six members, attaining a maximum number of eighteen members.

3. The members of the Committee shall serve in their personal capacity and shall be of high moral standing and recognized competence and experience in the field covered by the present Convention. When nominating their candidates, States Parties are invited to give due consideration to the provision set out in article 4.3 of the present Convention.

4. The members of the Committee shall be elected by States Parties, consideration being given to equitable geographical distribution, representation of the different forms of civilization and of the principal legal systems, balanced gender representation and participation of experts with disabilities.

5. The members of the Committee shall be elected by secret ballot from a list of persons nominated by the States Parties from among their nationals at meetings of the Conference of States Parties. At those meetings, for which two thirds of States Parties shall constitute a quorum, the persons elected to the Committee shall be those who obtain the largest number of votes and an absolute majority of the votes of the representatives of States Parties present and voting.

6. The initial election shall be held no later than six months after the date of entry into force of the present Convention. At least four months before the date of each election, the Secretary-General of the United Nations shall address a letter to the States Parties inviting them to submit the nominations within two months. The Secretary-General shall subsequently prepare a list in alphabetical order of all persons thus nominated, indicating the State Parties which have nominated them, and shall submit it to the States Parties to the present Convention.

7. The members of the Committee shall be elected for a term of four years. They shall be eligible for re-election once. However, the term of six of the members elected at the first election shall expire at the end of two years; immediately after the first election, the names of these six members shall be

chosen by lot by the chairperson of the meeting referred to in paragraph 5 of this article.

8. The election of the six additional members of the Committee shall be held on the occasion of regular elections, in accordance with the relevant provisions of this article.

9. If a member of the Committee dies or resigns or declares that for any other cause she or he can no longer perform her or his duties, the State Party which nominated the member shall appoint another expert possessing the qualifications and meeting the requirements set out in the relevant provisions of this article, to serve for the remainder of the term.

10. The Committee shall establish its own rules of procedure.

11. The Secretary-General of the United Nations shall provide the necessary staff and facilities for the effective performance of the functions of the Committee under the present Convention, and shall convene its initial meeting.

12. With the approval of the General Assembly, the members of the Committee established under the present Convention shall receive emoluments from United Nations resources on such terms and conditions as the Assembly may decide, having regard to the importance of the Committee's responsibilities.

13. The members of the Committee shall be entitled to the facilities, privileges and immunities of experts on mission for the United Nations as laid down in the relevant sections of the Convention on the Privileges and Immunities of the United Nations.

Article 35: Reports by States Parties

1. Each State Party shall submit to the Committee, through the Secretary-General of the United Nations, a comprehensive report on measures taken to give effect to its obligations under the present Convention and on the progress made in that regard, within two years after the entry into force of the present Convention for the State Party concerned.

2. Thereafter, States Parties shall submit subsequent reports at least every four years and further whenever the Committee so requests.

3. The Committee shall decide any guidelines applicable to the content of the reports.

4. A State Party which has submitted a comprehensive initial report to the Committee need not, in its subsequent reports, repeat information previously provided. When preparing reports to the Committee, States Parties are invited to consider doing so in an open and transparent process and to give

due consideration to the provision set out in article 4.3 of the present Convention.

5. Reports may indicate factors and difficulties affecting the degree of fulfilment of obligations under the present Convention.

Article 36: Consideration of reports

1. Each report shall be considered by the Committee, which shall make such suggestions and general recommendations on the report as it may consider appropriate and shall forward these to the State Party concerned. The State Party may respond with any information it chooses to the Committee. The Committee may request further information from States Parties relevant to the implementation of the present Convention.

2. If a State Party is significantly overdue in the submission of a report, the Committee may notify the State Party concerned of the need to examine the implementation of the present Convention in that State Party, on the basis of reliable information available to the Committee, if the relevant report is not submitted within three months following the notification. The Committee shall invite the State Party concerned to participate in such examination. Should the State Party respond by submitting the relevant report, the provisions of paragraph 1 of this article will apply.

3. The Secretary-General of the United Nations shall make available the reports to all States Parties.

4. States Parties shall make their reports widely available to the public in their own countries and facilitate access to the suggestions and general recommendations relating to these reports.

5. The Committee shall transmit, as it may consider appropriate, to the specialized agencies, funds and programmes of the United Nations, and other competent bodies, reports from States Parties in order to address a request or indication of a need for technical advice or assistance contained therein, along with the Committee's observations and recommendations, if any, on these requests or indications.

Article 37: Cooperation between States Parties and the Committee

1. Each State Party shall cooperate with the Committee and assist its members in the fulfilment of their mandate.

2. In its relationship with States Parties, the Committee shall give due consideration to ways and means of enhancing national capacities for the implementation of the present Convention, including through international cooperation.

Article 38: Relationship of the Committee with other bodies

In order to foster the effective implementation of the present Convention and to encourage international cooperation in the field covered by the present Convention:

(a) The specialized agencies and other United Nations organs shall be entitled to be represented at the consideration of the implementation of such provisions of the present Convention as fall within the scope of their mandate. The Committee may invite the specialized agencies and other competent bodies as it may consider appropriate to provide expert advice on the implementation of the Convention in areas falling within the scope of their respective mandates. The Committee may invite specialized agencies and other United Nations organs to submit reports on the implementation of the Convention in areas falling within the scope of their activities;

(b) The Committee, as it discharges its mandate, shall consult, as appropriate, other relevant bodies instituted by international human rights treaties, with a view to ensuring the consistency of their respective reporting guidelines, suggestions and general recommendations, and avoiding duplication and overlap in the performance of their functions.

Article 39: Report of the Committee

The Committee shall report every two years to the General Assembly and to the Economic and Social Council on its activities, and may make suggestions and general recommendations based on the examination of reports and information received from the States Parties. Such suggestions and general recommendations shall be included in the report of the Committee together with comments, if any, from States Parties.

Article 40: Conference of States Parties

1. The States Parties shall meet regularly in a Conference of States Parties in order to consider any matter with regard to the implementation of the present Convention.

2. No later than six months after the entry into force of the present Convention, the Conference of the States Parties shall be convened by the Secretary-General of the United Nations. The subsequent meetings shall be convened by the Secretary-General of the United Nations biennially or upon the decision of the Conference of States Parties.

Article 41: Depositary

The Secretary-General of the United Nations shall be the depositary of the present Convention.

Article 42: Signature

The present Convention shall be open for signature by all States and by regional integration organizations at United Nations Headquarters in New York as of 30 March 2007.

Article 43: Consent to be bound

The present Convention shall be subject to ratification by signatory States and to formal confirmation by signatory regional integration organizations. It shall be open for accession by any State or regional integration organization which has not signed the Convention.

Article 44: Regional integration organizations

1. "Regional integration organization" shall mean an organization constituted by sovereign States of a given region, to which its member States have transferred competence in respect of matters governed by this Convention. Such organizations shall declare, in their instruments of formal confirmation or accession, the extent of their competence with respect to matters governed by this Convention. Subsequently, they shall inform the depositary of any substantial modification in the extent of their competence.

2. References to "States Parties" in the present Convention shall apply to such organizations within the limits of their competence.

3. For the purposes of article 45, paragraph 1, and article 47, paragraphs 2 and 3, any instrument deposited by a regional integration organization shall not be counted.

4. Regional integration organizations, in matters within their competence, may exercise their right to vote in the Conference of States Parties, with a number of votes equal to the number of their member States that are Parties to this Convention. Such an organization shall not exercise its right to vote if any of its member States exercises its right, and vice versa.

Article 45: Entry into force

1. The present Convention shall enter into force on the thirtieth day after the deposit of the twentieth instrument of ratification or accession.

2. For each State or regional integration organization ratifying, formally confirming or acceding to the Convention after the deposit of the twentieth such instrument, the Convention shall enter into force on the thirtieth day after the deposit of its own such instrument.

Article 46: Reservations

1. Reservations incompatible with the object and purpose of the present Convention shall not be permitted.

2. Reservations may be withdrawn at any time.

Article 47: Amendments

1. Any State Party may propose an amendment to the present Convention and submit it to the Secretary-General of the United Nations. The Secretary-General shall communicate any proposed amendments to States Parties, with a request to be notified whether they favour a conference of States Parties for the purpose of considering and deciding upon the proposals. In the event that, within four months from the date of such communication, at least one third of the States Parties favour such a conference, the Secretary-General shall convene the conference under the auspices of the United Nations. Any amendment adopted by a majority of two thirds of the States Parties present and voting shall be submitted by the Secretary-General to the General Assembly for approval and thereafter to all States Parties for acceptance.

2. An amendment adopted and approved in accordance with paragraph 1 of this article shall enter into force on the thirtieth day after the number of instruments of acceptance deposited reaches two thirds of the number of States Parties at the date of adoption of the amendment. Thereafter, the amendment shall enter into force for any State Party on the thirtieth day following the deposit of its own instrument of acceptance. An amendment shall be binding only on those States Parties which have accepted it.

3. If so decided by the Conference of States Parties by consensus, an amendment adopted and approved in accordance with paragraph 1 of this article which relates exclusively to articles 34, 38, 39 and 40 shall enter into force for all States Parties on the thirtieth day after the number of instruments of acceptance deposited reaches two thirds of the number of States Parties at the date of adoption of the amendment.

Article 48: Denunciation

A State Party may denounce the present Convention by written notification to the Secretary-General of the United Nations. The denunciation shall become effective one year after the date of receipt of the notification by the Secretary-General.

Article 49: Accessible format

The text of the present Convention shall be made available in accessible formats.

Article 50: Authentic texts

The Arabic, Chinese, English, French, Russian and Spanish texts of the present Convention shall be equally authentic.

In witness thereof the undersigned plenipotentiaries, being duly authorized thereto by their respective Governments, have signed the present Convention.

Appendix 15: The framework of the Office for disability Issues

Long-term life outcomes for disabled people: ideally indicators below require analysis at total population level and by impairment type, ethnicity, gender, age, and location (i.e. urban vs rural)			
Intended outcomes	**Indicators**	**Data sources available**	**Data sources not available**
Citizenship: *"I participate in my community"* Disabled people have equality of choices, rights, responsibilities as non-disabled people	• Number of national and locally-based anti-discrimination programmes • Extent to which achievements of disabled people are celebrated • Extent to which perspectives of disabled people are included on ethical and bioethical debates • Legislative or strategy development aimed at promoting equality • Level of participation in democratic processes	• Review of legislation • Review of media • Documentation on ethical and bioethical debates	• Disabled people's heard voice through case studies • Electoral Commission has published research looking at Māori participation rates. Explore whether possible to do same for disabled people
Health: *"I feel healthy and well"* Disabled people have access to appropriate health and wellbeing services	• Level of awareness of, access to and use of disability support, health and wellbeing services • Level of awareness and use of needs assessment • Percentage of disabled people who perceive accessing disability supports, health and wellbeing services to be simple • Percentage of disabled people who perceive disability supports as fair and flexible Percentage of disabled people who perceive their health and wellbeing needs are timely met • Percentage of disabled people who feel they are at the centre of service and support provision	• Statistics New Zealand's post-census Disability Survey – support, equipment and services • Ministry of Health administrative data including the Client Claims Processing System (CCPS) database	• Perception based indicators assessed via case studies with disabled people

Long-term life outcomes for disabled people: ideally indicators below require analysis at total population level and by impairment type, ethnicity, gender, age, and location (i.e. urban vs rural)			
Intended outcomes	**Indicators**	**Data sources available**	**Data sources not available**
Education: *"I am learning new things"* Disabled people have equal opportunities to learn and develop in local educational centres	• Level of access to local early childhood, primary, and secondary schools for disabled children • Percentage of disabled children participating in formal education • Percentage of disabled children participating in some aspects of mainstream education • Level of access to New Zealand Sign Language, communication technologies and human aids to develop effective communications • Equitable access to resources for education needs • Percentage of disabled people with a school qualification • Level of access for disabled people to tertiary education • Percentage of adult disabled people attending tertiary institutions • Percentage of disabled people with a post-school qualification	• Statistics New Zealand's post-census Disability Survey – education • Ministry of Education's Special Education administrative data including distribution of resources for education needs • Coverage of disability issues and learning needs for disabled people in teacher training and professional development courses • Administrative data of tertiary institutions about their disability responsiveness	Perception based indicators assessed via case studies with disabled people

Long-term life outcomes for disabled people: ideally indicators below require analysis at total population level and by impairment type, ethnicity, gender, age, and location (i.e. urban vs rural)			
Intended outcomes	**Indicators**	**Data sources available**	**Data sources not available**
Employment: *"I have meaningful employment"* Disabled people have meaningful employment of their choice	▪ Number of and access to programmes to facilitate transition from school to work for disabled people ▪ Number of and access to vocation services by working-age disabled people ▪ Number of and access to career services by working-age disabled people ▪ Percentage of working age disabled people in employment ▪ Level of support available for working-age disabled people to access employment ▪ Percentage of working-age disabled people receiving appropriate support to enable work ▪ Percentage of working-age disabled people who are satisfied with their employment and vocational choices ▪ Percentage of employers who are aware of abilities, value and contribution of disabled people ▪ Level of availability of communication services, resources and flexible workplace options	▪ Statistics New Zealand's post-census Disability Survey – employment ▪ State Services Commission's data on disabled people employed in the public sector ▪ Ministry of Social Development's administrative data ▪ Review of performance reporting of providers contracted to provide transition and career service, placement assistance and vocational service	▪ Survey to measure employers' perceptions of disabled people (Workbridge has undertaken survey in this area in the past) Perception based indicators assessed via case studies with disabled people
Income: *"I pay for things"*	▪ Level of income support provisions ▪ Level of flexibility in income support benefits making transition to work and training easier	▪ Statistics New Zealand's post-census Disability Survey – income	▪ Type and availability of data from Ministry of Social Development's ACC's, union's etc requires further scoping

Long-term life outcomes for disabled people: ideally indicators below require analysis at total population level and by impairment type, ethnicity, gender, age, and location (i.e. urban vs rural)			
Intended outcomes	**Indicators**	**Data sources available**	**Data sources not available**
Disabled people's income supports their independence and their choices	▪ Level of income of working age disabled people ▪ Percentage of disabled people who manage their finances ▪ Number of disabled people active in unions and other staff and service organisations ▪ Percentage of disabled people who perceive their income is adequate to support their independence	▪ Ministry of Social Development's Work and Income administrative data ▪ ACC's administrative data ▪ Union and other staff and service organisations membership and governance data	▪ Perception based indicators assessed via case studies with disabled people
Housing: *"I have my own home"* Disabled people have a secure, accessible, affordable, quality home in the community	▪ Percentage of disabled people who own their home ▪ Percentage of disabled people living in long-term residential care (adults and children) ▪ Percentage of public housing stock accessible to disabled people ▪ Level of use of needs-based-customised modifications to enable accessibility within and from the home ▪ Percentage of disabled people who say it is easy to access suitable state and private housing through 'best match', cross-agency case management, and support and advocacy ▪ Level and effective use supply of modified housing stock	▪ Statistics New Zealand's Disability Survey – house and home ▪ Statistics New Zealand's Disability Survey – living in residential facilities ▪ Reporting mechanisms of Housing New Zealand and supporting agencies (i.e. information available from the Rental database)	▪ Type and availability of local authorities data about use of universal design requires further scoping ▪ Disabled people's voice heard through case studies

Long-term life outcomes for disabled people: ideally indicators below require analysis at total population level and by impairment type, ethnicity, gender, age, and location (i.e. urban vs rural)			
Intended outcomes	**Indicators**	**Data sources available**	**Data sources not available**
	▪ Level of use of universal design and accessibility principles in new public and private housing stock		
Transport and environment: *"I can move around"* Disabled people have available, accessible and affordable transport and access to built environment	▪ Proportion of public buildings, facilities, and environments that are accessible to disabled people ▪ Percentage of disabled people who undertake independent journeys ▪ Percentage of disabled people who can access and use public transport ▪ Percentage of public transport personnel trained in disability responsiveness ▪ Percentage of training requirements included in driver licensing and contract service delivery ▪ Percentage of disabled students able to use School Transport Assistance in a non-discriminatory and equitable basis ▪ Level of implementation and monitoring of national accessibility performance standards, as enforced by the Ministry of Transport	▪ Statistics New Zealand's post-census Disability Survey – travel and transport ▪ Data from Ministry of Transport, Land Transport ▪ Barrier Free Trust ▪ State Services Commission's accessibility survey	▪ Access to data from Ministry of Transport may need to be negotiated
Recreation: *"I have fun"*	▪ Proportion of disabled people involved in sports and recreation ▪ Proportion of disabled people involved in cultural activities	▪ SPARC ▪ Department of Conservation	▪ Type and availability of data from central government agencies requires further scoping

Long-term life outcomes for disabled people: ideally indicators below require analysis at total population level and by impairment type, ethnicity, gender, age, and location (i.e. urban vs rural)			
Intended outcomes	**Indicators**	**Data sources available**	**Data sources not available**
Disabled people enjoy cultural and recreation activities of their choice	▪ Level of training offered to staff and volunteers working in recreation who are trained in disability responsiveness ▪ Proportion of staff and volunteers working in recreation of disability responsiveness ▪ Proportion of disability support providers who are trained in sport and recreation and cultural activities ▪ Level of availability of and access to inclusive and exclusive sporting and recreation options for disabled people ▪ Proportion of disabled people who feel it is easy to access sport, recreation and cultural activities		
Relationships: *"I have friends and lovers"* Disabled people make and keep relationships	▪ Percentage of disabled people making their own choices about their relationships, sexuality, and reproductive potential ▪ Percentage of disabled people supported by families and whānau ▪ Percentage of disabled people who are supported to develop independent communication ▪ Percentage of disabled people who have opportunities to meet new friends ▪ Percentage of disabled people in long-term relationships	▪ None known	▪ Disabled people's voice through case studies

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Long-term life outcomes for disabled people: ideally indicators below require analysis at total population level and by impairment type, ethnicity, gender, age, and location (i.e. urban vs rural)

Intended outcomes	Indicators	Data sources available	Data sources not available
	• Percentage of disabled people who perceive they have opportunities to meet new friends • Percentage of disabled people who have access to supports to maintain friendships		
Value: *"I feel valued"* Disabled people are highly valued by society	• Number of positive media representations of disabled people and their value in society • Percentage of disabled people who feel their contribution to society is valued	• New Zealand based media analysis	• Disabled people's voice through case studies
Needs of diverse groups including Māori, Pacific people, children, women and the families/whānau and other providers of support to disabled people	• Assessment of the needs of each of these diverse groups across the life indicators above, more specific indicators are detailed below: – Level of disability support services designed and provided by Māori for Māori, and by Pacific people for Pacific people – Level of access to and cultural appropriateness of mainstream service providers for Māori and Pacific peoples – Level of training received by Māori and Pacific disability service provider professional – Level of training available for trilingual interpreters for Deaf people	• Statistics New Zealand's post-census Disability Survey – Māori and disability • Statistics New Zealand's post-census Disability Survey – Pacific people and disability	• Unknown the extent to which existing data about disabled people can be robustly analysed at these subgroup levels