

Examples of prior successful NDIS funding for adults with albinism



Please note that these are merely examples of prior successful funding by AFA members and are in no way meant to suggest that future applications will also be successful. Please consult the NDIS site.

Any funding must be related to your personal goals, with consideration of your specific eye condition and personal circumstances. It does not help to compare any funding received for one person with another, as albinism alone does not qualify you for funding.

Please see below under the following headings:

- Using Service providers
- Assistive Technology
 - Technology for personal use
 - Sunglasses/spf clothing and sunscreen
 - Prescription glasses
 - Other technology or home modifications
- Support workers to accompany you to meet goals of daily living

Using Service Providers

The NDIS will generally provide funding for you to work with the following health or technology specialists in order to improve skills, or for assessments for equipment to meet personal goals. As an older adult you may be taking these up for the first time or revisiting to update and reinforce your skills. It is about learning lifelong skills and capacity building, so that you will be more independent of supports in the future. You may find you only need a few of these – everyone is different!

- **Orthoptist** – functional vision assessment and recommendations for assisting vision.
- **Orientation and mobility specialist (O&M)** – learning to move around safely, including cane use and public transport use.
- **Occupational therapist** – accomplish everyday activities safely and efficiently eg. to bike ride, cook or use gardening or maintenance equipment.
- **Assistive technology (AT) specialist** – recommend the appropriate AT for you (eg cane, monocular, magnifiers or bioptics) and provide an assessment to support your need in NDIS plans.
- **Physiotherapist** – for ongoing treatment of pain caused by poor posture related to low vision. NDIS may only cover ongoing support.

- **Psychologist** – Consider this if you are suffering stress, fatigue or difficulties due to your vision, or other people’s reaction to your condition. Support for self-advocacy issues. NDIS may only cover ongoing support.

Assistive Technology

Technology are often designated as common use items - Smart phones, tablets (iPads etc), sunscreen, UV clothing and sunglasses can be considered something everyone uses and therefore may be knocked back by some planners. Last year the NDIS rules changed around funding decisions for common use items. They will now be based on outcomes (rather than whether the item is considered mainstream), or that it could be used beyond its original purpose. They may be a necessity for you to be able to access print, navigate as you move around, see in the distance, or as a replacement for your lack of melanin to protect you going outside (even for short periods) all year round - way beyond common use! It will also help if you can demonstrate that a device is the only efficient way to provide accessibility, or take the place of multiple other devices (thus decreasing the expense overall – “value for money”).

Note that the technology provided will depend upon your actual functional vision loss – those with better vision (closer to 6/18) will neither require or be approved for the same equipment as those with severe vision loss (6/60+) or severe photophobia. Therefore not all below will be applicable to everyone.

Technology for personal use

You will need to undergo an assistive technology (AT) assessment. This can be done by an AT specialist, orthoptist or an occupational therapist, who you should be able to source through one of the major low vision providers. They will recommend which technology is required for you in order to meet your specific goals.

Things to consider when asking for technology to meet goals:

- The NDIS will not provide funds to meet any education based goals, including doing homework.
- The NDIS will generally not provide technology that is normally used by those with full vision, that they normally pay for (eg tablets and smart phones), unless it can be demonstrated that, due to your very low vision, it is used beyond its normal purpose.
- Which technology is required in order for you to have access to print or other media, for other close work (like sewing or model building), or for distance vision in order to meet your goals. (eg to read efficiently for pleasure, apply makeup or to be able to see the craft or art you are working on).
- Are different items required for different purposes or locations or can one device service several needs? Do you need a portable device away from home?

Examples of matching technology to goals:

Remember that you can only apply for what is necessary and reasonable – many of the items below may only apply to those who have poorer vision (eg using electronic navigation aids to move around).

- Goal: to enable me to read for pleasure or research an interest at home. Technology: various electronic or non-electronic magnifiers, audio access. It will need to suit your vision and home situation (desk magnifier for reading books or newspapers, portable magnifier for reading things like labels or instructions away from the desk, computer or tablet with accessibility enabled software, provision for audio books and text to speech options).
- Goal: To enable me to write for pleasure or to communicate with family and friends (as I cannot see my own handwriting). Technology: desk magnifier for handwriting or computer/lap top/tablet with large, high contrast keyboard for typing and accessible software for enlargement, and if appropriate text to speech or audio to text for when the eyes are fatigued.
- Goal: To enable me to undertake fine craft or artwork. Technology: desk magnifier that will allow room for hands to operate underneath the camera.
- Goal: to enable me to read for pleasure when outside the home (at a library, home of family or friends, or in a car or other transport). Technology: portable magnifier to read printed text or a tablet to read loaded or online text using the accessibility for larger text (novel or newsitems).
- Goal: to enable me to read sheet music in a confined space in a band or orchestra. Technology: a tablet with stand to either enlarge music or load onto the device.
- Goal: to enable me to enjoy novels or other written material in audio form when my eyes are fatigued. Technology: a device that will access audible material (eg. novels or newsitems).
- Goal: to enable me to be able to independantly read menus or public transport timetables and routes when out on my own or with friends. Technology: This may simply be a monocular, or it could be a tablet that is capable of being used as a magnifier or taking a photo which can then be blown up to view.
- Goal: to allow me to navigate in unfamiliar areas, follow a route, identify exactly where I am on a street or work out public transport for that time or place using an audible source in bright sunlight. Technology: Smart phone or tablet with apps to audibly describe a route, identify where they are or what building they are in front of, which bus is approaching, or when the next one is due. (note that this may only be accepted for those diagnosed with significant photophobia or significant vision loss).

Sunglasses/spf clothing/sunscreen

An example from a successful application for a PWA with photophobia:

Goal: “I would like to be able to safely and comfortably participate in outdoor activities and events.”

T: 1300 22 16 19 albinismaustralia.org



Albinism Fellowship of Australia

How to meet the goal: “Through the use of funding to purchase UV skin and eye protection to eliminate the discomfort caused by the sun. This protection will allow me to go outside safely for short periods and to enjoy the outdoors for longer periods of time, thus improving my physical fitness and social and community participation.”

Category of Consumable Daily adaptive equipment (AT Level 1 & 2) as per Practice Guide Assistive Technology: “For provision to assist with the cost of eye and skin protection, such as specialised sunglasses with transition lenses modified to suit me, UV protective hats and specialised UV rated sunscreen. Specialist long UV protective clothing is required for any extended physical activity outside.”

Prescription Glasses

All optical examinations are covered by medicare, but the prescribed glasses, lenses or other appliances are not. It is important to distinguish between how people without a recognised disability are funded for glasses versus those with a disability! Frames and lenses for those without a disability are expected to be covered from private health insurance for things like long/short sightedness or to improve general clarity (generally common conditions, including in those with albinism). For those on low incomes, there may be state based schemes for free or subsidised glasses. https://www1.health.gov.au/internet/main/publishing.nsf/Content/optometry_eye_health

In order for glasses to be funded by the NDIS, the eye condition must be related specifically to the recognised disability (and not eg long or short sightedness). If your prescription is to help dampen nystagmus, if especially thick lenses are needed for loss of acuity due to albinism (which don't fit normal frames), or if you have significant photophobia and require tinted prescription lenses, you may be covered, as this goes beyond common eye conditions. A statement to this fact from the optometrist or ophthalmologist will help support the application.

Other technology or home modifications

If you move into an existing home or rental, or purchase a different car, you may wish to request the following adaptations in order to meet goals (they must be linked to goals). Please check the listed item numbers on the NDIS site to ensure these are still available!

- Environmental home assessment (with recommendations) by an O&M or OT specialist to identify safety hazards or identify areas requiring alterations in order to allow safe movement, protect eyes, allow better vision or prevent eye pain.
- Tinting of windows in the home or provision of blinds to reduce glare.
- Alteration to lighting to reduce glare in the home and provide adequate targeted light.
- Provision of a shade sail to protect skin outdoors.
- Alteration to existing stairs or surfaces that are unsafe because of low vision.
- Tinting of car windows (darkest allowed for rear passenger area) in order to protect the eyes and prevent severe eye pain.

NDIS Resource (as at June 2020):

You can access the following guide for the correct wording and codes to use in your plan: AT and consumables code guide. Scroll down page to find link:

<https://www.ndis.gov.au/providers/housing-and-living-supports-and-services/providing-assistive-technology>

Support workers to accompany you in goals of daily living

Some of our members who are legally blind have been able to gain support with personal assistants/carers to undertake normal daily activities, especially if they do not have another adult in the home to assist at the time. The following are examples of support received, not meant as a list that will be accepted.

- Assistance with cleaning, gardening or simple home maintenance like replacing light globes.
- Provision of a carer to drive you as you drop off or pick up young children to school or activities, where public transport is not available, especially in regional or isolated areas.
- If your goal is to improve fitness or increase independent community participation through attending a fitness centre or similar, you may qualify for a support worker to attend to assist you to move safely among the equipment or other participants, and to help you understand instructions that you may not be able to see.
- If you wish to take up jogging, distance running/cross country running or tandem cycling, they may cover the cost of a guide to lead you around the course. They will not fund something like swimming lessons but may subsidise for 1:1 beginner lessons if you cannot see an instructor in a group lesson (especially if you also suffer with pool glare).

