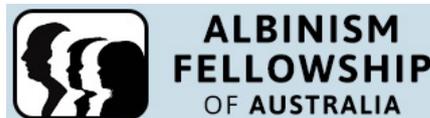


For Parents of Children with Albinism - A Guide to School

by S. George (Secondary Teacher)



An important partnership between students, parents and schools

Having high expectations and building a positive relationship with teachers and the school, is one of the most important things you as a parent can do, to ensure the best educational outcomes for your low vision child. When your child starts school or at the beginning of each new year, it is likely to be a steep learning curve for both you and the teachers, but with good communication and preparation it will ensure a smooth transition for your son or daughter (they generally handle this much better than the parents).

Allow for a settling in time when they get to know your child

It may take the teachers time to learn about your child and to work out the best way to meet their needs and work with them. Even if they have had a low vision child before, every child is different and it may take entirely different techniques and support structure to meet their needs. Both individual and whole group orientation sessions / days the year before are important, but sometimes things beyond the school's control can disrupt plans made (such as changes to staffing, funding or delays in equipment supply).

High Expectations and Developing Independence

Have high expectations for your child and do not allow them to do less because of their vision. They will probably need some assistance and accommodations along the way and it may take them longer to achieve some things, but have an expectation that they will complete the Core Curriculum, the Expanded Core Curriculum (ECC) for low vision, be a successful student and ultimately be employed. You may need to convey this message to teachers along the way.

Teachers and assistants will be keen to provide support for your child to have them excel, but no system provides one to one support all the time. Your child is one of approximately 25 in a class, so it is important that they learn to be independent and develop good organisational skills at an early age. It may be frustrating for them (and for you to watch) when they find a task difficult because of their lack of vision, but they will not learn the skill or become independent if things are often done for them. Encourage them to always "have a go" and not give up if things do not go well - building resilience is important! In the first few years of school they can often have difficulty with some skills, will be slow to learn them and sometimes "plateau" in their development of things like fine motor, writing and some movement skills. Be encouraging and give them time, they will get there!

Use the assistance of Support Services

Through NDIS funding, you can gain the assistance of a service provider (e.g. Vision Australia or Guide Dogs). They will allocate a Key Worker or Primary Contact, who will give you access to lots of services and guide you in the process of starting or continuing school. They will assist you from birth onwards to make the most of your child's vision or other senses to be successful in their environments. Early childhood specialists, Occupational Therapists and Physiotherapists can be helpful in the early years for some of the typical issues mentioned above.

Orientation and Mobility (O&M)

Service providers (e.g. Guide Dogs or Vision Australia) will work with you, your child, the school and teachers to provide a safe and accessible environment (in the classroom and yard). This may involve marking steps, changes in ground level, edges of play areas or equipment (either visual or tactile),

removing or reducing tripping or other hazards, optimal seating arrangements and developing processes to ensure all children know about changes in placement of objects, storage of equipment and keeping the floor area clear. They will also work with your child (and teachers) to develop the safest way of moving about and completing tasks in the environment of the school, in transit to and from school, or during excursions.

Education Support Services

In each state there is a unit associated with the education department that primarily works with low vision students in Government Schools (eg SVRC in Vic or RIDBC in NSW). They provide the Expanded Core Curriculum (ECC), either on their site and/or through Visiting Teachers who go to your school. The ECC includes additional skills our children need to learn, in order to fully access the Core Curriculum provided in schools to all students. This may include the use of access technology, visual efficiency, O&M, developing social skills, use of Braille and other communication modes etc. Other school systems usually provide their own visiting teachers.

The SVRC (Vic) and RIDBC (NSW) also provide professional development for teachers across all systems. **The Catholic Education Office** and **Independent Schools** in each state oversee provision of Visiting Teachers and ECC programs for low vision students in those systems.

Provision of Visiting Teachers can vary greatly according to the education system, individual school or geographical area. Those in the government system will visit your child at school on a regular basis (often weekly, fortnightly, monthly or each term, depending on vision requirements, skill and year levels). They are responsible for teaching the ECC to the child and working with staff to ensure these skills are practiced and used in the classroom under the supervision of the class teacher, through the child's Individual Education Plan (IEP or similar name in other states).

Teaching Assistants / Aides

Children who are legally blind (vision over 6/60) may be entitled to additional support such as under the Program for Students with Disability (PSD in Vic or similar in other states) and may include use of a teaching assistant and equipment. Those who have vision between 6/18 and 6/60 (6/24 and 6/60 in NSW and ACT) will have less support, but are entitled to support to ensure inclusion in all aspects of the school program (usually not a teaching assistant, but should include accommodations and technology). The provision of an aide is rarely full time, (unless your child has additional disabilities) and they usually work with a number of students in the same or different classes. All educational decisions and instruction of the student is the responsibility of the classroom (or subject) teacher. The assistant's role is to support the teacher and the student in the learning process – but from a distance. When used effectively they will ensure your child is provided with large print, braille, tactile maps, audio stories or specialist equipment so that they can access the curriculum at the same time, alongside their peers. They are not there to do some of the work for the child or to constantly sit next to them, as this separates them from their peers and does not develop independence. Many children with albinism do not require an aide!

Parent/Teacher meetings and Education Plans

You will be involved in the development of an ongoing Individual Education Plan (IEP), detailing the objectives and goals for your child's learning, and the accommodations or resources required. This will be reviewed and updated regularly (usually once a term) at meetings with yourself, teachers, the Visiting Teacher (VI) and any other professionals involved (In Victoria this is called a Student Support Group – SSG). Your child will gradually be included in part or all of the meeting as they get older. You may not be a

teacher, but as the person who knows your child the best, you are an important and valued contributor to this process. Your child will also be a contributor to this process, especially as they get older, when they are able to identify which accommodations work best for them and their learning.

If you are able to detail and quantify your child's vision and abilities, this will help greatly. Know your child's vision or other sensory abilities, social confidence and skills, O&M and how they may impact on learning and socialisation. Let them know what your low vision child can see at 10cm or one metre, how far away 30 point print is held in order to see it and what effect the environment has on their vision. By the time your child reaches secondary school, they will hopefully be able to do this for themselves.

Be proactive and remain positive.

Stay in touch with the teacher and Visiting Teacher, be proactive and remain positive about your child and the education process. Do ask about the things that your child can do, their achievements and progress. While difficulties need to be identified and resolved, this will only happen with meaningful, two way communication, focusing on the issues and being open to information, suggestions and solutions and giving the teacher time to implement them fully. It is tempting to be a helicopter parent, but this will not leave your child free to engage with peers and develop independence.

In many education settings, teachers have little preparation time or time to meet with other teachers. Your child will be one of over 20 students in a class (in secondary schools some teachers will work with well over 100 students, specialist teachers have closer to 200 students in multiple classes). It may take the teacher some time to really learn about your child and the adaptations necessary – have patience, remind and encourage them. You will get a feel for whether the teacher is really taking things on board to support your child. Bring issues to the support meeting, ask for strategies to be designed and implemented to solve them and expect to have a report on actions taken and outcomes at the next meeting.

Dreams for the future

Let kids dream without judgment - after all most kids want to be either a fireman or a ballet dancer and very few actually do. Don't limit their dreams because of their vision and do create an expectation that they will work. Encourage them to do all the things sighted kids do, to have responsibilities and complete jobs, ride bikes, have fun with peers and develop as many skills as they can. This way they stay in touch with social groups and are less likely to become isolated. Young adults with low vision who go on to successful careers often state that as children they were made to do everything their siblings did (from jobs around the house to activities and sports) and although it was sometimes difficult, they think it taught them resiliency and determination to succeed. Give them as many opportunities as possible and let them dream!