# Addressing specific issues NDIS and Vision Impairment

Phia Damsma, Executive Member VI-NDIS – SPEVI working group.

Working group

South Pacific Educators in Vision Impairment (SPEVI) Inc. acts as the professional body in matters pertaining to the education and support of children and young people who are blind or have low vision within the South Pacific region. This includes children and young people who are deaf-blind and those with vision and additional disabilities.

Following concerns arising from (preparation for) the introduction of the NDIS with regards to young people with vision impairment, SPEVI has decided to form a working group:

VI-NDIS – SPEVI.

The aim of this working group is to establish and promote Best Practice in supporting the needs and best interest of children and young people with vision impairment within the context of the NDIS.

The working group offers its support to the NDIA to provide advice in the development of effective strategies and other consultancy to ensure that the NDIS meets the needs of children with vision impairment. All members of SPEVI, including the Executive Members of the Board, are volunteers.

Below are outlined some of the issues we believe need urgent attention.

Planners need to have more professional specialised knowledge of vision impairment

One of the biggest concerns at the moment is the generalised, non-specialised professional background of the planner. Proper and efficient assessment of the specific needs of children who are blind or have low vision requires a professional with specific expertise in this field. Four areas capture a complete assessment of a child: clinical low vision evaluation, functional vision assessments, learning media assessments, and orientation and mobility assessments. The planner will not have enough specialised knowledge of vision impairment and will not be well enough equipped to do these assessments. The planner needs to know what the child needs, to be able to point the child and his or her parents in the right direction and guarantee the best outcome for the child and his or her family. If the NDIS aims to provide equity of access for everyone to a fair and reasonable support, it needs to ensure not only the best outcome for the individual child and his or her family, but also the best quality assessment and distribution of the required funding.

It is suggested that reports by eye specialists, which parents are required to bring to the interview with the planner, will provide sufficient information for the planner to base a proper assessment on. Unfortunately this is generally not the case. The clinical data on visual acuity alone do not provide enough information on the severity of the vision impairment (which in part will determine the funding amount), because a large number of other factors play a role. There may be a brain injury, or Cerebral Vision Impairment (CVI), or fluctuation of vision in children with Cerebral Palsy. Mentioned reports will not specify the actual impact on the functional vision of the child. The assumption that the parents of the child can then provide the necessary background information also needs careful consideration. In general parents do not exactly know to what extent the vision impairment will impact on the child’s life, development and education. This is especially true for the younger, inexperienced parents. They also do not know what available support there is, or what would benefit their child most, so they would not know what to plan or ask for.

Bringing along an advocate from a service provider/agency is not an option, as these will not be objective. They will be biased and hoping to get the parents to choose all services to come from this agency. We are pleased with the decision of COAG to instead outsource this to the Disability Advocacy Framework.

Involving external expert vision impairment consultants seems one way to assure that the planner gains sufficient insight; Upskilling planners (through specific training in vision impairment) is another option. Planners require a better understanding of the criteria for vision impairment, in order for them to have more information available about the functional vision of the child. An eye report is clinically based. Planners require expert knowledge to be able to interpret these reports and know what it means for the daily, functional vision of a child. To support this process, another working group has last year compiled a document (attached) which was submitted to the NDIA in NSW, and which can assist with determining the severity of the vision impairment. It is called ‘Severity Indicators of Vision Impairment’. It provides a straightforward, step-by-step method to assist a planner to at least make more sense of the clinical data reports provided by eye specialists. More will be required, but we believe that this document could serve as a valuable first step. Your feedback on this document would be greatly appreciated.

The members of the SPEVI Working group would like to have an ongoing discussion with the NDIA regarding this important issue.

Impact on schools of influx of external therapists

Another concern in the trial sites is the perceived influx of external therapists and ‘experts’ into schools, who are funded by the NDIS for particular children. Some schools find this hard to manage, and are anxious their relationship with the student and his or her parents will suffer if the access into the classroom of such an external therapist should be refused. How is this going to be resolved and what will be the impact on specialist education staff, who are highly qualified in this specific field, while some therapists may not have any such qualifications at all.

Safeguarding professionalism and best outcome for the individual

Agencies who have traditionally always provided aged care services, are now seen to be promoting their services to young children, with the aim to lock in as many clients as possible. They also aim to take over support that has traditionally been provided by specialist teachers for the vision impaired, such as in Social Skills, Independent Living, Assistive Technology and Orientation and Mobility. In Australia, these subjects have been implemented as part of what is called the Expanded Core Curriculum. They are embedded in the education system of the school, ensuring inclusion in the classroom and equity of access for everyone, with a fair and reasonable support.

These support services can now potentially be taken over by external agencies, with Occupational Therapists who only have experience with the elderly, and have no qualification in vision impairment. Agencies have also shown a tendency to close the ranks, acting without collaboration with other parties. This situation does not benefit the child.   
This issue definitely needs the attention of the NDIA.

Preparing parents

Early Intervention is generally acknowledged to be of the utmost importance, and this is especially true for vision impairment. Parents may need to be more educated on and better prepared for the NDIS. Ideally they should have more awareness of the meaning of the reports, the impact on their child, and determine what the child needs, to better support the assessment by the planner. But they also have to be supported in finding the best possible services, and make a well-funded choice for services provided by experts, not perse a convenient ‘one stop shop’ offered by some agencies (although of course they are free to choose that if they prefer, as long as they have a good understanding of the situation and the politics). In Brisbane the first special NDIS Readiness Forum for parents of children with vision impairment will take place (16 May). To help people really have choice and control, we should also look at training and upskilling the LAC’s in the field of Vision Impairment.

Accessibility

Finally, I would like to stress again that all NDIS information and resources for people with vision impairment and/or other disabilities are required to be accessible (including materials that will be collected in a database, as well as the database). OZEWAI, the Australian Web Adaptability Initiative, provides information on the Australian Standards <http://www.ozewai.org/index.php/en/aussiestandards>

On 18 March 2015 I sent some basic tips to YFS in the context of them doing a special NDIS Readiness Forum on 16 May, in Brisbane for people with vision impairment and their parents and carers. This information on accessibility in presentation, information materials and websites, specifically regarding accessibility for people who are blind or have low vision, was then, with my permission, forwarded to all other 8 Participant Readiness projects across Queensland.