Have your say

Please use the questions below as a guide when developing your submission:

1. Do you believe the current Framework encompasses your vision of advocacy in the NDIS environment? If not, what changes are required?
2. Are the [principles](#_Principles) of the Framework appropriate for guiding the delivery of advocacy for people with disability in a changing disability environment, including in the context of the NDIS? If not, what changes are required?
3. Are the [outcomes](#_Outcomes) of the Framework still relevant or should different ones be included? If so, what should be included?
4. Are the [outputs](#_Outputs) of the Framework still relevant or should different outputs be included?
5. Does the Framework identify what is needed in the current and future disability environment? If not, what changes are required?
6. Do you have any other comments, thoughts or ideas about the Framework?

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The South Pacific Educators in Vision Impairment (SPEVI) Inc. is the major professional association for educators of students with vision impairments in Australia, New Zealand and the South Pacific region. SPEVI acts as the professional body in matters pertaining to the education and support of persons who are blind, have low vision, deaf-blindness, or additional disabilities. SPEVI membership is open to educators, professionals and parent groups who support and promote education for persons with vision impairment. SPEVI’s Vision is to promote educational systems in Australia, New Zealand and the South Pacific in which diversity is valued and disability is not viewed as a characteristic by which to judge a person’s worth.

The SPEVI Committee of Management has endorsed the formation of an NDIS working group, called

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 in education within the context of the NDIS.

SPEVI believes that the National Disability Advocacy Framework should support advocacy for the best possible education outcome for participants in the NDIS who have vision impairment.

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1. Do you believe the current Framework encompasses your vision of advocacy in the NDIS environment? If not, what changes are required?

No.

**Education**

SPEVI recommends that the right of people who are blind or have low vision to Education is made explicit in the Framework Principles, and that advocacy efforts are made towards ensuring inclusion in education.

Background:

The Framework document page 1, dot point 8 states:

* The Framework recognises and acknowledges that people with disability can experience additional disadvantage including, but not limited to …, education,

The Advocacy Framework principles 2 and 4 state that

* Disability advocacy promotes the interests and wellbeing of people with disability and promotes their full and valued inclusion as contributing and participating members of the community
* Disability advocacy promotes leadership and capacity building by people with disability

The Framework defines Disability Advocacy as:

* supporting people with disability:
* to stand up for their rights and choices
* take part in their community
* find employment and training
* feel valued and respected
* achieve their goals
* have their say.

Regardless all of the above statements, SPEVI would like to point out here that, shockingly, the word ‘Education’ is not mentioned once in the Advocacy Framework, with the intended meaning to include people with disability in education, or education as a right for people with disability. In order for effective and necessary advocacy to take place to support people with disability to get a proper education (which may lead to them acquiring full and valued inclusion as contributing and participating members of the community, and find employment – as proposed in the Principles), SPEVI recommends that the right to Education of people who are blind or have low vision to is made explicit in the Framework Principles, and that advocacy efforts are made towards ensuring inclusion in education.

1. Are the [principles](#_Principles) of the Framework appropriate for guiding the delivery of advocacy for people with disability in a changing disability environment, including in the context of the NDIS? If not, what changes are required?

No, please also see 1.

The Framework’s Principles should explicitly mention advocacy for education, as well as advocacy for support for a student with vision impairment to achieve to their ability and goals in education (such as reasonable adaptations, assistive technology, accessible formats of resources).

In order for a student to self-advocate, the student needs to be empowered and have sufficient self-confidence. If a student does this during a NDIS related meeting, planners, LAC’s and others should respect the person with vision impairment’s capability to self-advocate and not doubt whether the goals they have and needs they express are authentic and worth following up on.

For others to advocate on behalf of people with vision impairment, it needs to be ensured that parents, teachers, and advocacy groups have high expectations for students with vision impairment to achieve in education and future employment. Too often it is assumed that a student with blindness or severe low vision will not have the ambition, or the ability, to be an academic student, or to find a job. The current national percentage of young people with blindness who are not active in the workforce is far too high. There appears to be a lack of sufficient advocacy for (and maybe by) people with vision impairment to succeed in education and lifelong learning.

**Early intervention**

Within the context of the NDIS, the interface between Disability, Health and Education needs to be properly defined. Advocacy for support within education needs to take place in the best interest of the child. Early Intervention is generally acknowledged to be of the utmost importance, and this is especially true for vision impairment. SPEVI wants to stress here that children with vision impairment are more often than not complex individuals, with multiple health issues and other diagnoses. This makes it even more essential that everyone working towards supporting these children are knowledgeable.

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 advocate on behalf of their child in a meeting with 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, for which they then advocate. 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.

One of the biggest concerns of the SPEVI NDIS working group is the generalised professional background of the planner. Proper and efficient assessment of the specific needs of young 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 (and LAC) 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. The NDIS needs to provide equity of access for everyone to a fair and reasonable support.

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 Visual 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 advocate on behalf of their child and provide the necessary background information also needs careful consideration. In general parents do not know exactly to what extend the vision impairment impacts of on the child’s life, development and education. This is especially true for the younger, inexperienced parents, for young children for whom early education is essential for their development. They also do not know what available support there is, or what would benefit their child most, so they would not know what to advocate for.

 **Expert Advocacy for Equity**

Concerns have been raised From one of the NDIS trial sites about an apparent lack of equity regarding students with vision impairments within the NDIS. Some students receive an NDIS package even though they have been dis-continued by the Education Department's State wide Support Service for Vision Impairment (they no longer meet the VI criteria of 6/18 corrected visual acuity) whereas other students with more severe vision impairment are still waiting.

When specialist assistive technology equipment is provided to the home there is not always sufficient consideration given to training needs.
Again, this clearly demonstrates that good advocacy is essential for the best outcome, and that this advocacy needs to be done by people with a thorough understanding and expert experience with children who have vision impairment, in particular in view of the before mentioned generalised (non-specialised) professional background of the planners.

**Improve advocacy outcomes in NDIS interview**

At a recent NDIS preparedness forum it was suggested that to improve advocacy outcomes, workshops would be provided for people of “like-groups” to discuss their needs and requirements with “like” people. SPEVI recommends special parent groups to be organised in local communities around the country, where parents can share their experiences, concerns and solutions with each other, before they go to a planner interview, to have a better advocacy outcome during that session.
Online “hubs” could also be created for children and young people with vision impairment to prepare and advocate for themselves (note: ensure high levels of accessibility and usability!).

**Tertiary education**

One would expect Disability Officers to advocate on behalf of students with disability in tertiary education. Universities of today rely heavily on online access of enrolled students to learning resources and teaching staff. The online ‘Virtual Blackboards’ that are used for this purpose are not always easily accessible for students who are blind and who rely on the use of screen reading software. However, unfortunately, because of the low incidence, Disability Officers in tertiary education in general have little to no expertise of vision impairment. Without in-depth understanding of a students’ needs, advocacy is often not done effectively on their behalf. This includes Advocacy for proper support for students with severe low vision, in particular when this vision fluctuates (the student will be able to see a bit one day, and next to nothing the next day). The Advocacy Framework should provide for better advocacy on behalf of students with vision impairment within tertiary education.

1. Do you have any other comments, thoughts or ideas about the Framework?

**Accessibility is essential for advocacy**

SPEVI would like to recommend that all NDIS information, workshops, communications and resources (including materials that will be collected in a database, as well as the database navigation itself) are more accessible for people with vision impairment.

*Framework* ***principle 6:***

*Disability advocacy strengthens the capacity of people with disability to speak for themselves by actively supporting and encouraging self-advocacy*

*People with vision impairment should also be encouraged and empowered to self-advocate*.

To enable a person who is blind or has severe low vision to self-advocate and have proper choice and control in the context of the NDIS, SPEVI strongly advices that all NDIA and other NDIS related information and all two-way communication needs to be in an accessible format for people with vision impairment, including materials that will be collected in a database, as well as navigation of the database.

The framework is underpinned by a person centred approach whereby policies and programs are designed to respond to individual needs and aspirations (p. 1, item 7).
Information and access also needs to be user centred in its design.

People cannot self-advocate if they have no access to, or cannot easily navigate and use, the information on which their choice and control should be based. All people have a right to access to information.

**Safeguard Specialist Teachers (Vision Impairment)**

SPEVI would also like to take this opportunity to advocate for safeguarding of professionalism of Specialist Teachers (Vision Impairment). Please refer to the website [www.spevi.net](http://www.spevi.net) for SPEVI’s Professional Standards for Specialist Teachers (VI).

Agencies who have traditionally always provided aged care services, are now, with the NDIS, 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. The NDIA should endeavour to ensure the continuing involvement of specialist teachers (VI).