

13 April 2011

Response to the Productivity Disability Care and Support Draft Report

About the Royal Society for the Blind (RSB)

The Royal Society for the Blind (RSB) is the primary provider of services to people who are blind or vision impaired in South Australia. A quality endorsed organisation currently providing the full range of rehabilitation services to over 11,500 South Australians. It is also the only blindness agency in South Australia with Regional Offices.

The RSB is committed to enabling people who are blind or vision impaired to become and remain independent, valued and active members of the community.

Services provided include:

- Adaptive Technology,
- Accommodation support,
- Braille training and support,
- Computer training,
- Community Support Programs,
- Counselling,
- Education and Training,
- Employment Services,
- Equipment,
- Guide Dogs,
- Independent Living Training,
- Information in alternative formats to print,

Our Services

Adaptive Technology
Community Education
Counselling
Employment Services
Guide Dog Service
Industrial Services
Library Services
Low Vision Centre
Mobility Services
Outreach Services
Peer Support
Print Alternatives
Recreation & Leisure
Systemic Advocacy

Adelaide

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Gilles Plains SA 5086
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Regional Offices

Mount Gambier
Noarlunga
Port Augusta
Smithfield
Victor Harbor

www.rsb.org.au

The Royal Society for the
Blind of SA Inc.

- Library Services,
- Orientation and Mobility,
- Recreation Services,
- Support for low vision, systemic advocacy and design advice, and
- Transport.

Further information on the RSB may be found via the website at:

www.rsb.org.au

Disability Care and Support Draft Report Overview

The RSB endorses and supports the Submission by the Australian Blindness Forum (ABF) to the Productivity Commission on Disability Support and requests that this Submission be read in conjunction with the ABF's.

The RSB firstly commends the Productivity Commission on its efforts to reform the disability system and ensure people with disabilities have an entitlement to services. It notes the significantly recommended increase in funding to achieve this outcome however expresses some doubts over the true demand and cost of an entitlement system. As noted the disability sector has been chronically under funded for many years and as with most service providers we would be grateful for any increase.

The concept of entitlement is also in accord with Australia's commitment to the United Nations Convention on the Rights of people with a disability (UNCRPD).

In particular the RSB fully endorses the Productivity Commissions initiatives including:

- Client Choice
- National benchmarks, and
- Early Intervention

However is disappointed that the architecture recommended is based on the needs of people requiring holistic personal care rather than providing a system creating independence, engagement with the community and enabling an individual to exercise their full rights of citizenship.

For people who are blind or vision impaired their primary needs relate to:

- Information, understanding and acceptance of their vision loss,
- Access to Information, built environment and specialist equipment,
- Transport, and
- Specialist Rehabilitation Services.

The RSB does not believe these have been adequately considered within the Draft Report.

In addition, the RSB is also concerned that the Draft Report is already limiting a person's eligibility based on a subjective amount of what is reasonable as opposed to an aspirational need. Whilst

the RSB appreciates that this is a method of cost control further information is sought on how and who decides this.

The RSB is also concerned over a number of recommendations in the Draft Report that are discussed in detail below including:

- The artificial separation of people between two systems for which there is neither an interface or a guaranteed consistency of services.
- Cost shifting of services for people over retirement age to the Aged Care Sector (for which no provision has been made).
- The concept of “tradeoffs” and how this will be applied to ration services.

The RSB’s goal is to enable people who are Blind or Vision Impaired to realize their potential through the acquisition of skills which provide independence and the ability to participate in their community. Whilst a similar stated goal is included in the Draft Report this is then lost on the focus on personal care rather than skill acquisition.

The Productivity Commission’s Draft Report has been developed to improve the quality of life for people with or acquiring disabilities in the future, therefore the RSB is seeking information on what research has occurred with regard to identifying who will be worse off as a result of their recommended changes and the impact of this on the individual.

In the RSB’s view, the Draft Report, not only needs to define circumstances that it considers to be “reasonable” but also confirm that a minimum entitlement to “reasonable” services includes consideration of the person’s quality of life and the UNCRPD relating to basic human rights including the ability to:

- Remain independently in your accommodation of choice.
- Seek and find employment.
- Participate and contribute to community life including involvement in recreation and leisure activities.
- To build social relationships within their community (refer later comments regarding community engagement).
- Enjoy the full rights of citizenship.

Recommendations

The RSB recommends that the Productivity Commission for Disability Support consider the following amendments:

1. Review the Draft Report to ensure that no person will be worse off under the proposed system or if a decision is made to continue irrespective identify who will be negatively impacted.
2. The RSB believes that the Productivity Commission needs to define more clearly what it considers to be a “reasonable” cost and who will decide the application of this.
3. That the Productivity Commission Reports into *Disability Care and Support* and *Caring for Older Australians*, be considered jointly. This is due to the introduction of an arbitrary boundary based solely on age and will assist in ensuring that all people who are blind or vision Impaired have access to their entitlement to specialist services.
4. The Productivity Commission review the Tier 1 structure and create a dedicated Strategy for Community Engagement.
5. Given the major source of new referrals for Early Intervention for people who are Blind or Vision Impaired is with the Primary Medical Sector that rather than create a new system of referral that the NDIA work with existing processes and providers.
6. The Productivity Commission acknowledges the unique needs and nature of services for people who are blind or vision impaired including the episodic nature of responses normally required and the emphasis on skills development, rehabilitation processes and client participation which are already in place.
7. For specialist services the Productivity Commission review the exclusion of block funding and work with the Vision Loss Sector to create appropriate benchmarks and outcome measures.
8. The RSB has suggested an alternate Tier structure for the Productivity Commission’s consideration which includes a “Quick Assessment” to triage people into appropriate service responses.
9. That the Productivity Commission notes the value of peer support and suggests that this be incorporated as part of a service response.
10. The RSB is seeking further information on eligibility and confirmation that people who are Blind or Vision impaired are eligible for Tier 3 funding (in the absence of a revised Tier structure).
11. That the Productivity Commission notes the need for information on services and all communication to be available in alternative formats irrespective of whether it is considered “reasonable” to do so.
12. That if a decision is made to segregate service access and responses based on an arbitrary age, that interfaces be created before any change to ensure that this is not provided in a discriminatory manner and that, irrespective of the funding source, services are identical in terms of quantum, quality, timeliness and payment for all people with vision loss.
13. The Productivity Commission define further how the current system of assessment and referral will work in the future and how it will minimize unnecessary assessments, barriers and obstacles created through case management of people requiring episodic interventions.

14. That the Productivity Commission in creating guidelines for what is “reasonable” have regard to the true cost of the disability.
15. That the Productivity Commission review the Options Coordination model for service delivery implemented and discontinued in South Australia.
16. That the Productivity Commission review the data relied upon within the Draft Report and in particular review the impact of unmet need and services funded independently by the Not for Profit sector.
17. The RSB is seeking further information with regard to how consumers not seeking an individual package of funding will access and receive specialist services.
18. The Productivity Commission develop strategies for ongoing research into not only the efficiency and cost effectiveness of interventions but to investigate and implement new strategies including new technologies.
19. The Productivity Commission develops strategies for the maintenance of specialist staff including for instance Orientation and Mobility Instructors, Guide Dog Instructors etc.

The Two Reports

The RSB notes the release of the two Productivity Commission Draft Reports on “Disability Care and Support” and the “Caring for Older Australians”.

It does not accept that vision loss is a natural part of the ageing process although there is a strong correlation between ageing and sensory loss with approximately 80% of RSB client's are over the age of 65 years. Accordingly in the absence of change, people who are blind or vision impaired will rely on both the new “Disability System” and new “Aged Care System” to maintain their independence and quality of life.

The Productivity Commission Draft Report on *Caring for Older Australians* makes no acknowledgement, provision or indeed comment on the needs for people over retirement age with a disability and how the system will respond.

As a result it is the RSB's belief that these two Draft Reports need to be considered together and not in isolation as is currently the case and if this approach is adopted that systems need to be created to ensure that the responses and outcomes are identical. Any new system needs to ensure that a “sub class” of client is not created based on the reputation of an arbitrary age.

Accordingly the RSB believes that the Productivity Commission needs to develop a more detailed explanation of how the continuum of care would operate between the two sectors and, in particular, detail the interface and the role that specialist service providers have within the two systems.

Community Engagement

The Productivity Commission Draft Report does not consider fully the need to create community engagement with and acceptance of people with a disability (other than a reference under Tier 1). The RSB currently provides a wide range of programs and information materials and believes that for NIDA to optimise the use of its resources it needs to work co-operatively with these programs.

Examples of this include:

- Exclusion from mainstream facilities,
- Reluctance of employers prepared to employ a disabled person, and
- Inability to participate in community activities including recreation and leisure.

Accordingly the RSB believes that the Productivity Commission needs to invest in educating and engaging with the community to ensure the integration and acceptance of people with disabilities including consideration of their needs in the design of products and the built environment. This will also create long term savings in the NDIA.

In addition the NDIA needs to review where the issue of systemic advocacy including design and access of products and buildings will be funded as appropriate consideration of these can lead to significant savings in the need for support or specialist services.

Early Intervention

The RSB supports the emphasis the Productivity Commission places on Early Intervention and the RSB agrees that this is a forwarding thinking strategy that is both cost effective and enables the avoidance of the crisis that may occur as a result of unsupported vision loss. This includes the loss of employment, mental health and physical health issues.

To be effective early intervention for people who are Blind or Vision Impaired needs to be available as close to diagnosis as possible and as part of a continuum of care. Accordingly the proposed system needs to educate referral bodies and provide support at this time, something that already occurs within the RSB. Indeed at the current time every Ophthalmologist in South Australia refers directly to the RSB on diagnosis, enabling where required, an immediate response.

It would seem that a better use of resources rather than replicating an existing system and adding a further layer of generic case management, as proposed, would be to strengthen what currently occurs and embed this in a new system nationally.

Examples of services provided by RSB that fall into the early intervention category include:

- Information on the impact of vision loss, strategies and equipment available,
- Counselling on the adjustment to vision loss,
- Peer support,
- Recreation and Leisure activities,
- Home safety assessments,
- Lighting assessments,
- Low Vision Clinics,
- Adaptive Technology,
- Orientation and Mobility, and
- Independent Living Skills.

The RSB has concerns over approval for specialist intervention being approved solely on clinical research undertaken by academics with no knowledge of the sector with an “accountant’s views” of resource allocation.

Clearly whilst the RSB believes in appropriate standards and benchmarks individuals recovering from the trauma of vision loss or other changes in their life will do so at different rates and need to be supported accordingly and not up to some artificially determined quantum of service. Any funding provided under Early Intervention needs to be sufficient to meet the outcome. It would be wasteful and not cost effective to deliver a mobility package where the funds available enable a person to orientate and navigate to the end of the street but not enable them to cross the road or utilize public transport based on research conducted in another State on another individual.

At the current time an RSB client is able to receive a level of service to achieve this outcome, this is not based on a budget created as an “average”.

Unique Needs of people who are Blind or Vision Impaired

People who are Blind or Vision Impaired face unique challenges which are overcome with specialist training or equipment and not through the provision of personal care which the RSB views as a dependence model.

For instance, an individual whose independence is threatened by an inability to clean their house, the Draft Report's response based on the model of generic assessments would be the provision of an ongoing cleaning service possibly from a person with no prior training or knowledge of the functional impact of vision loss. This may indeed, by default place the person not only disempower but also place the person at risk of falls or other injuries, for instance by the person reorganizing their kitchen or furniture.

However the RSB's response would be to retrain the individual to be able to undertake this task independently, hence both empowering the individual and providing a cost effective long term solution.

For RSB's clients, there are a number of ways of initially entering the Vision Loss Sector (Sector) however the vast majority of referrals (close to 100%) are from the primary medical sector providing a continuum of care. RSB is concerned that the proposed system by introducing a further unnecessary tier of case management is not only wasteful but will be also be likely to create delays and barriers to the receipt of services (refer attached case study and comments re Options Co-ordination). At the current time the maximum waiting time from diagnosis to attendance at the RSB Low Vision Clinic is two weeks, the RSB is unsure how the new system will ensure that this is maintained.

Services for people with vision loss are also "episodic" as opposed to a personal care model which tends to be whole of life. That is, people will seek rehabilitation support from specialist providers, achieve their goals and move out of the system, coming back typically at times of transition or change.

For instance if a person moves house and requires re orientating to their new environment this may require 4 hours of specialist training but will enable them to independently traverse their environment until there is a further change. Alternatively if this person requires a replacement cane tip, total cost \$10, in either of the above circumstances the most timely, cost effective and logical method of meeting these needs, is direct contact with a specialist agency not having to navigate the NDIA.

Given the specialist and episodic nature of services which are generally not available from a generic provider, the RSB is offering three suggestions to mitigate this namely:

1. The creation of "Trusted intermediaries" being specialist organizations trained in ensuring people are eligible for services based on National Disability Insurance Agency (NDIA) eligibility criteria for early intervention services. These organizations are empowered to deliver at a pre agreed rate a package of services to a fixed monetary amount for which they would report and invoice NDIA. Over this amount they would refer onto the NDIA for consideration and approval of larger service plans.
2. Creation of a fourth tier (if our suggested revamp of the proposed Tier system is excluded) which enabled a fast tracking by NDIA of people meeting a certain criteria to a specialist provider for a specific quantum of services. This is consistent with comments regarding "warm referral".
3. Block funding of specialist agencies to deliver services as exists under the current system.

Tier System

The RSB believes that the Productivity Commission needs to review the Tier concept as presented. It is our belief that the Tiers need to relate to how a person with a disability, be it mild, moderate, severe or profound, enters and receives services from a disability system.

The proposed Tier system mixes both an attempt at social awareness, excluding people that don't meet a specific criteria but may have a need or potentially benefit from a short or minor intervention and those who will receive access to an entitlement scheme.

In the absence of both a framework requiring compliance with Disability Discrimination and similar Legislation, together with a community engagement strategy. Tier 2 is ineffective.

For instance the response to refer a person who is blind or vision impaired to a mainstream provider such as the local library is pointless and frustrating to the individual unless the library is accessible and provides materials in an individual's format of choice. At the current time no public library, the RSB is aware of, has a collection of Braille. Further there is normally no accessible catalogue nor a wide range of materials in audio.

As noted below, the RSB believes that a genuine investment in community engagement will benefit both an individual with a disability and result in cost savings to NDIA.

The RSB believes that the Tier system should reflect the pathways that on referral an eligible person will follow. To achieve this it is suggested that the gateway for entry be a "Quick Assessment" to determine an appropriate response. The RSB is suggesting a possible revised structure as follows:

Tier 1: Provision of information to the individual on the disability and mainstream service supports.

Tier 2: Tier 1 plus the provision of a "restricted" service intervention which is in accord with the concept of Early Intervention and in the case of people who are blind or vision impaired may be referral to a specialist provider.

Tier 3: Is as described in the Draft Report.

Examples of how this may operate:

Tier 1: Margaret has been diagnosed with the early stages of Macular Degeneration, which at this stage does not impact on her functionality. However she is distressed and unsure of her future prognosis.

NDIA response, following a "Quick Assessment", is to provide her with information on available vision loss information services, in this case possibly RSB, Low Vision Centre or Macular Degeneration Foundation.

Tier 2: Tony has been previously diagnosed with Glaucoma which was under management by his Ophthalmologist. However due to a chronic episode he can no longer drive, read print and will eventually lose the remainder of his sight. Although at this stage he remains independent and able to manage his self care requirements.

NDIA response, following a "Quick Assessment" is to refer him to the RSB for a specialist assessment which, as a result, identified a need for:

- One service with a Counsellor to understand and accept his vision loss and provide reassurance,

- Two services with an Orientation and Mobility Instructor to increase his confidence using public transport, and
- Referral for access to talking books.

The total intervention is less than 5 hours at the conclusion of which Tony is able to continue with his life whilst his vision remains stable.

The RSB believes that this will not only provides a clear referral pathway with early triage and intervention, it will also stream people to the appropriate response in a timely manner, saving money in the longer term and optimising the benefits of early intervention.

Peer Support

The establishment of support groups, in particular peer support, is seen as an invaluable assistance in enabling people who are newly diagnosed with severe vision loss to accept and learn how to adopt and overcome the functional and emotional impact of their vision loss.

Advice and information provided by people who have been on a similar journey is more readily accepted than that from sighted professionals.

This is again a vital service which is cost effective however overlooked in the Draft Report.

Eligibility

Whilst the RSB supports, based on its understanding at the moment, that the vast majority of its clients, based on acquiring a chronic, congenital eye disease or traumatic incident, resulting in severe or total vision impairment would qualify under Tier 3 for funding. The RSB is seeking the Productivity Commission's confirmation of this.

The current medical definition by itself of legal blindness should not be the sole measure of eligibility and this needs to be considered in conjunction with:

- Functional impact, eg, the ability to read print and communicate, and.
- Likely progression of the condition, this relates specifically to access to early intervention services.

Accordingly the RSB believes that any assessment of eligibility needs to be based both on medical and a functional diagnosis.

Assessments

Generic disability assessment tools in spite of many attempts to the contrary do not reflect the needs of people with a vision impairment. Indeed, most are designed to assess the personal care services needed by people with an intellectual or physical disability or a brain injury. The RSB does not agree with this "one size fits all" concept and believes that for services to be effective they need to be built around the individual's aspirations with an appropriate assessor.

In order to assess the specialist needs of a person who is Blind or Vision Impaired, an assessor will require at the very least an understanding of:

- Eligibility criteria
- Physiology of different eye diseases

- Functional impact of vision loss
- Emotional impact of vision loss
- Strategies to overcome this functional impact
- Services and technology (which changes frequently)
- Environmental barriers e.g. internet or physical

These skills and knowledge do not exist in the generic disability sector.

Therefore the RSB believes that the Vision Loss Sector is best equipped to conduct specialist assessments, however, if a decision is made to adopt a generic assessment tool, then it is essential that it be tested to ensure it identifies the issues faced specifically by people who are blind or vision impaired and results in a referral for specialist services in a timely manner.

The RSB is working with Dr Neil Kirby at the University of Adelaide on the D-Start Assessment Trial however at this stage we do not know what the outcome will be.

Quality of Information

Given the proposed entry point for people to an NDIA is through a generic assessor (refer comments regarding assessments) it is vital that the assessor clearly is able, in a non biased manner, to provide accurate and current information on referral pathways and rehabilitation responses whilst respecting a person's independence.

For people who are blind or vision impaired this information must be available in their format of choice and they require equality of access to all information including that contained on the NDIA website. Similarly all electronic forms must be compatible with Adaptive Technologies.

Age

The Productivity Commission's Draft Report for Disability Support is recommending that people over retirement age receive access to specialist services from the Aged Care sector, where as the Productivity Commission's Draft Report, *Caring for Older Australians*, firstly makes no provision for these people and further states that a co-payment for personal support services will be required. Accordingly the RSB is seeking information on whether this co payment applies to specialist disability services. If it does what research has been undertaken to identify what the impact of this will be?

It is the RSB's view that if the Productivity Commissions support for one group of people with vision loss to an entitlement but not another based solely on an arbitrary age that this may be in breach of Commonwealth and State Government's Legislation dealing with both Age and Disability Discrimination. In addition it is in breach of the UNCRPD which requires an entitlement for all people with a disability without reference to age.

The RSB also rejects the notion that vision loss is part of the "natural" ageing process and that the needs or specialist services for people with severe vision loss change substantially for people over or under the age of 65.

Indeed, the RSB is querying, other than as a cost shifting mechanism, why an arbitrary boundary is required as the service responses are identical irrespective of age. It also appears from the Draft Report on the Age Care sector that there is no provision for any additional funding to support rehabilitation services to people with a disability. This appears to continue the misconception that the only services that will be required are of a personal care nature which demonstrably is untrue.

This approach is also contrary to the reality that people over the age of 65 remain valued and active members of the community.

Accordingly the RSB believes that irrespective of the funder or the age of the person that there is a right to equitable access to specialist services in a non-discriminatory way and the Draft Reports need amendment to reflect this.

Cost of Blindness

Whilst being conscious that the Draft Report notes the need to ration and be “reasonable” with regard to what services and supports will be funded there is also a need to realise that for a person who is Blind or Vision Impaired there are costs unique to the disability including:

- Personal costs associated with increased power charges to accommodate a higher level of lighting,
- Purchasing properties close to public transport and facilities at a premium price,
- Specialist equipment,
- Materials being transcribed into alternative formats,
- Opportunity cost of not being able to identify specials when shopping

For people who are Blind or Vision Impaired access to specialist equipment is a key component of being independent. Unfortunately in many states of Australia including South Australian people who are Blind or Vision Impaired are excluded from these schemes. A new system needs to ensure the inclusion of people who are Blind or Vision impaired and not accept that cost should be the driver for denying access to either services or equipment.

Clearly any assessment also needs to be capable of identifying and quantifying the realistic costs Blindness and Vision Impairment.

Architecture of the proposed system

The Productivity Commission is recommending a system for the future based on a very similar model trialled and subsequently discontinued in South Australia, “Options Co-ordination” (OC).

OC was created to separate the roles of:

- Funder
- Purchaser (Case Manager), and
- Service Provider

The RSB’s view is that this model was effective in part for people with Physical and Neurological disabilities who had few choices for services prior to the introduction of OC and for people with complex needs who benefited from the Case Management. There was little benefit or involvement in OC from the vast majority of people who are blind or vision impaired. Indeed the RSB’s experience was that people who are vision impaired were referred, in the case of new clients, directly to the RSB from the primary medical sector or were self referred.

For those other than with a complex need, OC represented only a further layer of management.

This system was subsequently discounted with all funds and responsibilities reverting to Disability S.A. The Social Inclusion Board (S.A.) is currently reviewing the effectiveness of Disability S.A. and redeveloping a “Blueprint” for the future.

The RSB urges the Productivity Commission to review the South Australian experience and in particular the feedback on Disability S.A. which is very similar to that being proposed to ensure that similar errors do not occur.

In addition the RSB is seeking information as to the costs of creating the extra layer of Case Management created by an NDIA which, for people who are blind or vision impaired, is redundant.

Data

At the ABF Forum on the Productivity Commission's Draft Reports it was acknowledged that the researchers did not have access to meaningful and accurate data. This is exacerbated by the fact that the current data collection by governments on disability is poor and relates primarily to funded services discounted to the Government contribution.

No data on services which are unfunded or unmet need is formally collected.

Given the RSB provides services to 11,500 South Australians that are blind or have severe vision loss, it believes that the Productivity Commission has underestimated the true demand for specialist services to people who are Blind or Vision Impaired.

Given comments as noted above regarding rationing, what will be the impact of this unassessed demand on both the Productivity Commission Reports and ability to provide in a sustainable manner a fair and equitable system. Of greatest concern is that this unassessed demand will cause the system to further ration or not accept new referrals in order to remain within a budget.

Individualised Funding

The RSB has observed the United Kingdom experience first hand with regard to Individualised Funding and noted that as it is a rationed system people who are Blind or Vision impaired with their episodic needs never reached the required priority level to receive a funded package. Given concerns as noted above regarding data and the demand, the RSB has concerns that people who are blind or vision impaired assessed under a generic tool for personal care will have a similar experience.

Whilst the RSB supports the Productivity Commission in providing consumers choice with regard to accessing services. The Draft Report is unclear with regard to the funding options for clients seeking direct access to specialist services.

Benchmarks

The RSB fully supports National benchmarks and has led the way for many years in obtaining quality accreditations including ISO9000 and DESQA. Clearly benchmarks need to be created in consultation with the Sector and represent best practice.

For the RSB the primary concern relates to ensuring that providers are able to deliver appropriate specialist services locally and in a timely manner.

As the system proposed is based on budgets with costs dictated by NDIA there is concern over services being delivered to a budget rather than a standard. This has been the experience in Germany for Guide Dog Services. Insurance Companies purchase on behalf of their clients a Guide Dog at a price determined by them resulting in a Guide Dog that is trained to this price and as a result potentially placing their clients at risk.

A further issue is local support from an interstate provider a person receiving a Guide Dog from an interstate organisation needs to have access to both regular follow up and immediate problem solving, if not their independence and safety are potentially placed at risk.

It is also important that “timeliness” benchmarks are established to ensure the full benefit of early intervention is realised.

Research

The RSB supports the Productivity Commission’s recommendation on the need for research and evaluation processes.

The RSB believes that research is vital both for current interventions and to assess new technologies and service methodologies. However it is concerned over the primary focus being linked to cost effectiveness rather than measures to assess the impact on an individual.

Further in a chronically under funded industry the costs of undertaking clinical research for skills development appear illogical given many of the specialist services provided are to enable an individual to undertake a specific task or activity. For instance:

- Orientation and Mobility services are provided to enable a person who is blind or vision impaired to independently orientate and traverse their environment. The outcome is whether or not the person is able to achieve independent travel, clinical evidence of this is irrelevant.
- Activities of daily living enabling a person to independently clean their own house is demonstrated by the ability to independently clean their house.

The RSB also has significant difficulty with the concept and the ethics of a clinical trial whereby people are denied services in order to compare the difference. Specialist Services for people who are blind or vision impaired are tailored to meet the individual aspirations, environment and life experiences which do not fit within the confines of a randomised controlled study that requires a large number of people with the same attributes to complete the same program.

Further if external organisations such as hospitals and universities are contracted to provide research as indicated then there needs to be significant discussion on primarily what is to be researched, is it based on Quality of Life?, Outcomes? If not what?

Where recognised therapies such as for instance:

- Orientation and Mobility,
- Counselling,
- Occupational Therapy,
- Guide Dog Instruction.
- Computer and Technology Training

Are provided. The RSB does not believe there is a need for clinical research to justify access to these, indeed it is believed that this would be a wasteful exercise unless it was directed at assessing new methods of service delivery or technologies.

The RSB believes that it is inappropriate for the NDIA to shift the costs associated with clinical research on accepted therapies to a service provider merely to satisfy its need to demonstrate a “financial cost benefit”.

Rather the RSB believes a far more effective solution be rewarding innovation and development. It also believes that by creating barriers in a commercial market setting as proposed that this will lead to the non sharing of information which will be regarded as intellectual property and a competitive advantage for a service provider.

The RSB believes that as with any intervention there needs to be measurement and justification for its delivery however the research as proposed is both narrow and will not assess fully the value of intervention. Accordingly the RSB believes that this requires further thought by the Productivity Commission.

The RSB has previously demonstrated the benefits of services through Quality of Life surveys in assisting people to maintain their independence and note that this does not meet the criteria suggested by the Draft Report, as it excludes consideration of cost effectiveness (which is not defined).

Workforce

The RSB is disappointed and again believes this can be linked to the focus on personal care that the Draft Report does not consider the need to maintain the specialist skills and workforce required to deliver specialist services to people who are blind or vision impaired. Indeed the RSB rejects the comment that staff only require “empathy, practice and good communication skills with on the job training”.

Whilst this may be true for personal care, the RSB would appreciate how this would apply to the training of a person with a Guide Dog or white cane.

It is critical that the Gateway systems being recommended for both assessment and early intervention have a workforce which is knowledgeable about the functional impacts of vision loss and the services available for rehabilitation from specialist service providers.

Many of the services noted throughout this response are very specialist in nature and require detailed knowledge of vision impairment and the service responses. In many instances the specialist knowledge and experience is obtained through cadetship or on the job training that will not be available in a generic setting. It is highly unlikely a non specialist provider will invest in training people in, for instance, Braille, mobility or training a Guide Dog.

At the current time, RSB agrees that the Industry Skills Council for Community Services is not proactive in assisting current courses to generate a supply of job ready people trained in the provision of specialist services for people with disabilities but rather focuses on personal care. Similarly all Undergraduate Courses focus on generic disability not the specialist needs of people who are blind or vision impaired. At the time of preparing this response consideration of “sensory loss” is not included in any generic disability course.

Role of Volunteers

The RSB currently utilises over 900 volunteers (70 FTE) throughout the State delivering a wide range of services including:

- Assistance with Daily Living, eg shopping, reading etc.
- Transport,
- Transcription,
- Recreation and Leisure, and
- Puppy Education

The RSB recruits, trains and matches a volunteer to assist a client in any activity to maintain their independence and involvement with the community.

The Draft Report does not acknowledge either the importance or cost benefit of these volunteers rather it views them incorrectly as a potential source of paid labour. This in itself demonstrates a lack of understanding of the volunteer ethic and why people volunteer in the first instance. It also completely misses the point that volunteers are providing their labour at no cost currently and attempts to recruit and reimburse these as paid labour will have a substantial impact on the ability of any organisation to maintain this current level of services.

Whilst the RSB notes that the Draft Report recommends the promotion, matching and removing the burdens of entry as the role of the NDIA, the fact is that the recruitment, training, matching and management of volunteers costs money. The return is free labour, however the NDIA ignores these costs.

This also further reinforces later comments (under data) that the Productivity Commission has not correctly understood the contribution from the Not for Profit Sector nor the consumers that are currently being supported without recourse to public funds.

Case Study

Other case studies can be provided on request

Jill is 48 and has a degenerating eye condition called Diabetic Retinopathy. She lives alone and manages independent living tasks well due to the rehabilitation training she has had in the past.

Despite managing her diabetes well she has recently developed kidney failure and has to go on dialysis three times a week at the local public hospital. She is placed on the list for a kidney transplant.

She requests urgent training in Orientation and Mobility to travel to the hospital and orientation to the ward.

Jill needs something to occupy the long hours while on dialysis and requests audio books from the RSB's Digital Library Service.

Eventually, she receives a transplant and looks forward to resuming her life. However, she receives a lot of instructional material on her discharge from hospital regarding the management of her health and requires this information in audio format within a few days.

As a result of her improved health, she is able to successfully complete training with a guide dog and participate in a range of recreational options. She also undertakes computer training with adaptive technology in order to access information and stay in touch with friends through email.

Detailed below is a comparison of how the current and new systems will operate as perceived by the RSB.

Service	Current System	Proposed System	Services which are Time Critical
Self Referral to Vision Loss Agency	√	√	
Vision Loss Agency refers to NDIA		√	
NDIA Assessment		√	
NDIA refer to Vision Loss Agency for Orientation and Mobility training		√	
VLA Specialist Assessment	√		
Provision of Orientation and Mobility training			
Completion of service protocols for NDIA		√	
Self Referral to NDIA for RSB's Digital Library Service		√	√
NDIA Assessment		√	
NDIA refers to Vision Loss Agency		√	
Provision of Digital Library Service	√	√	√
Completion of service protocols for NDIA		√	
Self Referral to NDIA for print transcription		√	√
NDIA Assessment		√	√
Referral to VLA	√		√
Provision information in audio by VLA	√	√	√
Completion of service protocols for NDIA		√	
Self Referral to NDIA for Guide Dog Training, recreation and leisure, computer training		√	√
NDIA Assessment		√	
VLA Specialist Assessments	√		
Provision of services by Vision Loss Agency	√	√	√
Completion of service protocols for NDIA		√	

Conclusion

The RSB has considered the Draft Report and congratulates the Productivity Commission on acknowledging the need for an entitlement system and a massive increase in funding to enable people with disabilities to participate independently in the community and enjoy their rights of citizenship.

However it believes the architecture created is to meet the needs of people with physical or intellectual disabilities or complex needs of a holistic nature and does not assess and provide timely intervention of specialist services for people who are blind or vision impaired.

The RSB is particularly concerned over:

- The focus on personal care,
- The arbitrary splitting of people between the Disability and Aged Care Sector with likely different services and co-payment requirements.

- The provision of generic assessments by generic assessors.
- The creation of a system created to a “price” not an entitlement.

It is our belief that the Draft Report, as it stands, will create a sub class of people who are blind or vision impaired, a loss of specialist expertise in the sector resulting in disempowerment and dependence.

Accordingly the RSB has provided a number of recommendations for the Productivity Commission’s consideration. In the interim if you require any further information regarding the above, please do not hesitate to contact the undersigned.

Yours faithfully

Andrew Daly
Executive Director