AUSTRALIAN BLINDNESS FORUM

SUBMISSION TO THE SENATE INQUIRY INTO THE FUNDING AND OPERATION OF THE COMMONWEALTH STATE/TERRITORY DISABILITY AGREEMENT

August 2006

BACKGROUND

The Australian Blindness Forum (ABF) was formed in the early 1990s as the national coalition to represent the interests of the major non-government, non-profit blindness agencies across Australia (listed at Attachment 1). On behalf of its members, the ABF has a keen interest in the Commonwealth State/Territory Disability Agreement (CSTDA).

The term 'blind' used throughout covers people who are blind as well as those who are vision impaired or deafblind. 'Blindness agencies' are the non-government organisations that provide supports to people who are blind. 'Blindness sector' refers to people who are blind, their families and blindness agencies.

INTRODUCTION

The CSTDA encompasses the Principles and Objectives of the *Disability Services Act* 1986 (Cth), the *Disability Discrimination Act* 1992 (Cth) and complementary State and Territory legislation. During the life of the three Agreements, there have been improvements, but significant weaknesses remain.

The fine rhetoric in the Agreement's national framework objective¹ on improving the quality of life of people with disability has not resulted in all governments collecting evidence of its effectiveness.

Funding continues to be in response to crisis and critical pressure and not to a planned response to unmet need, population growth and other factors driving demand. A minimum level of funding only is set at the signing of the five-year Agreement that is inadequately indexed and does not set targets for growth in response to need.

¹ Clause 4(1): The Commonwealth and the States/Territories strive to **enhance the quality of life** experienced by people with disabilities through assisting them to live as valued and participating members of the community.

Despite commitment in the Agreement to improve inter-governmental linkages, these remain problematic and interface needs to be more effective between governments as well as extended beyond disability.

The case for reform of the CSTDA is supported by recommendations in the Australian National Audit Office (ANAO) report², which have been accepted by the Department of Family, Community Services and Indigenous Affairs (FaCSIA).

THE NEXT CSTDA

The ABF supports governments' entering into a fourth CSTDA.

As a member of ACROD, the National Industry Association for Disability Services, the ABF strongly supports the focus and recommended changes to the next CSTDA in ACROD's submission to the Senate Inquiry.

In addition, the ABF believes that there are particular areas of interest to the blindness sector that require further emphasis because of their great potential to bring about an improved quality of life for people who are blind.

- A national strategy, as a supplement to the National Eye Health Plan³, for the rehabilitation of people with vision loss, including mapping of current service provision and funding of low vision and rehabilitation services in the blindness sector across States and Territories;
- A national unified model for children and young people so that people who are blind develop adequate lifeskills;
- A national coordinated plan for the provision of assistive technology;
- Improved interfaces between service systems for people who are ageing
- More equitable contributions by governments to the Print Disability Services Program;
- Continuation and strengthening of the National Disability Advisory Council;
- Recognition that individual advocacy underpins the development of systemic advocacy; and
- Equality of indexation for services provided by State/Territory governments their agencies and to non-government organisations.

Better Linkages and Improved Referral Pathways

The ABF asks for improved linkages across governments, and for better referral pathways between the education, health and ageing sectors to the blindness sector.

² Administration of the Commonwealth State Territory Disability Agreement, Department of Family and Community Services, The Auditor-General Audit Report No.14 2005-06 Performance Audit, Australian National Audit Office

³ Endorsed by Australian Health Ministers Conference (AHMC) in November 2005

A national strategy for rehabilitating people with vision loss is needed

In July 2004, the Australian Health Ministers Conference (AHMC) agreed to develop a national eye health plan to promote eye health and reduce the incidence of avoidable blindness. This initiative represented Australia's response to the World Health Assembly (WHA) resolution WHA 56.26 on the elimination of avoidable blindness in member countries.

The subsequent *National Framework for Action to Promote Eye Health and Prevent Avoidable Blindness and Vision Loss* (National Eye Health Framework)⁴, endorsed by AHMC in November 2005, only addressed part of the picture of vision loss and ignored non-treatable or non-preventable eye disease that leads to blindness or severely impaired vision. As a result, the ABF supports the Vision 2020 Australia submission⁵ to the Community and Disability Services' Ministers Conference (CDSMC), proposing a National Vision Loss Rehabilitation Strategy (see Attachment 2). The submission called for the establishment of a CDSMC working group or other forum to:

- a. Map the current provision and funding of low vision and rehabilitation services across all States and Territories; and
- b. Consult with the low vision and rehabilitation sector toward the development of a complementary strategy to the National Eye Health Framework.

In August 2006, a background paper is being prepared for Commonwealth and State/Territory Disability Services Ministers. It is understood that the Ministers have undertaken to consider the paper and the Vision 2020 Australia submission 'out of session' before referring it to a meeting of the Community and Disability Services Ministers Advisory Council⁶.

People who are blind are failing to learn lifeskills

National and international experience and research demonstrates that a child who is blind must have specialist assessment and specific training in the areas of lifeskills (see Attachment 3). The skills and knowledge that sighted students acquire by casually and incidentally observing and interacting with their environment are often difficult, if not impossible, for students who are blind to learn without direct, sequential instruction by knowledgeable persons.

The ABF is deeply concerned that in Australia specialist intervention in the form of assessment and instruction is inequitable and inadequate in their quality, scope and outcomes. Young people who are blind are leaving the

 $\underline{http://www.vision2020australia.org.au/documents/V2020AsubmissiontoCDSMClowvisionandrehabilit\\ \underline{ation.pdf}$

⁴ http://www.health.gov.au/internet/wcms/publishing.nsf/content/health-mediarel-yr2005-jointcom-jc021.htm

It is expected that the background paper will be finalised for Ministerial consideration by mid August and that it will again be considered for inclusion on the agenda for the November 2006 CDSMAC meeting (communication from Vision 2020 Australia, August 2006).

compulsory school system inadequately prepared to take on further study, seek employment, participate meaningfully in the community, live independently or develop personal relationships.

The interaction between educational establishments and blindness agencies providing children's services in each State/Territory, almost without exception, are seriously under-resourced. While specialist schools have mostly provided a reasonable program of lifeskills development, government, Catholic and independent schools consistently fail to deliver adequate programs, even with specialist input by blindness agencies. Many students have had problems created for them by being encouraged to pursue only part-time study or training, which delays their results and denies them involvement in typical social experiences in those settings.

There is no national consistency in the delivery of the required lifeskills services provided to children and young adults. What does occur is predominantly funded through the efforts of blindness agencies, not allocated by governments. Over the past ten years, the main response of blindness agencies across Australia (and internationally) to the problems confronted by a young adult who is blind has been to provide an extensive and expensive remedial rehabilitation program. However, these programs inevitably meet with limited success because it is unrealistic, untenable and ultimately unacceptable to attempt to redress:

- High levels of long-term dependency which have been reinforced throughout childhood and adolescence (particularly 'learned helplessness' inculcated during the 0-8 years developmental stage);
- The negative impact on families struggling over many years to raise a child who is blind without adequate information, resources, support and training;
- Access to only a limited range of lifeskills training and support through the local blindness agency (for example, orientation and mobility training may be available but independent living or social skills are not); and
- A lack of confidence, assertiveness and motivation to successfully engage in and complete the remediation program.

A young person leaving secondary school and wanting to apply for a guide or seeing eye dog to aid mobility and independence, can be unsuccessful because of the inability to meet the prerequisite competencies for using such a dog, that is: independent travel routes; independent living skills (personal as well as for the dog); leadership qualities; social skills; organisational skills; stable accommodation arrangements and assertiveness.

The consequences of children and adolescents failing to acquire adequate lifeskills are not limited to the cost of providing extensive remedial programs. There are significant costs to the individual and community through increased risk of family breakdown; long-term dependency on welfare; academic and social underachievement; physical, emotional or psychological health issues; long-term socio-economic disadvantage. As Dr Phil Hatlen (1996:6) accurately observes:

"... unless skills such as orientation and mobility, social interaction, and independent living are learned, these students are at high risk for lonely, isolated, unproductive lives"

The net result is

"... a modern tragedy, with too many products of our educational efforts living isolated, troubled lives" (Hatlen 1996:7)

The implementation of a national model that unifies the timely delivery of lifeskills supports from early childhood through the growing years would address the shortcomings of current approaches and provide much-improved outcomes for people who are blind and their families.

To achieve this, the national unified lifeskills model proposed by the ABF incorporates interconnected programs that are responsive to the needs of the child and family in the home and community, and calls for improved linkages across government departments responsible for education, health and community services and for better interaction with the blindness sector.

Assistive technology needs a national strategy

Although both the Commonwealth (through the Departments of Health and Ageing, Veterans' Affairs and Employment and Workplace Relations) and State and Territory governments administer schemes that provide cost-free or low-cost aids and equipment to people with disability, assistive technology⁷ is excluded from the CSTDA.

Overall, the existing network of schemes is under-resourced and contains significant gaps. In its 2003 study of aids and equipment, the Australian Institute of Health and Welfare (AIHW) found there to be 'a limited range of equipment, problems with cost, availability and shortage of referral services in remote areas of Australia, and a decline in equipment supply from traditional dispensing units such as hospitals. Systems for the provision of equipment appear to be nationally fragmented.'8

Although recent changes to the Workplace Modifications Scheme⁹ have removed some barriers to employment for people who are blind, those who require assistive technology to manage their daily lives and pursue recreation and leisure activities remain disadvantaged in obtaining communication equipment – those living in rural and remote areas are doubly disadvantaged.

http://www.jobaccess.gov.au/JOAC/Employers/Employer+incentives/Workplace Modifications S.htm

Australian Blindness Forum Submission on the Next CSTDA August 2006

5

⁷ Assistive technology for people who are blind can cover communication aids including voice recognition; computer access aids; education and learning aids; environmental and structural aids; hearing and listening aids; vision and reading aids; mobility and transportation aids; and ergonomic equipment

⁸ Disability: the use of aids and the role of the environment, AIHW, August 2003, p.16

Involvement in rehabilitation programs can be compromised by the inability of individuals to obtain the necessary assistive technology they need to independently access and utilise information. This is directly as a result of their inability to fund the purchase of the necessary aids and appliances.

Without some form of assistance, the inequalities that currently exist for people who are blind will be exacerbated by the constant challenge of technological change. Increasingly, they will face relegation to an isolated under-class within the community relying on the support of others, rather than developing skills and gaining in independence.

Being independent includes the ability to access information as freely as possible. The Commonwealth Government has already acknowledged this for people who are deaf with the creation of a scheme that provides hearing aids. A properly prescribed magnifier for a person with low vision meets the same need as a hearing aid for a person who is deaf. This need has been recognised by the Department of Veterans' Affairs, which provides its constituents who have low vision with such equipment.

In 2001, the ABF proposed a National Equipment Subsidy Scheme to assist people who are blind with the purchase of vital aids and equipment. The Scheme was not intended to replace or compromise any other assistance schemes currently provided to people who are blind. However, the Commonwealth Government did not proceed with the proposal.

A national assistive technology strategy under the CSTDA is needed now.

People who are ageing are missing out on services

Lack of a whole-of-government approach is damaging to people with a disability when they reach 65 years. Despite CSTDA bilateral agreements that specifically identify the need to improve linkages between aged care and disability services, those linkages remain poor. This interface is of growing importance because of population ageing, which increases the general prevalence of disability. Yet the existing funding arrangements and policy rules mostly deny a person simultaneous access to services from the aged care and disability service systems¹⁰.

Many people are acquiring blindness as they age. The Commonwealth State and Territory Strategy on Healthy Ageing provides a mechanism for positive ageing that coordinates activity between governments on community attitudes, health and wellbeing, work and community participation, sustainable resourcing, inclusive communities, appropriate care and support, and research and information. A similar approach that enhances the positive inclusion in the community of people who are blind is needed across government departments and pools of funding.

¹⁰ Submission to the Senate Community affairs References Committee Inquiry into Aged Care, ACROD, July 2004

The principle of 'top up' funding (with clients of disability service programs entitled to attract Commonwealth Aged Care) should be more widely applied in recognition of the fact that the needs that arise from ageing do not displace those associated with a long-term disability; they are additional needs.

The National Disability Advisory Council should continue

The National Disability Advisory Council was set up in 1996 to create better links between government, people with disabilities and their families. Until recently, the Council provided advice to the Minister for Family, Community Services and Indigenous Affairs on disability related issues and encouraged consultation between the Commonwealth Government and the disability sector.

The Council provided advice from a consumer perspective on matters referred by the Minister; sought references from the Minister on matters the Council identified as requiring further investigation; and, at the Minister's request, participated individually on special working groups, or conducted consultations, on matters relevant to the portfolio. The Minister appointed members from diverse backgrounds that included people with personal experience of disability, family members and/or carers and service providers.

During 2006, the Council has remained inactive. The ABF asks that it be revived and its advisory role strengthened.

More Equitable Contributions from States/Territories

The Print Disability Services Program needs more equitable funding

The Commonwealth Department of Family, Community Services and Indigenous Affairs, through its Print Disability Services Program¹¹, funds 13 print disability service providers that are not-for-profit incorporated organisations. The Program assists the service providers to produce printed material in alternative formats such as audiotape, Braille, large print and computer disks, and to provide this material to people who are unable to read, hold or manipulate printed material in standard form because of their disability. Material is delivered mainly through the 'free of charge' postal service under the Postal Concessions for the Blind Program.

The majority of users are people who are blind who wish to access educational or leisure material at public libraries and education institutions as well as through public, private and community sector organisations. A range of alternative format material for State, Territory and Catholic departments of education are produced by some of the print disability service providers.

¹¹ http://www.facs.gov.au/internet/facsinternet.nsf/disabilities/access-print disability services.htm#3

This is effectively a subsidy system where a proportion of the cost of each item is received by the producers as a Commonwealth grant. The subsidy rate depends on the nature of the item (audio tape, Braille, computer disk etc), Initially, the Commonwealth contribution was estimated at approximately 33% of the cost of production. Over the years this has declined to below approximately 15%. One major criticism of this system is that there has been no increase (beyond indexation) in grant levels since the Commonwealth State Disability Agreement came into force. As the program is a shared responsibility, there is an expectation that State and Territory disability service programs should also provide funding, but it is concerning that this has proven to be extremely limited.

A 2003 report, to the then Department of Family and Community Services (FACS), into the program¹² led to two recommendations being made:

- 1. FaCS commission research into the application of contemporary technology to the production of alternative format material; and
- 2. FaCS further review the funding model for services funded under the Print Disability Services Program.

In response to the first recommendation, further research was conducted and a report¹³ was made by the consultants, Jenny Pearson and Associates in 2005. The ABF calls on the Commonwealth and State/Territory governments to commit to implementing the recommendations from the report and to carrying out further consultation under the next CSTDA.

Individual advocacy is important to systemic advocacy

Under the CSTDA, advocacy is a shared responsibility of the Commonwealth and State/Territory governments.

In the blindness sector, the national secretariat of the peak body, Blind Citizens Australia (BCA), is funded by the Department of Family, Community Services and Indigenous Affairs. As one of its key roles, BCA conducts an advocacy service to assist people who are blind in the three main areas of social security difficulties, disability services and disability discrimination. While the Commonwealth Government acknowledges the advocacy roles of BCA, it does not provide funding for this to occur. BCA is being restricted in its work because of FACSIA's refusal to recognise that systemic advocacy underpins the work of the national secretariat as well as benefiting from the information and experiences gained through conducting advocacy for individuals.

The Victorian Government provides some funds to the BCA national secretariat for specific advocacy and information projects in that State.

¹² Print Disability and Postal Concession for the Blind Review Report, Commonwealth Department of Family and Community Services, 2003

¹³ Report on Research into the Application of Contemporary Technology to the Production of Alternative Format Material, submitted to Commonwealth Department of Family, Community Services and Indigenous Affairs, 2005 (unpublished)

However, BCA's branches in the ACT, NSW (four), Queensland, South Australia, Tasmania and Western Australia, do not receive any funding support from State/Territory governments.

It is essential that the review of advocacy currently being undertaken by the Commonwealth Department of Family, Community Services and Indigenous Affairs finds solutions to this inequitable situation.

Indexation needs to be realistic

Not only has indexation failed to keep pace with unavoidable cost increases, in some States, such as Tasmania, indexation for government agencies providing services to people with disability is unfairly higher than for non-government organisations.

The ABF considers it imperative that all governments apply an annual indexation formula (or provide equivalent supplementation) that reflects the unavoidable cost increases incurred by service providers. In line with the recommendation made in the Social Policy Research Centre study for the National Disability Administrators¹⁴, the Commonwealth should revise its method of indexing disability grants and use an alternative method based on the ABS Wage Cost Index with a small CPI component.

Contact:

Margaret Verick Project Officer (Australian Blindness Forum) PO Box 60 CURTIN ACT 2605

Email: margaret.verick@acrod.org.au

Phone: 02 6283 3214

¹⁴ Methods to Address Requirements for Changes in Funding Disability Services Brought About by External Change, Bruce Bradbury, Social Policy Research Centre University of New South Wales, Report presented to the Department of Human Services for the National Disability Administrators, April 2002

ATTACHMENT 1

MEMBERS OF THE AUSTRALIAN BLINDNESS FORUM, 2006

Association for the Blind, Western Australia

Australian Federation of Disability Organisations

Blind Citizens Australia

Christian Blind Mission International

Guide Dogs NSW/ACT

Guide Dogs Association Queensland

Guide Dogs Association of Victoria

Royal Australia and New Zealand College of Ophthalmologists

Royal Blind Foundation of Queensland

Royal Guide Dogs Tasmania

Royal Institute for Deaf and Blind Children, NSW

Royal New Zealand Foundation of the Blind

Royal Society for the Blind of South Australia

RPH Australia

Seeing Eye Dogs Australia

Senses Foundation, Western Australia

Vision Australia

ATTACHMENT 2

National Vision Loss Rehabilitation Strategy

A study by Access Economics for the Centre for Eye Research Australia in 2004 identified:

- Almost half a million people have impaired vision and over 50,000 of these are blind:
- Nearly 300,000 have vision impairment because of under-corrected refractive error; 180,000 have vision impairment due to other causes that cannot be corrected by spectacles;
- The prevalence of vision loss trebles with each decade over the age of 40, increasing dramatically in the last decades of life;
- Data show a higher use of social services and admission to nursing homes for people with vision loss;
- By 2024, the number of Australians with vision loss is expected to increase to nearly 800,000; and
- The most prevalent causes of blindness and low vision in Australia are the agerelated degenerative eye diseases such as Macular Degeneration, Glaucoma and Cataract.

Severe and permanent vision loss can occur at any stage in a person's life. However, unlike some other disabilities, the service responses will be episodic in nature and intensity and needed when there are changes in a person's life, for instance when changing accommodation, employment, loss of further sight or death of a partner. With appropriate and early intervention, a person who is blind will not require ongoing personal care or other holistic support.

The National Vision Loss Rehabilitation Strategy, developed by Vision 2020 Australia in conjunction with members of the Australian Blindness Forum, aims to be supplementary to the *National Framework for Action to Promote Eye Health and Prevent Avoidable Blindness and Vision Loss*¹⁵ (National Eye Health Framework).

While low vision and rehabilitation were not specifically addressed in the National Eye Health Framework, the importance of linking with low vision and rehabilitation services was recognised, including the need to:

- Improve early detection of vision loss by establishing appropriate referral pathways;
- Treat access to low vision services as part of the continuum of eye care programs;
- Explore mechanisms to improve access to eye health care services in rural and remote communities;
- Raise public awareness of the range of low vision and eye health care services;
- Develop pathways including referrals to available vision rehabilitation or low vision services; and

¹⁵ http://www.health.gov.au/internet/wcms/publishing.nsf/content/health-mediarel-yr2005-jointcom-jc021.htm

• Involve people with, or at risk of developing, low vision and blindness in significant service design and delivery decisions.

The background paper being prepared for Commonwealth and State/Territory Disability Services Ministers in 2006 asks for an initial period of five years and proposes:

- Specific initiatives are implemented in conjunction with the National Eye Health Framework to raise the awareness of blindness, its functional impact, treatments, referral and available rehabilitation services;
- People with vision loss are accepted as valued members of the community;
- Primary health care providers are aware of and refer to appropriately resourced low vision and rehabilitation services as part of a continuum of care;
- The needs of people with vision loss are considered in the provision and development of all government services;
- A minimum level of access to low vision and rehabilitation services is available to every person who is blind in Australia, irrespective of their geographic location, demographic or special needs;
- Specialist assistive technology is available for people with vision loss, similar to the availability of a hearing aid or pair of spectacles;
- Specialist transport services and concessions are available to all people with vision loss and that these services and concessions are recognised in all Australian States and Territories:
- Digital technologies are introduced to enable equitable access to information for people with vision loss;
- Strategies are developed and implemented in consultation with people of Aboriginal or Torres Strait Islander background to create culturally appropriate low vision and rehabilitation services;
- The planning and delivery for future low vision and rehabilitation services is based on objective data and best practice; and
- Sufficient resources are allocated to enable all key outcomes to be attained within the life of the Strategy.

Rehabilitation and support services include early intervention; orientation and mobility training; independent living skills; vocational training and placement; recreation; technology; counselling; mentoring and peer support; and information and library services. All of these services need to be available as part of a continuum of care in conjunction with the primary health sector.

The vision loss rehabilitation sector is unique and works best when there are partnerships with the disability, education, health and aged care sectors. Unlike other sectors, blindness agencies tend to generate and contribute a substantial amount of their own resources into the provision of services; in fact, Guide Dog associations receive no government assistance at all.

An example of good practice is the partnership model in South Australia in which all Royal Australian and New Zealand College of Ophthalmology members refer people with vision loss to the Low Vision Centre of the Royal Society for the Blind of South Australia. The Centre employs ophthalmologists, optometrists and counsellors and, while not a primary health service, provides information, optimisation of remaining vision, supply of equipment and acts as a gateway for referral to other services. Other models exist in other States.

ATTACHMENT 3

National Unified Lifeskills Model

The National Unified Lifeskills Model (NULM)¹⁶, developed by Royal Guide Dogs Tasmania in conjunction with other members of the Australian Blindness Forum, aims to integrate three main elements:

- 1. **Family:** information, resources, support and training to enable and empower families to effectively raise a child who is blind;
- 2. **Lifeksills**: high quality, comprehensive and coherent training to develop the child's skills in and across all areas including orientation and mobility; independent living; social; literacy through Braille; leisure/sport/recreation; assistive technology; vocation/job seeking; and efficiency with remaining vision;
- 3. **Environments and routines**: the varying needs of the child and family within the home, school and community environments and at key transition points in their lives.

All elements are responsive to the constantly changing developmental and transitional (such as moving from pre-school to school) needs of the child while assisting the family to provide the child with consistent opportunities to develop and reinforce skills as part of daily routines. This approach not only develops skills for independence in the short-, medium- and long-term but, importantly, it also develops a spirit and expectation of independence in the child and the family.

Since 1996, research in the USA¹⁷ has identified eight distinct areas of blindness specific skills, knowledge and understandings that must be developed by a child who is blind to successfully make the transitions through the key developmental and life stages of childhood, adolescence to adulthood. The development of such skills equips the child to maximise their potential to live a productive and independent lifestyle as a contributing citizen in the community. The eight key areas are referred to as the 'Expanded Core Curriculum (ECC)¹⁸ and consist of:

- 1. compensatory or functional academic skills, including communication modes
- 2. orientation and mobility
- 3. social interaction skills
- 4. independent living skills
- 5. recreation and leisure skills
- 6. career education
- 7. use of assistive technology
- 8. visual efficiency skills

Significant variations exist within and between Australian States and Territories in the quality and scope of service offered to families of children who are blind. A number of factors have an impact on this situation, including:

¹⁶ Errol Ingram *National Unified Lifekills Model (NULM)* (unpublished typescript, 2006)

¹⁷ Dr Phil Hatlen, Superintendent, Texas School for the Blind http://www.tsbvi.edu/school/index.htm

¹⁸ The 'Core Curriculum' generally consists of knowledge and skills related to academic subjects. Because educators of students with vision impairment have developed expertise in curriculum adaptation, it should be possible to take any curriculum and make it readily available for students with vision impairment. Also see American Foundation for the Blind at http://www.afb.org/Section.asp?SectionID=44&TopicID=189&SubTopicID=4

- Varying experience, qualifications and skills of individual blindness agencies employed to work with children and their families across States/Territories;
- Lack of nationally recognised benchmarks for service quality;
- Lack of comprehensiveness and coherency across all eight fundamental lifeskills areas of the ECC (for example, an agency might offer services in orientation and mobility, assistive technology and independent living skills, but little or no services in social skills, career education or communication modes);
- Lack of awareness by parents and blindness agencies of alternative models of service delivery that could provide more effective outcomes;
- Inequitable access to assistive technology hardware and software;
- Lack of opportunity for adolescents and young adults to engage in social activities and employment;
- Difficulty for parents in finding the right information instead the parent needs to ask the right person the right question at the right time in the right way to hopefully get the right answer;
- Unhealthy dependence, almost over-reliance, on an individual guide and mentor to manage the maze of information, agencies and services has significant implications for service standards, accountability and equity;
- Lack of access to quality services adds to the lack of opportunity for lifeskills training in regional areas;
- Parents need support and mentoring as well as for the young adult who is blind;
- Ability to read and write Braille is essential for people who are blind to achieve a level of literacy that is comparable to sighted people – one of the key determining factors in finding employment is competency in Braille; and
- Importance of access to lifeskills/recreation camps to benefit the young person and provide respite for the parents.