

# **The Needs of Children and Young People (0-19 years) with Vision Impairment in New South Wales and ACT**

**A joint research project of  
Royal Blind Society and  
Royal Institute for Deaf and Blind Children**



**Royal Institute for  
Deaf and Blind Children**



with support from



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**in New South Wales and ACT**

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**1999**

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Its Steering Committee comprised the following officers of the two agencies:

Mr Alan Baynham, Royal Institute for Deaf and Blind Children  
Ms Carol Ireland, Royal Blind Society  
Ms Helen Lunn, Royal Blind Society  
Ms Jan North, Royal Institute for Deaf and Blind Children  
Dr John Race, Royal Institute for Deaf and Blind Children  
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Research Officer for the project was Ms Marilyn Leeds  
Consultant: Mr Craig Tapper

Members of the Steering Committee and its Research Officer thank the families who participated in the study. Many parents and some young people took the time and effort to complete the questionnaires. Similarly, many parents and young people were available for detailed interviews that addressed aspects of personal and family life. All participants willingly discussed many issues related to vision impairment and other disabilities as well as the response of service systems to their needs. Thanks are also extended to the Chief Executive Officers of both agencies and to the Department of Ageing and Disability, Government of New South Wales, for funding the project.

## EXECUTIVE SUMMARY

### Introduction

The aim of this study has been to provide the two sponsoring organisations, *Royal Blind Society of New South Wales* (RBS) and *Royal Institute for Deaf and Blind Children* (RIDBC) with information in a number of such specific areas as –

- the problems faced by clients and potential clients in obtaining information about, and access to, services;
- the ways in which needs are currently met;
- areas of unmet need;
- needs with regard to their education; and
- identification of areas which require further investigation.

### About children and adolescents with vision impairment in NSW and ACT

The first part of the study attempted to estimate the numbers of children and adolescents in New South Wales (NSW) and the Australian Capital Territory (ACT) likely to have vision impairment. Vision impairment was defined as blindness and vision problems which are not correctable by such aids as glasses. Data from Australian Bureau of Statistics indicate that approximately 7,000 children and adolescents in NSW may be affected and data from the Australian Institute of Health and Welfare suggest that 547 children and adolescents with vision impairment may have "severe" disabilities. The extent of vision impairment within such population groups as Indigenous people and people from non-English speaking backgrounds is unknown.

### Literature Review

An extensive literature review of the needs of children and adolescents, as stated by clients, drew on New Zealand, North American, British and Australian research. The review examined such broad areas of need as education and the several therapies. These broad areas of need changed as the child became older.

Initially, the needs of parents focused on problems related to identification of the child's impairment and the diagnosis. The treatment of parents by medical professionals, social workers and other hospital personnel and whether they gave parents helpful information were important issues.

After medical recognition of the impairments of babies and children, an intense period of therapies and other services were usually recommended which often generated concerns for parents. The location of services and interactions between parents and professionals and other service providers was a source of difficulty for many parents. This period, usually before the child started school, was one in which parents, particularly mothers, needed understanding from others.

The literature review also revealed the importance that parents placed on education which they wanted to be the best for their child in the school sector they had chosen. Parents whose child attended a "mainstream" school and parents whose child attended a special school or unit had concerns related to the teaching of disability-specific skills and the recognition by the school of the child's difficulties in particular curriculum areas, for example, mathematics and sport.

Attaining independence including travel skills were important needs for both adolescents and parents. Fear of road traffic and the need for orientation and mobility skills were repeated themes in both parent and adolescent responses to questionnaires.

Parents also raised concerns about the social and psychological wellbeing of their children and adolescents. Needs related to employment became important for adolescents. Needs for information about employment were widely expressed, but adolescents and their families did not know where to obtain it. Other needs were specific, for example, should the issue of impairment be raised at a job interview? After having attended special school, families were generally concerned that the young person should become involved, either in gainful employment of some sort, or in a program of community participation where skills would be improved and maintained. Need for the provision of further training opportunities was also expressed. These types of outcome were not always available.

Family relationship issues were also a recurrent theme in the literature. Some parents and adolescents mentioned the importance of (a) accessing technology and (b) information on a range of such subjects as medical treatments and sports for children with vision impairment.

### **The postal survey of clients.**

Data for the study were primarily obtained directly from client families in two ways: (a) through a postal survey and (b) through interviews.

The postal survey primarily employed the database of one organisation (since there was a close correspondence of client names on both organisational databases). Response to the survey (26%), yielded such data as, for example, the proportion of children and youth who had other disabilities in addition to vision impairment (52%), the most common medical diagnoses (cataract, congenital nystagmus, albinism and cortical visual impairment), the extent of the vision impairment (most parents described their child as having "partial sight"), languages spoken at home (91% spoke English only) and the current and future needs of parents (educational issues were those most nominated as concerns for both categories of respondent).

### **Interviews with client and non-client families**

Structured interviews were held with 31 families of clients and six "non-client" families (whose names were obtained by advertising for parents who were not clients of either organisation). Clients were invited to discuss what needs had arisen in the past and what needs they foresaw. Interviews were prompted by the interviewer raising issues that had been identified in the literature review. The aim of these interviews was to obtain data which were analysed qualitatively to yield explanations about the type and substance of respondent need. For example, what did respondents mean when they spoke of

particular needs?; in what ways did their "needs" arise?; what did respondents consider to be "good" solutions to their needs?, and what solutions did they consider inappropriate?. In the following section, the dominant themes of need which were identified from the interview data have been summarised.

## **Medical treatment**

When parents were first presented with the diagnosis that their child had a vision impairment, they generally expressed the desire that they had wanted an approach by medical and other associated professionals which recognised them as autonomous, caring adults. Of those interviewed, 43% wanted a "good" medical response to their child. This meant, for example, that in general, doctors should not try to persuade parents to institutionalise the baby. As further examples, it meant that medical students not invade parent privacy, that families be given information about the condition and community support organisations and as well, be given opportunities to ask questions.

A major need expressed by mothers who had the responsibility for children in hospital and children at home (49% of respondents), was that hospital administrators recognise those dual responsibilities and allow the mothers to negotiate the time they spent at the hospital.

It was further reported that children with multiple disabilities attending special schools and units in non-metropolitan areas, required a variety of therapies from school therapy teams, but for such reasons as lack of local "paediatric" therapists, these services were often not available.

A small number (8%) of parents and adolescents expressed concern at the slow recognition by medical practitioners of late onset vision impairment and its impact on families. Further, adolescents with these conditions expressed concern about the need for information on genetic counselling.

## **Personal feelings and relationships**

Approximately 70% of parents expressed themselves as worried or anxious about an aspect of their child's life. Many parents associated obtaining more information with allaying their anxiety. Parents expressed the need to establish a good understanding with their spouse (35% of respondents). However, when relationships between spouses deteriorated because of caring for their child with a vision impairment, or when the father distanced himself, parents were generally unaware of possible sources of help. At the time of diagnosis, many parents wanted contact with families who had a child with a similar impairment to their child but this need in some instances faded over time. Comparison between children of the severity of impairment and consequent disability occurred at some early intervention groups, producing ill-feeling among parents. Having to focus their attention on the child with the impairment, made a small number of respondents feel guilty about their treatment of the child's siblings and concerned that the siblings would resent the child with the impairment.

The psychological problems of children with vision impairments, for example, those "lacking in confidence" and those with "fearless and aggressive" behaviour, were a concern to some parents (51% of respondents) who lacked information on where they should turn for assistance. Similarly, many parents (54% of respondents), were concerned about teasing and bullying at school especially those

who were unsuccessful in having teasing and bullying stopped and who lacked information on where to turn to resolve the problem.

### **Respite, holidays, and recreation**

When parents used respite care, they acknowledged its benefits for themselves and also for their child. However, some families (27% of respondents) were unable to use respite when it was too expensive or when they lacked the room to accommodate a carer, or they wanted the carer to come into the family home but this form of respite care was unavailable. Holidays were a problem for only a few parents (8% of respondents). Those who took a child with multiple disabilities on vacation found that they generally worked throughout the vacation because assistance was unavailable away from the family home. Parents who had few or no "vacation care" programs in their local area or were unaware of these programs had to make special arrangements, for example, to take time off work to care for their child or adolescent.

Satisfying the need for suitable recreation for children and adolescents was a difficulty for 56% of the respondents. Children and adolescents participated in "mainstream" activities generally only if teachers and coaches had an attitude which promoted inclusion. Parents were pleased to have their child participate in recreation programs operated by disability organisations if these were carefully planned, operated by trained staff and if there were varied activities which interested the participants.

### **Mobility**

Some 86% of respondents expressed needs related to personal mobility and accessing the community. Meeting the mobility needs of non-ambulatory children was frequently hindered by stringent means tests imposed as part of such government support schemes as the Program of Aids for Disabled People (PADP). Safety concerns both inside and outside the home dominated parents' thoughts; adolescents' were also concerned about their safety and about becoming disoriented when in an unfamiliar place.

### **Education**

Some 76% of the parents who responded were concerned that their child received the best possible education, equal in quality to that which other students at the school received, although the child's learning mode might be substantially different. Outside the classroom, students with vision impairment wanted to mix equitably with their peers in an atmosphere free of harassment. However, some parents and adolescents (54% of respondents) reported having experienced teasing which ranged in intensity from "mild" to "severe", and some male students reported having experienced physical bullying.

### **Employment**

Casual part-time employment while at school, and future permanent employment were two issues which pre-occupied 31% of respondents in the adolescent group. Many students and parents reported that they (a) lacked information on the requirements of particular occupations, (b) successful strategies for acquainting employers of the impairment, (c) information on the assistance available for employers



and (d) assurance of the adolescents' placement in activity programs for students leaving special units and schools.

### **Financial assistance to meet the extra costs of disability**

The need for some form of financial assistance was expressed by 38% of respondents. Government assistance was reported to be restricted by age (for example in the Continence Aids Assistance Scheme) and by income levels (for example in PADP and the NSW Government Spectacles Program), except for the Child Disability Allowance which parents considered "meagre". The extra expense of a child's disabilities was, therefore, borne by families who responded to the child's need for equipment by deferring other avenues of expenditures (for example, dentistry), by having mothers who had not intended working prematurely, returning to employment and by seeking assistance from a variety of community service clubs.

### **Information**

The need of parents and adolescents for information was strong (70% of respondents), but parents generally perceived information sources to be scarce. They felt unable, for example, to ring professionals with the questions which arise some time after consultations. The Internet offered opportunities for information for "online" parents but did not provide information at the local level, for example, on where to seek help with managing a child's behaviour.

### **Conclusion**

Parents generally reported that they wanted to be in control of their child's primary and secondary care and to work in partnership with professionals and other service providers. Parents often themselves, without agency help, sought government financial assistance to help them in their caring role.

Throughout the interviews it was widely observed that parents from non-English speaking backgrounds often had an incomplete understanding of essential concepts (for example, respite care) and of the existence of certain types of services (for example, mobility and orientation training).

The ways in which Aboriginal and Torres Strait people wish their needs to be met has not been addressed in this study and should be the subject of further research.

## RECOMMENDATIONS

This research arose from a desire, expressed by the Chief Executive Officers of the two sponsoring agencies to work more closely and cooperatively on issues affecting children and youth and their families who form part of their agencies' clientele. One important conclusion arising from this needs analysis is the critical importance of both agencies working together to mutually address the many important areas of need that the research has revealed. It is therefore proposed that planning to this end be considered a core activity within each agency and the matter of further clarifying and implementing the 28 clusters of recommendations generated from the research be placed in the hands of an **Implementation Committee** comprised of designated senior managers from both of the sponsoring agencies. The chair of this committee might rotate between agencies, and the committee be given powers to initiate a number of time-limited working groups and task forces to examine and attempt to target and systematically address clusters of the recommendations, as well as be given power to coopt membership to these several working groups. The following recommendations derive from the needs study presented in Chapter 4 of this report. They are clustered under major headings to facilitate the implementation process .

### 1. Medical issues

The Implementation Committee should plan to:

- 1.1 Inform medical practitioners throughout the State of the importance of considering the needs of parents when a child has been diagnosed with vision impairment.
- 1.2 Seek input to medical students so that future practitioners are sensitised to the needs of parents and family members at the time of diagnosis.
- 1.3 Collect and publish parent and family stories on good practice at the time of diagnosis, the material to become a practical resource for "new" parents.

### 2. Genetic counselling

There is a need to:

- 2.1 Systematically inform parents and adolescents with vision impairment about the purpose and availability of genetic counselling.
- 2.2 Ensure that information on sources of genetic counselling are available at venues where adolescents with vision impairment are likely to visit or congregate, for example, teen camps.

### 3. Hospitals

There is a need to:

- 3.1 Increase links between community organisations concerned with vision impairment and professionals in hospitals.

- 3.2 Inform social workers in hospitals of the results of this research.
- 3.3 Seek input into the education of student nurses about the difficulties faced by parents.

#### **4. Therapy supports**

There is a need to:

- 4.1 Monitor the "phased implementation" of recommendations of the Review of Therapy Services (Lea Maher & Associates, 1998) for their effect on programs for children with vision impairment, and inform the parents of agency clients of that Review.
- 4.2 Increase links with school therapy teams.
- 4.3 Establish a standard practice that therapists working with children who are about to start school ensure, as much as possible, that their clients are referred via the principal to a school therapy team member who is fully briefed on the child's needs.
- 4.4 Ensure that therapists inform parents about school therapy and what steps parents might take if services are not currently available to them.
- 4.5 Consider responding to a call to tender for the provision of therapy services to school students with vision impairment, should there be a decision to organise therapy services for school students on an area basis (Lea Maher & Associates, 1998).
- 4.6 Verify that all funded services have a leaflet in plain English, detailing the entry and exit criteria for therapy and other services, descriptions of the way in which services are organised (i.e., based upon an Individual Service Plan and the "complaints" mechanisms that are currently available). Parents should be encouraged to request this information from all service providers.
- 4.7 Consider the need to play an increased advocacy role on behalf of school students with vision impairment.
- 4.8 Inform professionals on such issues as methods of writing useful "parent-friendly" reports.
- 4.9 Ensure that both parents are informed of the availability and content of therapy programs

#### **5. Counselling**

There is a need to:

- 5.1 Advise parents about the role of counsellors, psychologists, and social workers and where these services are available.

#### **6. Assistance from Social Workers**

There is a need to:

- 6.1 Inform hospital social workers of the role of the major organisations serving children with vision impairment and about the focus of relevant community organisations.



## **7. Aids and equipment**

There is a need to:

- 7.1 Provide comment to the Commonwealth and State Governments on such services as Contingence Aids Assistance Scheme (CAAS) and Program of Appliances for Disabled People (PADP).
- 7.2 Investigate ways in which information on the need for inexpensive, "child friendly" aids and appliances can be conveyed to relevant industries and seek representation on committees providing consumer-related advice to industry.

## **8. Enlarged print and taped books**

- 8.1 Make copies of this report available to librarians throughout the State.
- 8.2 Agency children's services staff, parents, and students should discuss the availability of attractive leisure reading for children with library staff.

## **9. Recognition of late-onset conditions**

There is a need to:

- 9.1 Facilitate parent and peer support for adolescents affected by late-onset vision impairment.

## **10. Reducing parental anxiety**

There is a need to:

- 10.1 Provide more information to parents of children with vision impairment.
- 10.2 Inquire regularly from parents about areas on which they might require further information, particularly where the needs are for information in languages other than English. Alternatively, parents could be informed of ways to obtain this information.

## **11. Relationship between spouses**

There is a need to:

- 11.1 Ensure that appropriate referrals for parent counselling are possible.
- 11.2 Investigate such strategies as groups or camps to specifically target fathers.

## **12. Parent support**

There is a need to:

- 12.1 Facilitate parents supporting each other using a variety of parent support models, for example, family social events.
- 12.2 Become more alert to the difficulties inherent in operating "mother's-only groups" and other support groups.

## **13. Regaining life control**

There is a need to:

- 13.1 Ensure that parents of children or babies with multiple disabilities are informed of sources of home help and respite.
- 13.2 Ensure that social workers and other professionals in contact with families monitor closely those in which there are children or babies with high support needs.

## **14. Needs of siblings**

There is a need to:

- 14.1 Review existing programs that address the needs of siblings.
- 14.2 Offer counselling for siblings by appropriately qualified staff.

## **15. Psychological needs**

There is a need to:

- 15.1 Provide parents with information on appropriate behaviour expectations.
- 15.2 Provide a wider variety of recreational activities for children and adolescents which stimulate confidence-building and assertiveness, for example, camps for primary school aged children.
- 15.3 Draw to the attention of the appropriate authorities the alleged general tolerance of teasing and bullying of students with disabilities in schools which was revealed in this research.
- 15.4 Educate parents on the existence of "anti-bullying" strategies.
- 15.5 Educate parents and adolescents about "discrimination" and the methods available to combat it.

## **16. Respite care**

There is a need to:

- 16.1 Check that parents, particularly those from non-English speaking backgrounds, understand the nature of respite care and its availability.

- 16.2 Actively support the establishment of a range of "best-practice" respite care options in local areas.
- 16.3 Actively support a policy of equitable access to respite care in which the costs of caring and the time available does not discriminate against the families of children and adolescents with high support needs.
- 16.4 Inform agencies which perform care services, for example, NSW Home Care, about the particular needs of children and adolescents with vision impairment and their families.

## **17. Holidays**

There is a need to:

- 17.1 Invite parents to contribute articles for newsletters on the ways in which they manage holidays so that these various methods can be shared with other parents.
- 17.2 Support proposals to extend quality vacation programs which would cater for children and adolescents with vision impairment.

## **18. Mobility**

There is a need to:

- 18.1 Ensure that families understand the nature of referral to such agencies as the Guide Dog Association of NSW & ACT.
- 18.2 Ensure that there is adequate information exchange with agencies providing orientation and mobility services.
- 18.3 Inform agency client families of the equipment and modifications available for caring for children at home and other related sources of technical assistance (for example, the Independent Living Centre at Royal Rehabilitation Centre, Ryde).
- 18.4 Remind client families periodically of the opportunities to continue orientation and mobility training.
- 18.5 Cooperatively with Guide Dogs Association of NSW and ACT, ensure that the community access needs of client families are included in representations to Local Government Access Committees.

## **19. Schooling needs**

There is a need to:

- 19.1 Provide opportunities for parents to meet with public and private education authorities in order that parents understand the education system's offerings to students with vision impairment.
- 19.2 Seek opportunities to represent and advocate for students with vision impairment at all levels of the education system.

## **20. Support from itinerant teachers**

There is a need to:

- 20.1 Support parents with information about educational possibilities for students with vision impairment through provision of guest speakers at family workshops and by making available informative reading material.
- 20.2 Encourage parent groups to write booklets for other parents based on their experiences with schools.

## **21. Interaction with peers**

There is need to:

- 21.1 Press education authorities to become more accountable for the implementation of policies directed at student harassment and discrimination.
- 21.2 Continue to work with children and parents on the problems associated with teasing and bullying at school.

## **22. Beyond school**

There is a need to:

- 22.1 Invite representative of tertiary institutions to publicise their support role for students with vision impairment who are entering tertiary education.
- 22.2 Conduct further research on the experiences of students with vision impairment in tertiary level education and beyond.
- 22.3 Invite students with vision impairment studying at tertiary level to talk to adolescents and parents about their experiences at tertiary level education.

## **23. Recreation**

There is a need to:

- 23.1 Publicise, for the information of parents and those working with children and adolescents with vision impairment, the variety of sports and recreational activities for children and adolescents and sources of community and government assistance.
- 23.2 Lobby for increased funding for recreational activities and holiday programs with a view to supporting these efforts.
- 23.3 Prepare parents, children and adolescents, when dealing with the emotional component of vision impairment, for the disappointment that is experienced when it is realised that particular sports cannot be played. Information on the range of activities which children and adolescents with vision impairment successfully undertake should be readily available.

## **24. Employment**

There is a need to:

- 24.1 Provide the best quality educational experience and careers advice for children and adolescents with vision impairment, so that their chances of employment are maximised.
- 24.2 Facilitate sharing between adolescents and employed people with vision impairment in which the latter group talk of such experiences as obtaining work, working and the types of equipment employers have provided.
- 24.3 Sponsor a project in which stories of people's employment experiences are collected and published in appropriate formats and which serve to inspire and inform other young people and parents.
- 24.4 Familiarise itinerant support teachers and career advisers with the concerns of parents and adolescents in relation to careers and employment for people with vision impairment.
- 24.5 Monitor the post-school experience of adolescents who leave special schools/units and, where necessary, advocate for the expansion of post-school options programs and employment support programs.

## **25. Extra costs of disabilities and government assistance**

There is a need to:

- 25.1 Lobby for extra financial assistance for families of children and young people who incur extra, unavoidable costs due to disability.
- 25.2 Examine the Review of PADP when this is released by the Department of Health and the Ageing & Disability Department and inform client families of its implications.
- 25.3 Check that parents from a non-English speaking background have been given information on community services and assistance in appropriate languages and formats.
- 25.4 Discuss with such personnel as ethnic community workers, ways in which they might work together to ensure that services reach people of non-English speaking background.

## **26. Information**

There is a need to:

- 26.1 Investigate means by which agency information can be made available to client families.
- 26.2 Develop reading lists of books and articles on topics which are identified by parents and adolescents. These could be made available through the Internet.
- 26.3 Make lists of recent articles and books, prepared by library staff, available to parents who request this service. These could be made available on Websites.
- 26.4 Encourage parents to exchange information with each other and, where possible, to resource each other.
- 26.5 In conjunction with ethnic community organisations, community organisations and government departments, provide information on eye conditions and community resources in community languages for individual clients.

## **27. Family membership**

There is a need to:

- 27.1 Take account of the needs of foster parents regarding respite care.
- 27.2 Offer information on the services of the major organisations serving children with vision impairment to adoption agencies.

## **28. General recommendations**

There is a need to:

- 28.1 Continue to model exemplary Individual Service Plans and other forms of quality practice.
- 28.2 Ensure that client families understand the role of the various professionals they encounter.
- 28.3 Undertake research with selected communities from non-English backgrounds.
- 28.4 Record or videotape information sessions and make these available to families in appropriate formats and through the Internet.
- 28.5 Further investigate models of co-operative research and ways of working with Aboriginal communities.

# **The Needs of Children and Young People (0 - 19 years) with Vision Impairment, in New South Wales and ACT**

## **1. INTRODUCTION**

### **Project aim**

The aim of this project was to examine the needs of children and adolescents with vision impairment (19 years and under) and their families in New South Wales.

### **Specific objectives**

- ♦ To provide information that will enable Royal Blind Society (RBS) and Royal Institute for Deaf and Blind Children (RIDBC) to evaluate, develop and promote their respective services.
- ♦ Identify problems for clients and potential clients (children and young people aged 0-19 years and their families) in obtaining information about services or in gaining access to services.
- ♦ Provide comprehensive information on the characteristics of those participating in the study, particularly focussing upon people of Aboriginal and of non-English speaking background.
- ♦ Examine the ways in which the needs of the State's population of children with vision impairment (and their families) are currently being met by disability and health agencies and other sources.
- ♦ Produce evidence of any unmet need(s) so that these may be addressed.
- ♦ Identify areas for further investigation.
- ♦ Extend and complement the information on people with vision impairment gathered in previous surveys.
- ♦ Provide information on current educational practice and processes, particularly as these are reported by parents and children.

### **Background to the project**

It is now "normal" practice for the majority of children with disabilities in Australia to live with their families at home. In the early 1980's, a shift in social policy towards "deinstitutionalisation" produced the demise of many large congregate facilities. The correct place for children with disabilities is currently, in most industrialised nations believed to be "integrated" with others in such generic facilities as schools and recreational programs.

Living in the community is, wherever possible, supported by services from a range of organisations, both government and non-government. In addition, financial support is available and aids and appliances may also be supplied. Most organisations require that applicants are "assessed" for their appropriateness to receive services and support. In some cases, assessment includes the financial capacity to pay for services or support.

Both the Commonwealth and New South Wales governments have introduced Disability Services Acts and Standards. The aim of these Acts has been to empower consumers of "disability services" to express their needs and to mandate that service providers become sensitive to these needs in what they offer and in the ways it is offered.

Mainstream organisations must also heed the needs of people with disabilities. Legislation operates at both the Commonwealth and State levels - respectively, the Commonwealth Disability Discrimination Act (DDA) and the New South Wales Anti-Discrimination Act (ADA) and Section 9 of the New South Wales Disability Services Act (DSA).

While these provisions operate for "people with disabilities", there exists little information on the needs of children and adolescents with vision impairment. Similarly, with the provision of "care" as the responsibility of families, service providers have little information on the needs of the families of the children and adolescents.

The focus of this project is to understand the needs of people in these groups and, with them, consider ways in which their needs can best be met.

### **The consumer movement**

This project is based on the opinions of "consumers". The "voice" of people with disabilities began to be heard in the early 1980's when the Commonwealth Government reviewed its "Handicapped Persons' Programs". That review highlighted the needs of disabled people who stated that they wanted to be treated as "people first", not seen as disabled, sick or different. They wanted to make decisions and take risks regarding their lives and they wanted to have "a say" in programs designed to meet their needs as well as in the management of these programs.

People with disabilities also spoke of their expectations of services. As a group, they stated that they wanted a place to live, paid employment, training and assistance in becoming competent and self reliant, as well as facilitation to participate in community activities. The fulfilment of these needs, it was believed, would result in people feeling secure, having choices and establishing an image which is regarded positively by others. People who were "*print handicapped*", in addition, mentioned the need for more early intervention for children and greater access to information, reading material or relevant aids (Report of the Handicapped Programs Review, 1985).

Since the late 1980's, people with disabilities have increased their political involvement. The "social model" of disability has been accepted by many Australians. This model, which many people with disabilities support on the basis of their own experiences and needs primarily, explains disability as "marginalisation" from society (Dejong & Lifchez, 1983; Oliver, 1990, Leipoldt, 1993). According to this explanation, the needs of people with disabilities may be summarised as "inclusion" in society



manifested by participation in all facets of social life, for example, in employment, education, politics, and culture.

## **Assumptions**

The assumption underlying this report is that the majority of Australian children and adolescents with vision impairment are currently being socialised in the family, in their schooling and elsewhere to be active participants in society when adults. This means they are being prepared to interact with others as equal, confident, autonomous beings with interpersonal and communication skills. As well, children and adolescents are acquiring skills likely to lead them to employment or the capacity to spend time meaningfully and to participate in recreational pursuits. This "apprenticeship" for adulthood is placed within the individual's chosen cultural milieu.

## **Overview of the project**

A detailed methodology for the project is presented as Appendix I. Briefly, there were two main parts to the project. The first part relied on a mailed questionnaire form. This was sent to clients on the RBS database. (A check of this database indicated that there was a significant overlap in clients of the two organisations). The questionnaires were completed by parents and in two cases, adolescents. This questionnaire furnished important information on characteristics of children and adolescents in the sample. Parents and adolescents also indicated their existing needs and what they expected their future needs would be.

The second part of the project was to interview participants and obtain greater clarification of the needs nominated in the questionnaires. These data were analysed qualitatively because this methodology yielded explanations rather than numeric data.

The project was overseen by a Steering Committee of senior officers of the two agencies who met regularly to advise the researcher. In addition, a project on the needs of Aboriginal people was undertaken.

This report contains a brief discussion of the incidence of vision impairment and a number of related matters. This is followed by a literature review of needs as nominated by people with vision impairment.

The results of the survey are presented in the following section. In the chapter which follows, a qualitative analysis of interviews is presented. The implications of particular "*needs*" are briefly discussed and this is followed by recommendations.

## **Definitions and terminology**

The term "*vision impairment*" has been used throughout the report to include blindness and vision problems which are not correctable by such aids as glasses. However, where an author in the literature review has specifically written "*blind people*" or has been in some other way categorical, this convention has been followed.

The definition of "need" in the project is generally - an experience of concern, some problem, some lack which one feels should be remedied or reduced in severity, irrespective of whether a remedy is available (Kelley & Gale, 1998 ).

Disability, as used in this report, was defined by the Australian Bureau of Statistics (1993) as *"the presence of one or more of a selected group of limitations, restrictions or impairments which had lasted, or were likely to last, for a period of six months or more"* (p.49).

## **Limitations**

The research has focused on *"vision impairment"* within a particular age group. Some of those with vision impairment have no other disabilities, some have one other and some have multiple disabilities. The severity of the additional disabilities is variable. The consequence is that the *"needs"* of some families have comparatively little relationship to *"vision impairment"* alone.

The ability of a researcher who is not from a non-English speaking background to form the necessary relationship required for interviews with parents from non-English speaking backgrounds is limited by language and perceived cultural differences. These problems are not overcome by the presence of an interpreter. The consequence is that there is a superficiality in the data that have been reported. This problem might be overcome by in-depth research on specific communities by researchers from the same ethnic background as those who participated.

Similar remarks apply to non-Aboriginal researchers attempting to interview Aboriginal people. Aboriginal people are also interested in participating in the design of *"solutions"* which follow from an identification of problems.

## **Children and adolescents with vision impairment in NSW**

Little information is available on the numbers of children and adolescents with vision impairment in NSW and on their circumstances. This section reports what is known.

## **Disadvantages**

In North America, children with vision impairment are considered a *"disadvantaged"* group within society (Chalifoux & Fagan, 1997). There have been no similar studies on the effect of vision impairment on Australian children, but it is likely that the conclusions of the Chalifoux and Fagan study are applicable. Those authors have argued that much of the disadvantage stems from factors other than sight disability.

One facet of childrens' disadvantage stems from lower-than-average family income, which is generally because only one parent is employed. This situation frequently arises from the *"care"* responsibilities of the mother which prevent her employment in paid work. While there is little direct evidence, lower family income usually results in poorer quality housing in less desirable areas. This affects education, ability to do homework. Living in a *"less desirable"* area can help to produce an over-protective environment for the child.

Children with vision impairment, Chalifoux and Fagan contended, often have educational deficits in disability-specific areas, for example, such inappropriate social behaviours as gaze, facial expressions, and eating skills as well as deficits in mainstream education ( for example, physical education, home economics and art). Moreover, many children with vision impairment are at risk of poor health. Many have health problems related to their disabilities but in addition they are, in general, less physically fit than sighted children (Chalifoux & Fagan, 1997). They also experience a number of factors (for example, isolation, fear of bodily harm) which have a negative impact on their mental health and which may result in bizarre behaviours (Chalifoux & Fagan, 1997).

In addition, it is likely that the family of children with vision impairment will experience difficulties because of the high rate of separation and divorce in families (Chalifoux & Fagan, 1997). Later, parents' fears can lead to over-protectiveness which limits the development of independent living skills. In Australia, there is little information on whether or not children and young adults with vision impairment, as a group, are disadvantaged. However, employment statistics indicate that young adults are handicapped in the labour market. Survey data (ABS, 1993) point to an unemployment rate of 55% of possible labour force participants (Table 1.1). This implies that unless positive action is taken, children with vision impairment stand a strong chance of unemployment. The lower participation rate of young women in the labour market also requires further investigation.

**Table 1.1: Labour force status by sex (Australia, 1993) for persons (15-24 years) with vision impairment, in households**

Labour force status	('000)		Persons N=15.0	
	Males N=11.7	Females N=3.3		
Labour force participants:				
- Employed	2.4	0.1	2.5	45%
- Unemployed	2.5	0.5	3.0	55%
Not in labour force	6.8	2.7	9.5	
Labourforce participation	42%	18%	36%	

Source: ABS Disability, Ageing and Carers - Visual Impairment, 1993, Cat. No. 4434.0.

### Incidence of vision impairment

Vision impairment and blindness are of comparatively low incidence in the Australian population. Survey data, based on self-reporting rather than clinical assessments, indicate that in 1993, approximately 18% of the Australian population had one or more disabilities and that 9 % of these had a sight disability (Australian Bureau of Statistics, 1993). For persons less than 15 years of age, 0.4 % of the total Australian population was estimated to have a sight disability. Table 1.2 shows an application of ABS percentages to the New South Wales population for ages relevant to this study.

**Table 1.2: Estimated numbers of NSW children with sight disability**

<b>Age group</b>	<b>NSW Population</b>	<b>0.4 % of population</b>
0-4 year	439,290	1,757
5-14	872,598	3,490
15-19	422,728	1,690
<b>TOTAL</b>	<b>1,734,616</b>	<b>6,938</b>

Source: ABS Regional Statistics, NSW, Cat. No. 1304.1, 1998 and ABS Disability, Ageing and Carers - Visual Impairment, 1993, Cat. No. 4434.0.

In the population under 15 years of age, ABS data indicate that males and females with vision impairment are of approximately even proportion but, from 15 years to 64 years, a higher proportion of males reported vision impairment. The numbers of young people 19 years and under with vision impairment are also presented in Table 1.3. These figures are derived from data collected by the Australian Institute of Health and Welfare (AIHW) for the Commonwealth/State Disability Agreement (CSDA) Minimum Data Set (MDS) they are likely to indicate only the numbers of young people with "severe" disabilities, given that the MDS is obtained from service providers who generally have entry criteria which direct services to those with moderate to high support needs. Many children's services do not appear in MDS since they do not receive Commonwealth funding.

The ABS (1991) Census recorded that 19% of people in New South Wales spoke English poorly or not at all. Information on service user indicate under-use of Home and Community Care programs and Disability Services Programs by people from non-English speaking backgrounds (AIHW, Minimum Data Set, 1998). The numbers of children and adolescents from non-English speaking backgrounds with vision impairment are unknown but the proportions are likely to be similar to that for all children and adolescents. Thus, there is the suggestion of under-use of services by children and young people with vision impairment by those who are "mainly non-English speaking".

The number of people who reported being of indigenous origin was 1.7 % of the NSW population (ABS, 1996). The numbers of children and adolescents with vision impairment in this percentage is not known. This is due, partly, to Aboriginal and Torres Strait Islander people not necessarily distinguishing disability from the hardships of life and, partly, to their shunning disability labels. The exceptions are such highly visible conditions as spinal cord injury (Gething, 1995; Mokak, 1997). Consequently there are few reliable statistics on disability within this particular population (Mokak, 1997).

**Table 1.3: Persons aged 19 or less with vision disability in New South Wales**

<b>Persons recorded with vision as primary disability</b>	
Vision as primary disability	112
Deafblind	14
<b>Persons with primary disability recorded as below but also having a vision disability</b>	
Developmental delay	98
Intellectual disability	192
Autism	7
Physical disability	58
Acquired brain injury	25
Hearing	4
Neurological	37
<b>TOTAL for both groups</b>	<b>547</b>

Source: AIHW, *New South Wales data for people with vision disability receiving CSDA services, aged 19 years and under*, unpublished data, 1998.

Whether or not Aboriginal young people and children have vision impairments to the same extent as non-indigenous people continues to be the subject of speculation. Evidence from the Northern Territory Education Department's Advisory Services for Children and Young People with Vision Impairment suggests that they have higher incidence but from the same range of causes (Mason & Gale, 1997).

The numbers of people with deafblindness are unknown in NSW, but Ward, who cites Queensland estimates of 10:100,000 persons, stated that there would, therefore, likely be 27 students in NSW (Ward, 1994). Little is known about Aboriginal people with this condition; similarly, few people of non-English speaking background are known to be deafblind.

### **Causes of vision impairment**

The World Health Organisation (WHO) divides the causes of blindness into those occurring at conception i.e. genetic diseases; those occurring in the intrauterine period e.g. rubella, those occurring

around birth e.g. retinopathy of prematurity and those occurring in childhood and adolescence e.g. Vitamin A deficiency and the Usher Syndrome group. The main causes of vision impairment in any community are determined by that community's socio-economic status. In such "Western" countries as Australia, the main causes are genetic, affecting the retina and optic nerve and retinopathy of prematurity associated with low weight babies (WHO, 1992).

Jan and Freeman (1998) are critical of the assumption that the main causes of vision impairment are ocular impairments. They have maintained that the underlying physiological cause of vision impairment has changed in recent years. There has been a drop in ocular-based vision impairments with brain damage, as a cause of sight disability, has increased due to the survival of more new born babies and critically ill children. These children often do not appear to be visually handicapped and when their eyes are examined they may be normal or have lesions (Groenvelde, Jan, & Leader, 1990). However, their vision is frequently residual, variable, even on an hourly basis, and changes sometimes improving or sometimes worsening with age (Morse, 1990).

The shift in causes of vision impairment away from ocular impairment to brain injury has major implications for service provision. Jan and Freeman (1998) questioned visual acuity measures as indicators of need, arguing that many children with reduced acuity fare comparatively well while others who can see function poorly. "Total absence of light might have been better than a severely disturbed and inefficient visual sense with good acuity" (Jan & Freeman, 1998). Moreover, they argued, educational services for vision impairment have been based on enriching the visual environment of a person with sight disability but frequently when the cause of the disability is brain damage the opposite treatment is required, namely restricting or controlling visual input. In addition, brain damage is frequently accompanied by other disabilities such as developmental delay and autism, which require different forms of service provision from those needed where vision impairment only is present.

The shift in causes of vision impairment has not been specifically discussed in the professional literature for Australia. However, the shift is likely to have occurred here because Australia has experienced advances in medical science and technology which have largely eliminated causes stemming from nutritional deficiencies and lack of public health, although these causes may still apply in Aboriginal communities (Taylor, 1997).

## **Summary**

American literature suggests that children and adolescents with vision impairment may live in disadvantaged social circumstances but this type of information for children and adolescents in NSW is unavailable. Statistics indicate, however, that in NSW adolescents with vision impairment experience high unemployment rates and low participation rates in the labourforce.

The incidence of vision impairment in the population under 15 years of age is low but this gradually increases with age. Many children and adolescents with vision impairment have other "severe" disabilities as indicated by data from AIHW. No data are available on numbers of children and adolescents from non-English speaking and Aboriginal and Torres Strait Islander backgrounds and it is tentatively assumed that they have at least similar incidence rates to those in the population in its entirety.

## 2. LITERATURE REVIEW

The literature review commences with a brief examination of the concept of "need".

In the following section, the review concentrates on vision impairment: the needs of adults, children and their parents and adolescents. Such specialised areas of need as mobility and new technology are then examined.

### About needs

Need is subjective and is shaped by many influences. To be able to express a need means that the need must be translated into a communicable form - that is, it must move from inner feeling and be articulated. This articulation may not only be affected by communication skills but also by a sense that the need will appear "legitimate" to the audience. What an individual states as a need is influenced, for example, by advertising or by promises of politicians or by the publicity surrounding medical advances. Needs also emerge in response to such personal circumstances as onset of illness and such external events as the closing of a service or cessation of transport. Need is closely related to personal financial resources but not all needs are material, for example, friendship and social contact are common needs of most people.

Personal beliefs, often religious in origin, may also affect what particular problems or misfortunes individuals may want recognised and addressed; others may wish to live not expressing any needs, "accepting God's will".

How people see themselves (which is influenced heavily by interactions with others), is also an important determinant of particular needs. People who see themselves as potential members of the workforce have different needs from those who view themselves as unable to work. Similarly, a person may indicate a particular "need" because it is seen as a means to an end they regard as important, for example, they might "need" a computer to enhance employment chances.

Although needs are highly personal and are continually changing for individuals, it is possible to discern themes in personal accounts so that a representation of needs for particular communities is developed. Further, it has been observed in numerous accounts of people with disabilities that their needs follow a similar "career" path which parallels such stages as diagnosis, grieving, searching for cures and treatment or, for children, developmental stages.

In addition to consumers' views on needs, two other social groups make pronouncements on needs. Each group expresses an opinion from a different position in relation to resources and priorities and this makes it unlikely that the views of the three parties will concur. This study provides an account of needs from the perspective of one group, service "consumers" - parents speaking for children and young people with vision impairments.

A second group, health and welfare professions, also form opinions on the needs of their clients or patients who include people with vision impairments. Professional opinions of need are usually technical and carry authority derived from specialised knowledge, the social status of the profession and often organisational authority. Most people find it difficult to dispute a professional opinion of need.



Service providers too, form views on the needs of people which are reflected in the services they offer. Lovelock (1995) has argued that in the United Kingdom a gap has formed between the services offered and the "felt needs" of people with vision impairment. He suggested several reasons for the gap. One reason is that many organisations have based their services on clients who are physically and mentally fit, with vision impairment as their only disability, an assumption which rendered many services of little benefit to those who have vision impairment and other impairments. Having only vision impairment is not the reality for many children and adolescents, as discussed later.

Lovelock also found that the "felt needs" of clients have not been represented in the organisational structure of many service organisations, thus allowing organisations to reflect interests other than client needs. A third reason for the gap between services offered by organisations and felt needs of clients was that agencies have traditionally concentrated on particular sets of needs and have masked others. It is therefore critical to ask how and why some needs are not met.

A fourth reason for the gap was that researchers investigating needs have often taken existing definitions and ways of meeting "needs" for granted and whether needs have changed over time has not been checked. These problems can be addressed by regular "needs" reviews and seeking the views of "non-users".

A fifth reason was that needs and their solutions are frequently framed as technical problems, which precludes other versions of needs and their solutions. Lovelock (1995) gave an example of the incompleteness of technical views of need by mobility officers in an organisation. They were surprised at the low motivation of their "students" until they gained an understanding of the meaning of mobility to the students and the range of things that impacted on their mobility. Lovelock acknowledged that some needs of blind people will fall outside the services of disability organisations. These needs must be met by other service providers in which case disability organisations, Lovelock argued, should play strong advocacy roles in respect of those needs.

In Australia, both the Commonwealth and State Disability Services Acts and their Standards have mandated that the opinion of consumers be heard both at individual service delivery and management levels. This means that it is now possible for the "felt needs" of consumers to affect organisational service delivery, although considerable difficulties may still exist for consumers in exerting meaningful influence (Drake, 1992).

A study of needs from the perspective of consumers may give the impression that people are passive, waiting for solutions to be given to them. This would be a misleading impression as in many cases people make adaptations to meet their needs but these may be at the expense of their health and time.

### **Needs of adults with vision impairments**

This section of the review will present an examination of literature on the needs of adults with vision impairment.

Not all people with vision impairment view themselves as in "need" and requiring services from community agencies. Josephson (1968), interviewed 684 blind people over 21 years of age living in four different states of the United States and noted that 42 % of his total sample required help - in the form of "services" - but the majority who did not accept help - "the unaided" - had either no needs or left



their needs unstated. The "needs" of those using services were for financial aid, medical treatment, help with travelling, housework, shopping and vocational training. Other problem areas included mobility, dependence on others, social isolation and coping with sighted people. Josephson argued that social policies often regarded blind people as helpless and dependent and hence many reacted in helpless and dependent ways, not seeking work and becoming isolated.

In a study by Moore (1987), for Royal Guide Dogs for the Blind Associations of Australia, people with vision impairment described "practical or basic" needs which contrasted with the more theoretical or psychological needs attributed to them by rehabilitation professionals. In common with Josephson's respondents, the quality of interactions with others was a major concern, with many people stating that they were treated as "stereotypes" rather than individuals. Many needs related to independence, for example, more aids for independent mobility. Alleviation of financial strain and more information on entitlements and resources also emerged as important needs. Many people wanted to be employed in permanent, meaningful work and asked for assistance to obtain employment. Skill to enable social acceptance and end loneliness was also an area of expressed need. Other needs centred on communication, for example, a need for current magazines in braille.

People also expressed a strong desire for changes in public attitude; in particular, that the public increase in understanding. A need for the medical profession to refer people to community agencies was also expressed. Community agencies, some respondents stated, should overcome their rivalries and their paternalism and cross-refer clients (Moore, 1987).

Royal Blind Society of NSW (1996) conducted a major survey of the needs of adults who are blind or vision impaired. This gathered the opinions of 517 clients of the Society and 220 non-clients and included people from non-English speaking background as well as "solid" representation from people living in country areas. Approximately 64% of respondents were over 65 years of age and the needs of many were complicated by such factors as hearing loss and the presence of other health or disabling conditions.

Survey data indicated that the needs of many people related to accessing everyday information - they had difficulty reading ordinary print in, for example, newspapers and telephone directories. Similarly, people were restricted in their ability to travel, to shop and to use such community facilities as "automatic teller machines" while at home, many experienced difficulties with housework and meal preparation.

Independence and family support were highly valued. The family was the main source of help, although 25 % of respondents lived alone. Respondents used comparatively few community services. Many feared placement in nursing homes.

Ward (1994), examined the needs of deafblind people (adults and children) in Australia. Ageing parents of deafblind people who were living at home had a strong desire to have their deafblind children settled and living independently in the community. Parents of younger deafblind people stated that there was a general lack of respite support for parents.

Educational issues were a concern in the Ward report, although New South Wales has "high quality education programs from early intervention to school leaving, based on individual assessments" (p.23), at Royal Institute for Deaf and Blind Children. Ward was primarily concerned that the educational

philosophy of developing programs based on educational need rather than a student's disabilities would disadvantage many deafblind students who can only develop adequately with one-to-one support.

Employment opportunities for deafblind people are scarce. In Australia in 1994, 68 deafblind people were known to be employed; half of these in Victoria (Ward, 1994). Access to technical aids and access to telecommunication and information were also recognised as significant needs.

## **Summary**

This brief survey of the needs of adults with visual impairment is important because it illustrates what might be the future for children and adolescents unless appropriate measures in education, training and other areas are implemented. Employment, as a factor, appears pivotal to quality of life and the avoidance of poverty.

## **Needs of parents and children with vision impairments**

### The initial diagnosis and following events

For many parents, the first set of "needs" they encounter relates to the diagnosis and events immediately following the birth of their child. A conference of mothers of disabled children emphasised that parents want honesty and sensitivity from medical professionals, with delay between birth and diagnosis minimised. They also want as much written information as possible given to parents (Steinberg, 1981). These particular needs including written information, continue to be reiterated (Godridge, 1996; RNIB & LOOK, 1996).

A study of 51 Western Sydney families of children with severe disabilities including sight disability by Rees & Emerson (1984) identified from parents' comments three factors that were important to them at this time. These were: (1) whether those conveying the diagnosis (usually medical specialists) were sympathetic; (2) whether they were helpful, that is, they answered questions and gave information, and (3) whether parents were given referrals to other services. Parents also expected sensitivity and privacy from medical professionals and that professionals would wait until both parents were present before conveying "bad news" (Rees & Emerson, 1984). They also expected that student doctors and others would absent themselves at "sensitive" moments, for example, when a diagnosis is given (RNIB, 1996). Moreover, parents also wanted the mother and baby accepted and supported by hospital staff who had, in some cases, avoided or rejected them (Rees & Emerson, 1984; Steinberg, 1981.)

In addition to information from professionals, a common need after diagnosis in Australia, United Kingdom and North America was to meet other parents who had a child with a similar disability, a need which is seldom met (Rees & Emerson, 1984; RNIB, 1996). Although some parents were offered formal counselling, parents stated that they wanted informality, practical help and support (RNIB & LOOK, 1996; RNIB, 1996; Walker, Tobin & McKennell, 1992).

Parents also pointed out that there were often difficulties in having their opinions listened to and in having their observations investigated by professionals. This was particularly the case when impairment was not diagnosed at birth but gradually became apparent months or years after the birth (Rees & Emerson, 1984; RNIB, 1996).



Rees and Emerson found that, after diagnosis, parents wanted prompt referrals not only to other medical services but also to community services. However, medical referrals were usually to other medical services (doctors and the therapies - physiotherapy, occupational therapy, and speech therapy). In hospitals after birth, parents expected that social workers would pass information on to them regarding community services, but social workers often did not meet the parents. When diagnoses were made at outpatient clinics, information about community services was similarly overlooked. The effect of this lack of awareness of community services was that parents were needlessly kept without information, and possibly without services, for long periods. In 1984, Rees and Emerson estimated that unreferral parents took an average of 10 months to "discover" community services.

The period after diagnosis is usually filled with many medical appointments. Parents needed these services to be available locally in a "one stop shop" but often discovered the services they had been advised were "important" were not available or they had to have their name on a waiting list (Llewellyn, Dunn, Fante, Turnbull and Grace, 1996; Rees & Emerson, 1984). Moreover, the treatment centres were distant, sometimes each treatment at a different location, and it was necessary to travel several times a week to these locations. These situations forced some families to buy second cars or eventually, if travelling on public transport, to "give in" and not attend (Rees & Emerson, 1984).

Parents expected that professionals would treat them with respect, be interested in their child and heed parental observations. Murphy's study (1992), which involved semi-structured interviews of 20 parents of children from seven months to four years of age with more than one disability, one of which was a "significant sensory impairment" indicated that relationships between parents and professionals were a concern to many parents, although the relationship usually improved as parents gained more experience (Murphy, 1992).

Parents expressed satisfaction with professionals when the professional was warm and spontaneous and there was equality in the relationship and interest and responsibility was maintained in the case (Rees & Emerson, 1984). However, the behaviour of many professionals disturbed parents. One aspect related to professionals treating parents as, what was perceived as, "inferior" and "lacking in respect" (Murphy, 1992). Professionals were often late for or cancelled appointments. They disbelieved parents and were not always accepted and treated with respect. Another disturbing aspect occurred when professionals disregarded the need of parents to feel in control of services for their child. Parents were embarrassed when asked to state "goals" without prior notice of the question or when explanations of professionals' roles were not given to parents. On the other hand, some parents acknowledged support from therapists, particularly in the period following diagnosis.

Parents accepted that therapy would benefit their child but they wanted therapists to consider the busy schedules of parents. When designing programs, some parents felt under pressure to carry out therapy programs with their child while others were less conscientious; for some mothers fitting in home therapy sessions added to their stress (Rees & Emerson, 1984). Murphy (1992) stated that families in her study wanted ideas on activities to do with their child "in a low pressured way". This need is supported in Jordan's study (1998) of what information parents find useful. In this study of 10 parents who had children with multiple impairments including vision impairments, parents stated the most useful information was practical suggestions - ideas for visual stimulation, sensory stimulation, play activities and mobility. Murphy also found that there is a need for parents to be consulted on programs. Parents felt insufficiently consulted on program directions and activities and whether these fitted into

the family's routine; consequently, many parents rejected the professional input when left to implement it (Murphy, 1992).

Nagel (1997) collected the "stories" of 10 New Zealand families with a child or young adult with vision impairment and these have been analysed by the researcher of the project for "needs". The analysis reveals that parents want more information from professionals. Three parents said they would have welcomed information on how to "handle a difficult baby", and other practical matters, for example, "how to get a child to eat tidily". Moreover, parents from non-English speaking backgrounds pointed out that culturally it was difficult for some social groups to ask questions of professionals. These parents also echoed the "lack of respect" theme that Murphy had encountered and they stated "honesty" and "respect" and admissions by professionals of "I don't know" were valued.

New Zealand parents also expressed concern regarding the negative approach of many professionals. Parents wanted their child's developmental problems approached positively, building on the child's abilities, allowing hope (Nagel, 1997). Many parents saw developmental assessments as negative because they focused on children's deficits and disregarded the unique developmental mode of children with vision impairment (Nagel, 1997; Murphy, 1992; Davidson & Simmons, 1992).

A recurrent theme for parents in Nagel's accounts is the need for professionals to have "child centred" approaches and treatments. Keeping children waiting long periods in consultants' rooms, asking toddlers to wear heavy, thick glasses, impatient assistants to ophthalmologists and children who became bored and restless were difficult mixtures. There seemed to be little understanding of children as patients.

The difficulties of travelling to professionals are overcome when community organisations send their professionals to the family home. MacDonagh's (1996) survey of the parents of 161 children and young people (0-25 years) in the United Kingdom found the sense of complete "abandonment" experienced by mothers after diagnosis in the seventies was less likely to occur in the nineties because specialist teachers from the local education authority visited the home. However, many parents found the visits unsatisfactory. They were viewed as irregular and unreliable and the quality of the help was "arbitrary" because it bore no relationship to the "severity of the vision impairment" or "degree of parental desperation" (MacDonagh, 1996). Many parents found the development of local support groups where parents were both givers and receivers of help to be of benefit.

### Family stress

Parents, particularly mothers to whom the major caring role fell, wanted to feel free of tension as they cared for their child. However, many mothers interpreted their experiences as stressful (Rees & Emerson, 1984). Physical tiredness was one component of stress; another was anxiety about living up to expectations of a "good mother" or a "good wife" and having a "normal" family (Murphy, 1992; Rees & Emerson, 1984; Voysey, 1975).

Continued support, understanding and acceptance from the friends and families of parents was an important need. In four out of ten family stories collected by Nagel (1997), grandparents and other close relatives of the child were a source of stress with calls to institutionalise the child, stating that the child was cursed and a source of shame, or making querulous statements that "it [the impairment] doesn't come from our side" and grandparents themselves requiring comfort over the birth (Nagel,

1997). Over time, these differences were often reconciled but equally, over time, enthusiastic offers of family support waned, with relatives having to be asked rather than offering. In many cases families found their friends gradually distanced themselves although some parents also avoided relatives and friends. Rees and Emerson (1984) argued that avoidance was related to parents having no clear understanding of the original diagnosis and of the implication of the child's disability.

### Extra costs

The fourth component of mothers' stress identified by Rees and Emerson was concern about extra financial costs. This topic will be further discussed, below. At this point, it is important to note that the literature suggests that there is likely to be less stress in certain households: those where parents are supportive of each other and are supported by families and friends, where there are high, secure incomes and large well furnished houses (Rees & Emerson, 1984).

There is general agreement that extra costs are borne by families who have a child with a disability (Mathews, Graham & Doyle, 1988; Llewellyn, et al., 1996; Rees & Emerson, 1984). In their study, Mathews et al. interviewed 50 Sydney families receiving Child Disability Allowance for their adolescent children about the impact of disability on family resources. Expenditure was divided into direct costs (extra expenditure identified by families which had a mean value of \$1560 per family [1986 prices]) and quality of life costs, for example, private school fees, education or communication equipment and private health insurance. Expenditure was highest for children with moderate to severe mobility problems, incontinence or self care problems. The number of prescribed drugs also affected costs. The indirect cost of the child's disability was also high in that over half of the mothers were not working because of the need to be available to care for the child (Mathews et al., 1988). Moreover, parents' expenses were exacerbated by the "tightness" of means tests and the lack of childcare for older children with disabilities. Parents were divided over the best way to address their needs, with poorer families supporting cash benefits and richer families preferring services.

Earlier, Rees and Emerson (1984) found a similar picture of expenditure for children under five years. Medical insurance was needed to afford such services as physiotherapy when not available through community services and to ensure "good treatment if there's a crisis". Many special schools required the payment of fees and a number of parents enrolled their child in special programs. Education aids, respite care, special foods and extra clothes were other costs. Like the older group, children often lacked access to childcare and pre-schools because centres felt unable to care for a child with a disability.

### Information for the future

Parents have a strong desire to understand the future options for their child, to reduce uncertainty and to have a sense of control. This manifests itself in an appetite for more information about events which may affect their children in the future. Godridge (1996), a parent, admitted that she knew little about such developmental needs of blind babies as the need to help develop walking, and found information hard to locate. Barton (1997), concerned about her son's future employment, visited worksites for blind people; similarly, the parents of another child were keen that she should "contribute to society" and looked at future options for work (Cuthbertson, 1991). In the survey of 122 parents (RBS, 1996a) parents indicated their need for more information and to hear about other people's experiences on a range of such issues as employment and medical matters. Further, parents wanted to understand what

their child could and could not see, so that they could evaluate safe and dangerous situations and understand the child's behaviour. Rees & Emerson found parents concerned that their child would be institutionalised on their deaths. Parents were planning for their child's future living arrangements, for example, purchasing a home with other parents and making investments for its running costs; This was also a concern of New Zealand parents (Nagel, 1997). In addition, mothers wanted genetic information to guide them with family planning (Steinberg, 1981; Ahmad & Atkin, 1996).

### Parents supporting parents

A constant theme in parents' expression of their needs, especially in the period following diagnosis, was the need to meet with other parents. Often parents wanted more sustained contact with a number of families in the form of parent support groups. From their experience in these groups many parents learned about resources and social policies and progressed to roles as activists and advocates for children with disabilities (Darling, 1988).

The low incidence of vision impairment, as well as the numerous diagnostic categories within vision impairment and the presence of other impairments complicated placing parents in contact with each other and forming parent support groups. In Australia, distances in non-metropolitan areas between parents are also likely to deter people from meeting. Yet, parents "searched" for another child with the same diagnosis in Australia and other countries (Nagel, 1997). In the absence of a local support group in England, Williams (1997) turned to the Internet to "meet" other parents and "to be able to liaise and compare experiences" after the "numbing devastation" of the diagnosis of his child.

Nixon (1988) argued on the basis of his qualitative analysis of interviews of 33 parents and 35 professionals in the United States, that whether parents benefit from support groups depends on a number of factors. First, parents join groups for a range of reasons - emotional support, "information seeking", the opportunity to help others and to feel "needed", to "grumble" about service gaps and to plan advocacy and political action. Obviously, the closer the fit between parent needs and the group's focus, the more beneficial the group. Differences in male and female needs exist, according to Nixon, so that mixed gender emotional support groups brought together variable capacities for "openness" and "self-disclosure" as well as different purposes for attending a parent support group. Moreover, the need to participate in parent support groups waned for many people for various reasons. Second, marginalised social groups such as the poor, those with limited education, people from ethnic groups rarely joined parent-support groups; the joiners were those already likely to have social supports (Nixon, 1988).

Some parents felt no need for parent support groups. In some cases this was because parents viewed their child's condition as "unique" and thus felt it useless to talk to other parents. Some parents stated they would have found groups useful when their child was young but now no longer felt any need. Other parents wanted to orientate themselves to mainstream activities. Afro-American families and Asian families also had not joined any groups. The former felt "alienated" and unable to trust recommendations of white authorities; Asian families seemed excluded by language, social and cultural barriers (Nixon, 1988).

A further reason why parents may state they have no need for parent support groups may be because they hear and see later stages of a deteriorating condition such as neurofibromatosis which is



uncomfortable (Llewellyn, et al., 1996). For other parents, such deteriorating conditions as gradual loss of vision increased the need for support groups for children (RBS, 1996a).

## Education

All parents wanted the best possible education for their child and this concern was maintained to tertiary levels. This concern was so important that some parents moved the whole family to be closer to educational facilities. There are no data on the views of NSW parents on the pre-school period.

Overseas, studies have shown that parents are concerned at the lack of information on their educational choices (Nagel, 1997; RNIB(a), 1996; RNIB(b), 1996). Whether the child would go to a special or "mainstream" school and, if the latter, finding a school with no prejudice, and helpful, supportive and enthusiastic teachers was a task for New Zealand parents (Nagel, 1997). In a survey by Royal National Institute for the Blind (RNIB(b), 1996), parents in England wanted practical knowledge about schooling, for example, whether children would learn braille and what technologies they would use. Some of the 56 parents in a Scottish survey wanted "objective information" on educational choices from sources independent of schools; the role of voluntary organisations, for example, advising parents to visit schools was welcomed (RNIB(a), 1996). In the United States, parents enrolling children at public schools had three main questions for school authorities: how education would be implemented, how safety would be ensured, and how children acquired special skills unique to their situation; in addition, parents had to begin learning the role of the state, sources of funding and resources (Barton, 1997).

Some New Zealand parents wanted their child in the integrated classroom to have equality of educational opportunities with other students and they reasoned that this required some different and extra educational input to achieve this outcome (Nagel, 1997). This input was important not only for long term effects on the child's life chances but also for the short-term consequences. However, an analysis of the experiences of the families shows that the quality of their education was highly variable.

Parents needed visible signs that teachers were making efforts to ensure their child could learn (Nagel, 1997). Thus, parents interpreted teachers who "consistently" forgot tasks required to ensure their child's participation, for example, enlarging "handouts" for lessons, as spoiling their child's chances; they contrasted these teachers with ones who always remembered to "shut the curtains and use the right coloured chalk or pens". Parents in NSW reported that children who could not see became bored, misbehaved and had trouble following instructions; sometimes they cheated - probably to minimise attention from teachers (RBS, 1996a). In the United States, Barton observed that her son also encountered some teachers who were unwilling to "move away from their visual teaching styles" (Barton, 1997).

In New Zealand, parents expecting that their child would learn at school checked for signs of this occurring. Sometimes, parents suspected that school was "no better than baby-sitting" and the child was "parroting" rather than understanding schoolwork. Moreover, parents of a New Zealand student with blindness and brain damage argued that their child was "neglected" in the mainstream classroom (Nagel, 1997).

Parents were concerned that the school environment did not act sympathetically towards the needs of their child. Resource teachers did not advocate on behalf of their child but distanced themselves,

leaving advocacy to parents (Nagel, 1997). Further, the administration within schools had failed to develop mechanism for informing relief teachers of students' special needs so that the lessons of relief teachers were a "waste of time" (Nagel, 1997). The withdrawal of "peripatetic" teacher services from a beginning student's class (Godridge, 1996), and insufficient service by itinerant support teachers (RBS, 1996a) were further evidence of the actions of some schools having disregarded the child's learning needs.

Some parents not only want teachers in mainstream environments to accommodate the needs of their child but they want teachers to go further and understand the difficulties of vision impairment, for example, fluctuating vision (Nagel, 1997). The reason for this was not clear but presumably parents believed that teachers would then anticipate difficulties which would reduce the parental "advocacy" required. A further element of teacher's understanding related to what one parent referred to as her child's "lack of concept development". This parent was concerned that teachers saw her child as "intellectually handicapped - without realising what it's like not to have concepts developed". Other parents were concerned that teachers did not realise that their child had expressive language skills but lacked commensurate comprehension (Nagel, 1997).

Both New Zealand and American parents wanted students taught "disability specific skills", for example, daily living skills, orientation and mobility and keyboard skills within their integrated environments (Nagel, 1997; Barton, 1997). Hatlen (1990) contended that integrated students in the United States were "academic automatons" with no life skills and no career and vocational skills. This problem, he argued, was caused by overlooking the "unique needs" of students with vision impairment which must be approached on an individual basis. Similar questions have been raised about education in Australia's Northern Territory (Gale, 1994). She argued that good quality education is delivered but the "disability-specific" needs are hard to address effectively.

While some children remained at special schools, others moved on to secondary school where, in all countries, the number of teachers that is necessary to alert to students' special needs increased dramatically, the work became harder and homework was more demanding. Again, parents had to "select" a high school which they believed would best serve their child's interests; some high schools chosen by parents, however, stated that they did not want the student (Nagel, 1997; Barton, 1997). When a school accepted their child, many parents, to be assured the teachers understood the needs of their child, themselves embarked on educating school staff (Barton, 1997).

As in primary school, parents expected that students with vision impairment would receive education that enabled them to have educational opportunities equal to their peers. At the same time, students and their parents needed recognition that many homework tasks, for example, projects and mathematics took longer for a student with vision impairment than for a sighted student and this required negotiation for extra time or other arrangements (Barton, 1997). Sacks and Wolfe's (1990) ethnographic study of three adolescents with vision impairment indicated that for academic success students required additional time and assistance from teachers, parents and para-professionals to complete their homework and projects. (Wolfe & Sacks, 1997; Sacks & Wolfe, 1998).

Students also needed recognition of their difficulties in studying mathematics. Affected students were less likely to take higher mathematics at senior levels in high school and blind and partial sighted students took longer than sighted students to read the questions. In addition, they were often disadvantaged in "graphical-spatial topics" and in reading sub-and super-scripts and brackets,



especially in braille notation. In contrast to sighted students, they were less likely to have difficulties with the conceptual aspects of mathematics.

Two accounts written by adolescents of their needs, stress the importance of the attitudes of non-disabled people to disabled people, particularly those influencing education. Ireland (1993) argued for a more positive attitude from the "so called experts in the primary years of education" and additional opportunities in education so that people with disabilities can contribute to society. Similarly, Auges (1997) contended that people with disabilities want their abilities and the fact that they are "normal" emphasised. Both adolescents traced the source of negative attitudes to professionals. Ireland claims their negative attitudes filtered through to the family, eventually making it hard for the adolescent to feel positive. Auges observed that professionals allocated little time to listen to her parents.

### Harassment

Many parents saw a need for schools to develop an atmosphere which is free of teasing and bullying. These harassments which are a disadvantage of mainstream education occur commonly (Nagel, 1997; RNIB, 1996; RBS, 1996a) but can be prevented. In the parents' view, the pivotal factor is the attitude of the principal who may interpret teasing and bullying negatively or as "character-building" and therefore not to be prevented (Nagel, 1996; RNIB, 1996). In the RBS (1996a) survey of children of primary school age, 45 of 122 parents (36%) commented on these harassments. This is likely to be an underestimate as not all parents would be aware of the occurrence of harassment. Apart from the effects on the child or adolescent, parents who helped their child deal with effects reported that this is an area on which they needed advice. Moreover, parents were angered when bullying resulted in broken property (e.g., glasses) and they had to meet this expense (RBS, 1996a).

### Social skills

The development of social skills and social networks by their children with vision impairment is regarded by parents as an important need. The expressions of two parents that they want their children to grow up "confident, happy and feel good about [themselves]" and "First, we want Kate to have friends" epitomised the wishes of parents (Godridge, 1996; Cuthbertson, 1991). The reality for many children, though, is quite different according to the RBS (1996a) survey of parents of primary aged children. This indicated a number of problems for children: exclusion from play with peers (30 % of respondents), not mixing with peers (28 %), not making friends (21%); elsewhere, parents stated that their children were never invited to the homes of peers. Given this picture and the school harassment which appears widespread, it would be surprising if self-esteem and self-confidence of children and adolescence were not damaged. It is likely that the social attitudes felt by the children and adolescents are the genesis of the low self-esteem and lack of assertiveness which Downie observed in high proportions of clients of a large blindness rehabilitation agency (Downie, 1993).

Adolescents who are "mainstreamed" in their education express a need to "normalise" their experiences by meeting with other young people with vision impairment. At a pilot peer support program at Homai College, New Zealand, many adolescents stated that they were the only students with vision impairment within their schools. Because they missed contact with other students having similar experiences and problems, they resolved to keep in contact with each other (Nagel & Skilton, 1995). Similarly, "mainstreamed" adolescents have been reported as more "relaxed" in the company of others with vision impairment and as spending much time maintaining their networks by phone each

day (Sacks & Wolfe, 1998; Wolfe & Sacks, 1997; Barton, 1997). The fact that many students with vision impairment are isolated from similar others and are predominantly mixing with sighted students undoubtedly leads to their reluctance to use adaptive computers and other technical devices in the classroom, as observed by Wolfe and Sacks (1997).

### Recreation and leisure

The need for children and adolescents to participate in recreational activities after school, during weekends and holidays has been generally recognised. Wolfe & Sacks (1997) found limited opportunities for social integration and acceptance of vision impaired adolescents into activities with sighted adolescents. In addition, the preferences of adolescents with vision impairment were not clear. If there was likelihood of acceptance in such mainstream activities as football and soccer, then most children and adolescents tried for acceptance. If the judgement was wrong, however, the participants had to recognise this and retire or risk criticism from fellow players (RBS, 1996a). Parents also sought an alternate mainstream activity for their child when the child's peers were joining teams for ballgames (Barton, 1997). The scarcity of recreational activities for children and adolescents with disabilities was worsened by the severity of vision impairment and ballgames were generally not played by blind children (RBS, 1996a). Participation in activities was also affected by the presence of other disabilities, for example, behaviour problems, and parents expressed their disapproval of holiday activities that were designated for those "only blind" (Walker, et al., 1992; Nagel, 1997).

The lack of recreational activities available for children and adolescents with disabilities produced certain predictable patterns of time use. Of the three groups, blind, low vision and sighted, in the Wolfe and Sacks (1997) study, adolescents with vision impairment were most likely to engage in passive activities, with low vision adolescents spending most time passively and also sleeping more hours than the other two groups. Similarly, Sacks and Wolfe (1998), in their ethnographic study of three students, observed that students spent more time alone or on the phone or in other sedentary activities compared with sighted students. Parents pointed out that if organised recreational activities for children and young people were unavailable or the workers at services were insufficiently skilled, as evaluated by parents, then providing recreation became a family task. This was often difficult because of the ages and interests of siblings or because of behavioural problems (Nagel, 1997). Parents investigating community housing for their child in the future noted that lack of recreational activities continued in adult life as residents appeared idle.

### Independence, orientation and mobility

Many parents in the above studies indicated the need for their child to attain independence (Nagel, 1997; Barton, 1997; RBS, 1996a). Included in the "independence" concept, is "getting a job" or "being productive", "looking after themselves", "moving out of home" "even if it's into a granny flat" and "not having to rely on others". With adolescents and children with such additional disabilities as intellectual disability, cerebral palsy, hemiplegia or deafblindness, parents felt they had to put extra effort into moving towards independence. Parents looked to school education to help develop independence through daily living skills and orientation and mobility training. Conversely, some parents were aware of their child learning "helplessness" from other children or from lowered expectations by teachers or helpers and took firm steps to prevent this happening (Cuthbertson, 1991; Nagel, 1997).

The development of independent travel abilities is very important to both blind and partially sighted people (Johnson & Petrie, 1998). Acquiring orientation and mobility skills provoked anxiety in parents because the acquisition competed for time spent on academic skills or holiday relaxation and because parents worried about the street dangers and "getting lost" (Barton, 1997). Moreover, when 139 children and young people (6-16 years of age) with vision impairment and additional "handicapping conditions" were asked about their fears, being hit by a car or truck was foremost (Wilhelm, 1986). The acquisition of skills and confidence is related, in part, to parent protectiveness, encouragement of independent travel and socialising after school; once young people have acquired the skills and confidence they travel regularly (Sacks & Wolfe, 1998).

### Employment issues

Concerns about employment preoccupy older adolescents. When adolescents with vision impairment (13-20 years) in a peer support program in New Zealand were asked to nominate their needs, most responses related to employment. Adolescents wanted increased information on courses to take to prepare them for work, increased knowledge of training and educational opportunities after school and increased information on jobs (Nagel & Skilton, 1995). This argument is supported by Auges (1997), who added that adolescents also require assistance in aspects of interacting with non-disabled people. The job choices of adolescents appear to reflect the experiences of many adolescents, with 31 % selecting "the helping professions" (Tobin & Hill, 1988). Many adolescents in the study had entertained more ambitious ideals than they eventually selected to follow: e.g. one young woman who wanted to be a nurse changed to a receptionist or typist. The process which led young people to move away from the original choices was not explored in this research.

Adolescents also felt the need to obtain part-time work or at least a job over the summer holidays. This was a concern in the United States but it is becoming increasingly important for Australian adolescents. Some young American adolescents with vision impairment were able to find work through excelling at a hobby; others were offered opportunities. Many adolescents trying for jobs experienced parents refusing permission or rejection by employers worried by "safety" considerations (Barton, 1997; Sack & Wolfe, 1998). Wolfe and Sacks' (1997) study compared the work experiences of blind, low vision and sighted students, aged 15 to 21 years. Almost all had worked - 88 % of blind students and 94 % of sighted students. However, 81 % of the sighted students had found their own jobs, which contrasted with only 19 % of the blind students and 31 % with low vision. In the occupational categories of the jobs of the three student groups, sighted students were distributed evenly across a range of work activities where the other groups were concentrated into few categories (clerical, telephone and reception work).

For students who attended special schools, the vagueness of their future distressed parents. In the stories of New Zealand families (Nagel, 1997), parents were unaware of their options. However, one set of parents was dismayed to discover that the school's "transition education" was a euphemism for employment in a workshop rather than an exploration of employment. Other parents were concerned that the training for independent living for their son, who had behaviour problems in addition to vision impairment would be lost if he had no program at the end of school (Nagel, 1997). Further, parents recognised that employment training for such groups as deafblind people could not be a short term proposition. It was important, therefore, that "post-school options" programs continued to develop communication and independence skills after school (Ward, 1994).

Wolffe, Roessler, and Schriener (1992), found that adults reflecting on their preparation for work were dissatisfied with the skills training and career options made available to them as adolescents. The authors surveyed 76 members of the American Council of the Blind aged 17 -71 who had higher educational attainment and employment rates than the majority of people with vision impairment. The primary concern for the respondents of the mail survey was "Getting and keeping a job". Help in searching for a job, accessing Social Security information and having job skills to earn over the minimum wage were also important. A second set of problems for the group was financial assistance to buy adaptive devices and obtaining adequate information about career opportunities and placement assistance. The third set of problems identified, included a lack of encouragement to participate in job-training, receiving adequate vocational preparation services and having access to good career counselling. There was a strong indication that respondents thought schools and rehabilitation agencies needed to better address their skills, training and career development needs.

Women with vision impairment whose participation in the US labour force is half that of all women are at high risk of unemployment (Corn, Muscella, Cannon, & Shepler, 1985). High unemployment rates for women with vision impairment mean that they experienced economic deprivation. The authors sought the opinions of 41 women who were nominated by rehabilitation counsellors and who had a range of education levels and occupations. The women noted that vocational counsellors usually recommended training and placements along gender lines. Assertive women were viewed as "maladjusted" and vocational choices in non-traditional female occupations were acceptable only as a "necessity". The women viewed themselves as facing greater barriers to employment than women generally. They attached greatest importance to the need for women to acquaint themselves with legal rights pertaining to employment and rehabilitation.

Current data in Australia indicate that women are less likely to participate in the labour force than are men but employment rates are similar for men and women with vision impairment. The cause of women's lower participation rate, and one which requires further investigation, has been attributed to rehabilitation professionals envisaging stereotypical passive roles for women (Morris, 1993; Meekosha, 1990). The Social Security Review (1988) noted that women with disabilities were also under-represented in labour market training programs; whether this situation applies currently to women with vision impairment is also worthy of further investigation.

#### Relationship between parents

At the same time that parents, usually mothers, are learning about community services and organising for therapy services, other household adjustments are also occurring.

One of these is accommodation between marital partners. Each parent needed their partner to adopt an attitude and involvement compatible with his or her own. Rees and Emerson (1984) observed there are three types of involvement by fathers: (1) continuous involvement; (2) occasional interest and involvement, and (3) relative disinterest. "Continuous involvement", possible where fathers had flexible jobs, helped fathers to feel less stressed and their input helped the focus to remain on the whole family rather than the child with a disability. Where fathers displayed the latter type of involvement and were very negative, wives said they felt relieved when they left (Rees & Emerson, 1984). Moreover, the participation of fathers was not encouraged by many employment practices that made it difficult for fathers to request time from work to attend medical and other appointments with the child's mother. This situation "makes the wife get ahead in information", to which a husband may respond by



withdrawal and resentment (Nagel, 1997; Murphy, 1992). Further, many women were supported by professionals and others, while husbands were working but these support sources were absent for their husbands (Nagel, 1997; Rees & Emerson, 1984 ).

Llewellyn et al (1996) observed that there is little help for parents in sorting out marital discord. Counselling at community centres is rare and if available involves long waits; informally, managers in local disability services can become mediators in marital issues when parents visit to talk about their child but talk instead of their relationship.

### Family support

The analysis of the stories of New Zealand families (Nagel, 1997) suggests that families with children with a disability spend more time considering the impacts of various family decisions and communicating between members than do families without a child with disabilities. Parents talked about the need to reconcile different perspectives between parents and siblings and the ways in which all decisions must be carefully assessed.

Parents craved a way of meeting the needs of the child with vision impairment without causing the child's siblings any deprivation. Parents also hoped that all siblings would be friends (Barton, 1997). Many parents stated that siblings missed, not only parental guidance and attention but also outings and other social opportunities, for example, eating in restaurants and playing sport (Nagel, 1997). Moreover, in some families, if the child with vision impairment had to wear dark glasses and a broad brimmed hat, then all of the children wore them. Some siblings doubted the extent of the impairment and thought it was a trick to escape household chores. When families decided to move closer to vision impairment services this fractured siblings' friendships. These difficulties made parents' dream of friendship between siblings difficult to be realised, although with time in some families there was acceptance by siblings of blindness as another personal characteristic (Barton, 1997). On the other hand, some adolescents reacted by stating that they did not want to be seen in public with their sibling with vision impairment (Nagel, 1997).

Some parents wanted relief from the "constancy" of caring. For some parents this meant "watching every moment" and "looking out for danger"; other parents included the inability of a child to be self-entertaining and to learn basic skills by observing. Losing things and tripping, walking into objects, holes and so on were part of the vigilance. Moreover, a number of children continued to need help or supervision beyond that of their age peers in eating, food preparation, use of electrical appliances and aspects of personal care (RBS, 1996a).

The parents of children and adolescents whose vision impairment was accompanied by other disabilities (e.g., brain damage or autism) also spoke of the "constancy" of caring. This was the case when a child did not sleep "normal" hours, had behaviour problems, had "restless legs" syndrome, a drug side effect, self-injurious behaviour, screaming and constant demanding behaviour (Nagel, 1997).

### Respite care

Although parents wanted relief from caring, respite care was not always seen as the perfect solution. Llewellyn's (1997) interviews with service providers revealed that respite care had to satisfy two requirements: (1) it must meet parents' need for relief and time for energy renewal, and (2) it must

meet the needs of the child. Parents also needed choice in types of respite care - for example, when only institutional care was available one family felt they would "have to start all [their training] over again" when their adolescent returned. Parents, who initially felt "guilt" in leaving their child, wanted assurance of quality of care and safeguards against physical and sexual abuse (Nagel, 1997). Availability in some areas was also a problem and service providers had observed that there was less respite care available for children and adolescents with major behaviour problems and such complex health needs as ventilator dependence (Llewellyn et al., 1997).

When the range of parents' comments is considered, their needs can be summarised as support for families, Rees and Emerson (1984) and Llewellyn et al. (1996) argued. In 1984, Rees and Emerson, for example, argued that government policies aimed at enabling families to care for children with disabilities at home but the operation of these policies faltered, placing excessive burdens on families, often mothers. They identified a number of problems in social mechanisms, for example, the failure to provide information and the aid parents require, the extra financial costs and the organisation of therapy and other services. The study by Llewellyn et al. found that support for families in New South Wales has generally remained insufficient. Thus some families considered seeking alternate care for their child. Both studies analysed parents' remarks and found that parents, ideally, wanted to care for their child within the family. Llewellyn et al maintained, that if the child's needs were greatly different from the needs of the family, and there were parental concerns about the effects on siblings and the child did not fit into the local community there was a strong chance that parents would look for permanent care outside the family. The authors suggested that more services should be directed at helping the family (parents, siblings of the child and the child) to manage and less emphasis should be given to the child's disability and services related to disability. Services also have a role to play in helping the child's participation in the community.

### Technology

Few comments were made in the literature on this topic except that parents and adolescents required assistance in understanding the developments in technology for vision impairment. Barton (1997) has argued that in high school, students are expected to draw on a wide range of resources, for example, libraries, databanks and interviews and that the ability of a student with vision impairment to do this is related to access to such resources as computers and appropriate software. Parents usually lack knowledge and have to learn about what is available. In addition, "the equipment is expensive and quickly outdated"

People with vision impairment have to know about the "massive leaps forward" in adaptive technology - and this is difficult with decisions to be made, for example between "stand alone specialised computers" and software on conventional computers. If they assess that it is useful for them, parents and adolescents have to be able to afford to update. The adaptive equipment often costs more than a mainstream computer, but, McMorow (1997) indicated that, for many students and working people, it is necessary to upgrade to maintain their skills.

Further, there is a need for people with vision impairment to communicate their needs to technology researchers who are currently receiving little input from people with disabilities about their needs. Therefore, emerging technologies are likely to develop to serve the interests of others and their effects may be adverse to people with disabilities, affecting such issues as choice, control and access (Johnson & Moxon, 1998). Another concern is that technologists will consult with only some people

with disabilities - usually those easiest to consult. Jolley (1997) has contended that technology offers communication which is crucial for the liberation and empowerment of people who are blind but they must ensure that new technologies are accessible. This can be achieved by discussion among disability organisations, researchers and industry through consultative groups, awareness-raising and collaborative research.

### People from a non-English speaking background

No experiences of people who are blind or are vision impaired and are from non-English speaking backgrounds were revealed in the literature search. However, their experiences can be hypothesised from the experiences of other people with other disabilities from non-English speaking backgrounds.

The need for support and access to services is likely to be as important for such people, as it is for the rest of the community. Evert (1996) interviewed 22 "ethnic" families with children with disabilities in their homes. She found that the stereotypical help from "extended families" did not occur for many families. Mothers cited as their main sources of help their partners, their mothers, siblings of the disabled child and the mothers' siblings. Many had no extended family in the country to assist or, if present, members were unable or unwilling to help. Some 36% percent received help from such external sources as home help. Similarly, Ahmad, and Atkin (1996) examined family care within ethnic minorities in England and also found that the "extended family" stereotype operated for very few, due to restrictive immigration policies and other factors.

The need for accurate information is critical in non-English speaking background communities where language differences may prevent one securing and verifying information. Families, in the Evert study, had knowledge of some children's services, for example, Long Day Care and playgroups but low awareness of Family Day Care, Occasional Care, Out of School Hours programs and vacation care programs, (Evert, 1996). Many misconceptions existed, such as parents believing that services would not take a child with disabilities were only for working mothers.

The study supports the need of families from non-English speaking backgrounds for support in caring and for assuring the quality of care from service providers. Family Day Care raised issues of trust and communication although many parents stated that the ethnic background of the carer was irrelevant as long as the carer was "caring and sensitive". Parents were interested to know about Out of School Hours programs and vacation care programs and many parents stated that they wanted respite for themselves and stimulation for their child at holiday time. Parents pointed out that most special schools had no programs before or after school.

In the United Kingdom, Ahmad and Atkin's (1996) examination of ethnic families caring for children supports the need for better explanations by professionals at the time of diagnosis. The range of emotions parents had on learning of the diagnosis was similar to those of the majority population. These were, however, exacerbated by the lack of accessible information about benefits and services, the barriers to services imposed by non-recognition of needs, the inability of services to meet the needs of those whose language was not English and "racist stereotypes held by professionals" (Ahmad & Atkin, 1996). Caring for a child imposed extra costs and affected employment opportunities in similar ways to the majority population, but Ahmad and Atkin argued that their impact was more profound because ethnic minorities experience "racial inequalities in income, employment and housing" and state benefits were frequently not used because they invoked stigma or shame (Ahmad & Atkin, 1996).



Stuart (1993), a member of an ethnic minority in the UK, has written a personal account of the "oppression" of persons with a disability. He argued that acceptance and lack of prejudice towards disability was needed within ethnic communities and this should replace the "oppression" of people with disabilities which has stemmed from the inability to perform traditional roles, for example, contributing to family resources. A further oppressive element was the "racism" which exists in the social distribution of such resources as employment and housing. Further, there were the aspects of disability, for example, isolation and frequent hospitalisation which were also "oppressive".

#### Aboriginal and Torres Strait Islander people

The effects of disability are compounded for Aboriginal and Torres Strait Islander people by other factors. Socio-economic disadvantage means low income, lowered life expectation, higher than general population children and adults' mortality rates, and higher accident rates (Gething, 1995).

People living in remote and rural areas face, in addition, disadvantages associated with distances from major population centres. This issue is discussed further below.

Taylor (1997), identified lack of environmental health as an issue for people in remote and rural Aboriginal communities in Australia. He attributed the cause to problems in housing construction and related drainage: poor design, poor supervision, construction faults and lack of long-term planned and funded maintenance.

With regard to vision, Aboriginal people have been noted to have excellent distance vision with little refractive error but it is now estimated that blindness occurs up to ten times more frequently in Aboriginal and Torres Strait Islander people than in the overall Australian population (Taylor, 1997; Doyle, Keefe, McCarty and Taylor, 1997). Vision problems are now also seen in young people and children. Some young people had developed cataracts (Taylor, 1997). Diabetic retinopathy is also reported in teenagers although peak prevalence is at 40 years of age (Taylor, 1997). Trachoma, "the disease of the creche", is "hyperendemic" in many areas and unproblematic in others. The early stages of this disease, "follicular trachoma", are seen in young children. While not causing vision impairment at this stage, the disease frequently progresses in middle age to "trichiasis" which is characterised by "opacification of the cornea" and blindness.

Many of these vision impairments are preventable. Blindness from diabetic retinopathy can be prevented by early detection in regular eye examinations followed by appropriate laser treatment. Follicular trachoma can be treated by antibiotics and prevented by improvement to household sanitation and water supply and promotion of face washing in children; surgery can be performed on trichiasis (Taylor, 1997).

Who will meet their needs and by what methods and philosophies is of central concern for Aboriginal and Torres Strait Islander people (Windsoet & Wood, 1996; Wolstenholme, 1996). Wolstenholme's data from a study of 40 carers and consumers in rural northern New South Wales revealed the importance of families as carers of people with disabilities. Her study revealed there was "richness" and "variety of involvement" in care and "complex interdependencies" between extended family members. A further facet of Aboriginal care was a reluctance to use mainstream, "white" services. Stemming from a historical mistrust of government and institutional services this is manifested in

Aboriginal people expressing a clear need to have direct and personal care services from Aboriginal people and a strong preference to be participants in the design of service provision. Further, indigenous people want low levels of awareness and preventive education addressed by indigenous people (Gething, 1995; Windsoet & Wood, 1996; Mokak, 1997).

### People outside the metropolitan area

Gething (1997), on the basis of consultations and interviews with people with disabilities, their carers and service providers has argued that people with disabilities and their carers in rural and remote areas experience extra disadvantages related to their location.

Foy (1997), drew a similar conclusion when she examined the grieving experiences of newly diagnosed parents. A major source of disadvantage stemmed from the fact that most services were located in the city. Travel to the city involved financial, emotional and physical strain. She noted that such difficulties as regular trips to the city exacerbated parents' grieving.

Rural families and people with disabilities were also disadvantaged in obtaining information, a factor which also compounded parental grieving (Gething, 1997; Foy, 1997). Low numbers of people with disabilities meant that there was little chance of meeting other individuals or families or participating in support groups or lobbying groups. Loneliness and isolation were thus commonly experienced. Moreover, Foy observed that there was a rural ethos, which valued self-reliance and independence and placed a high value on physical work. In this ethos, disability was "alienating". Thus, parents experienced tensions in allocating time to carry out a program of home therapy, especially where work equated with survival.

People with disabilities were also disadvantaged by the number and quality of services available (Gething, 1997). Service providers were often lacking in education on disability issues and people with disabilities felt their rights were ignored. Advocacy services were scarce. Many people with disabilities commented that where there were local professionals, they were frequently inexperienced in treating disability. They were also often "culture shocked" and stayed for comparatively short periods, with the result that clients were continually having to re-establish themselves with new professionals.

### **Summary**

At diagnosis and during the following period, the literature revealed that a commonly felt need of parents was for information to help them understand the meaning of impairment for their lives and the child's. Both medical and practical information was required. Parents wanted the information passed to them in a sensitive manner, preferably supported by written information. Parents also wanted both parents and possibly other family members with them when "bad news" was given. There was a strong desire to meet others with a child who had a similar diagnosis.

In the community, there was a commonly expressed need for services to be available locally and preferably at one location. Parents wanted to understand and participate in the delivery of services. They required professionals to value their role and their experience. Parents, and later adolescents, stated their need for positive comments from professionals rather than concentration on their deficiencies. Parents also regretted some professionals' lack of "child centred" approaches.

Many parents wanted relief from the stress they felt. Support from close relatives was helpful, but not if relatives had divergent views about the child's future. Women needed the support of their partners and if discord developed, spouses wanted the services of mediators which were difficult to find. Many parents required relief from extra costs which stemmed from the child's disability. There was also a need to relieve anxiety by supplying information on community services for older children and adolescents.

Parents wanted the best possible school education for their child within the school type they had chosen. Decision-making regarding the particular school was accompanied by much apprehension. Parents expected schools to deliver education in ways that recognised the particular needs of the child. They also wanted their child to experience no harassment in the playground. In fact, they wanted their child to develop friendships and to participate in games and sport with others.

An important goal of parents was that the child would attain independence in the future, by which they generally meant paid employment, living away from the family home, the ability to travel and communicate with others. Parents wanted help in the teaching of these skills from schools and community organisations.

The need for paid employment became increasingly important with age. Accessing courses, equipment and training to improve work chances were the main concerns. Women did not want their employment chances curtailed by stereotypic assumptions about their abilities. Parents wanted clearer information about the future for adolescents finishing special school.

An important need of the parents was that family life could accommodate the differences of the child with disability without injurious effects on relationships between siblings and between parents. Many parents saw that quality respite care could help with family care.

When faced with the "world of technology", most parents had needs for information and education on what products were available and their function and they were also troubled by the costs and the speed at which equipment became outdated.

People from non-English speaking backgrounds had similar needs to the mainstream population but they had the extra impediment of language differences which diminished their information and communication with professionals. Moreover, many people from non-English speaking backgrounds were experiencing socio-economic disadvantages and stigma within their own communities.

The primary need of Aboriginal people was that services were delivered in an Aboriginal context - that is, by Aboriginal people and as part of Aboriginal strategies to deal with disability. Aboriginal people, too, had their needs intensified by socio-economic disadvantage and their use of mainstream services was hindered by historically based mistrust and cultural differences.

When families lived in rural and remote areas, their chances of support from individuals and groups lessened. Community values in some cases were antagonistic, creating tensions for parents. Parents found that some services were absent or of poor quality; similarly, professional services were unavailable or lacking in important qualities.

### 3. SURVEY RESULTS

#### Introduction

An objective of the study, as outlined by its Terms of Reference, was to "provide a comprehensive picture of the child and family characteristics of clients, particularly ensuring adequate coverage of Aboriginal and people from a non-English speaking background".

These data were obtained by a postal survey of agency clients who were children and adolescents. The survey form and accompanying letter to parents of clients is presented in Appendices 3 and 4. As there was an overlap of clients of the two organisations, the decision was made to use the Royal Blind Society database.

Almost 2,000 survey forms and postage paid envelopes were mailed to parents. The response, after reminder postcards were mailed, was 512 responses (26.5%). Details are presented in Appendix 1.

Survey results are presented in the following section. They are also presented in tabular form in Appendix 5.

#### Survey results

The following is a summary presentation of the survey results.

##### Total numbers of responses

A total of 512 useful responses were received (Appendix 5, Table 1).

##### Gender division

Of these respondents, 56 % were male, 42 % female and 2 % were invalid responses (Appendix 5, Table 2).

##### Age groups

Respondents' ages spanned 19 years. They were placed into the following three groups: (1) Before school - infants (0- 5 years); (2) Primary school age (6- 12 years); (3) Secondary school age and beyond (13-19 years). Of these, 42% referred to primary school age children, 32 % to secondary and beyond and 27 % to infants (Appendix 5, Table 3).

##### Residential address of children and young people

Respondents were classified as "metropolitan" and "non-metropolitan" on the basis of their telephone numbers. Of these, 41 % lived in Sydney, 58 % out of Sydney and the remainder (1 %) were invalid responses (Appendix 5, Table 4).

##### Children and young people with disabilities in addition to vision impairment

Of the respondents, 48% of children had no additional disabilities other than vision impairment, 18% of children had one additional disability, for example, hearing loss, and 33 % of children had more than one disability, for example, cerebral palsy, developmental delay, and epilepsy (Appendix 5, Table 5).

#### Eye condition

Major conditions reported were as follows: Cataract (14%), congenital nystagmus (12%), albinism (12%) and cortical vision impairment (10%) (Appendix 5, Table 6).

#### Effect of vision impairment

Some 12% of children and young people were described as "blind", 82 % were described as having "partial sight" and 0.6 % had normal vision. The category "partial sight" includes "one eye blind, other normal", "one eye blind, other partial", "normal monocular vision", "one partial, one eye normal", "partial" which included visual field loss (Appendix 5, Table 7).

#### Languages spoken at home

Some 91% of respondents indicated that English or "Australian" was the only language spoken at home, 8 % indicated that they spoke another language as well as English and 2 % spoke no English at home (Appendix 5, Table 8).

#### Aboriginal or Torres Strait Islander respondents

Only one respondent checked this category.

#### Main activity in 1997

Most children and young people had participated age-related activities in the previous year. Two young people (one primary and one secondary age) lived in institutions; one primary and three secondary age young people spent 1997 at home and did not attend an educational institution or join the workforce.

#### Vision related services received in the past

Services most nominated by parents and young people were, in descending priority, (a) professional services (for example, therapies and counseling); (b) early intervention; (c) assessments; and (d) itinerant teacher (vision) services.

#### Current and future needs

Responses to need were grouped under the categories presented in Table 3.1. These categories were derived from analysing a sample of approximately 100 responses.

Categorisation of responses to the question on "Current needs" revealed that. "education needs" (38%) and "broad needs"(16%) most concerned respondents. Similarly, in "Future needs" "education needs" (31%) and "broad needs"(14%) were the most reported needs

Appendix 5 presents responses to questions on current and future needs.

**Table 3.1: Categories of need used in data analysis**

Category of need	Examples
Access to community	Related to moving around the community e.g. ability to use public transport, ability to travel 'independently' in the community.
Accommodation	Relates to concern about future residence e.g. group home in community, 'suitable' nursing home accommodation.
Broad needs	Parents/young people expressed needs in broad terms e.g. 'a happy life', 'good health'.
Change in community attitude	Need for the public or community to change its attitudes e.g. show more patience, understanding .
Educational	Related to educational environment e.g. an atmosphere free of teasing, knowledge of tertiary education options, such specific skills as braille,.
Employment	Related to participation in the labour force, gaining employment skills and experience.
Equipment	Technical devices e.g. closed circuit television, magnifier, white cane.
Medical	Relates to fixing/curing eye condition, surgery, 'breakthroughs' in medical science.
Motor skills	Related to movement and co-ordination e.g. parents want child to be independent, want development of fine motor skills.
Personal/social skills	Related to attitudes and skills of child e.g. parents want child to accept " <i>who she is</i> ", or want child to interact more with others or to develop communication skills, confidence, money skills.
Specific service needs	Specific service requests and change in quality of services received e.g. more consistency in services, more assessments.

## **4. RESULTS OF THE NEEDS SURVEY**

In this section of the report, the results of data analysis from interviews with parents and adolescents are presented. The data from six participants were derived from advertising for "non-clients" and the remaining data were obtained from random selections in the three age groups (infants, primary school age and secondary age). Need has been interpreted as an expression of concern about an "absence" in the interviewee's circumstances which the interviewee believes should be corrected. Some of the causal factors for needs have been identified in passing and the implications of not satisfying a need have also been identified. Recommendations follow this discussion.

The participants were 37 parents and adolescents. Interviews resulted in the needs of 39 children and adolescents being represented, as two families had two children with vision impairment. Information on pertinent characteristics of both the interviewees and the children and adolescents are presented in Appendices 7 and 8. Information on the analysis and interpretation is presented in the Methodology section, Appendix 1.

Presentation of results follow the approximate order of life events - that is, results related to diagnosis are presented first and these are followed by needs of a young child and the needs of children at school.

### **1. Medical treatment**

To most parents, the medical world is characterised as one of high status professionals, mystifying language and technology conducted in an increasingly corporatised environment. Interactions are usually based on trust rather than full understanding of decisions. Difference in social status hinders questioning professional decisions. Recently, due to a number of influences, individuals have begun to question medical professionals, seek other opinions and raise such issues as side effects and quality of life.

Parents wanted "good" medical treatment from the many doctors they visited and all 32 parents who were interviewed had experienced "good" and "bad" doctors. Paediatricians, ophthalmologists and sometimes, general practitioners, were the usual professionals who informed parents of the child's diagnosis. Parents were usually shocked with the news. Moreover, when parents reflected on the management by the medical profession of the diagnosis and the immediate period following, many were disappointed with their approach.

Parents had specific views of their needs when impairment was discovered at birth or in the months or years following. When their original doctors, had not detected a problem or had misdiagnosed or had shown discomfort in treating children, parents changed doctors.

The behaviours that parents judged as "good management" by medical professionals had a number of components. Parents (48%), stated they liked doctors to "explain everything" and "explain well". Moreover, they said that in their opinion, a good doctor looked up information for patients and was "approachable" so that parents could ring and ask questions. "Good information" on useful community organisations and support groups was important to parents.



In the words of the parents of CK:

*"There's a bit of hole you can fall into after your child's diagnosed with a problem. It was remiss of the specialists, the paediatricians, not to say, 'These are the appropriate organisations for you and your child'."*

Many parents (53%), made evaluative comments about the medical services they received and over half of these parents volunteered what they considered to be "good" medical service. These parents appreciated doctors who engaged in extra effort beyond their professional role, for example, a doctor who checked the child's well-being after a child had gone home after an operation. The "good" doctor was also patient both with children and parents, examined thoroughly, was understanding and did not charge "excessive" fees.

All of the parents who made evaluative comments had experiences with the medical profession which they considered negative. At birth, one mother had encountered pressure from doctors who tried to impose their values. In her words:

*"They just can't believe anyone would want a child with disabilities. They tell you to put the child in an institution - the paediatricians and the specialists - because they can't deal with it. They say things like, 'You'll get attached. Put the child in an institution and have another one'."* (Mother of BA)

Some parents (29%) were disappointed that problems were not detected earlier by medical professionals at such opportunities as the "six week check-up". Mothers who had noticed unusual behaviour in their child were frequently disbelieved by medical professionals and the observations of the mothers were not investigated. Later, these observations were recognised as indicators of impairment. One family remained angry more than a decade later after a "frightening prognosis" based on "sheer ignorance and a wrong diagnosis". Many parents (24%) wanted better explanations of the diagnosis and prognosis and they required discussion on why the impairment had occurred and what the genetic consequences were. These expectations were often unfulfilled. When parents of children with multiple disabilities (31% of the children and adolescents ) are given information in small amounts, parents form the impression that doctors are deciding what parents need to know and are withholding information. While medical professionals usually referred parents for further medical services, 35% of parents received no referrals to community services.

Parents also disliked being given the responsibility for deciding on an operation for their child when they knew little about the risks involved. Moreover, the passage of information between doctors and who was responsible for its transmission, was often unclear to parents. In the words of the parent of CG:

*"[I went to] Dr B ... The outcome was CG's eye had deteriorated. I thought he would let Dr M know that this had happened and I waited to hear. I rang Dr M in January and he was rather staggered that he hadn't been informed and he said we must investigate this immediately."*

In addition, parents of non-English speaking background (38%) had received treatment from English speaking medical professionals and when the spoken English of parents and their child was not clear, some doctors lacked skills and time to listen, especially to the child. Thus, even when parents of non-

English speaking background believed they had understood their doctors, parents sought explanations and information in their own languages:

*"Sometimes I use a translator machine [electronic machine] to understand [information] but yes I would like information in my own language."* Parent of IA

Parents outside the metropolitan area (35% of parents interviewed) had restricted options. The treating doctor was sometimes the only doctor available and changing to another doctor meant travelling long distances. Moreover, when non-metropolitan parents were convinced there was a problem but could not persuade their medical professional or when the treatment of the medical professionals was producing no results, parents outside the metropolitan area could not get second opinions easily. Parents, then, waited until the medical professional stated the need for further investigation.

When children and young people had other impairments, these very often overshadowed vision impairment and parents responded to the other impairments because of their dominant nature. Of the children and young people 21% had one other impairment in addition to vision impairment and 31% had more than one additional impairment. Parents of the latter group did not view vision impairment as their major concern. In three cases of life threatening impairments, these impairments received precedence over vision impairment. Lack of mobility or communication also competed with vision impairment for attention. In the words of the parent of CM: *"Her eyes tend to be the least of our problems"*. Similarly, when the behaviour of the child or adolescent was anti-social, this became the main issue.

## **Implications**

Generally, when parents have little information, they remain trapped in their doubts and anxieties. If medical professionals have an impatient manner, parents become caught up trying to manage the tone of the interaction which affects their ability to advocate for their child and themselves. Without information about the impairment, the ability of some parents to make sense of the impairment is diminished and they feel less able to take charge, to manage their child and their situation.

Moreover, the way in which information is given is critically important to most parents (53% of interviewed parents). The emotional shock caused by diagnosis prevents parents from being "efficient" receivers of information. Parents from non-English speaking background may be given the message that time is money and that language difference is the parent's problem.

If medical practitioners impose their values on parents who do not share the medical values the effect on some parents is to leave the medical environment as soon as possible. But for other parents, the notion that something is "wrong" with a child or baby works to keep them isolated and contributes to the development of stigma.

For many parents (53%), there is a gradual recognition that they must become "educated" and vigilant themselves. This recognition is derived from overlooked and mistaken diagnoses and prognoses and the dismissal of parents' observations and concerns about their child which are later validated.

Reflecting later on their experience, 35% of parents realised that their stumbling around without practical information and support could have been prevented if they had been informed of such community resources as blindness organisations and support groups.

Moreover, the medical experience often sets the pattern of thinking that it is the impairment which prevents a child from participating in society rather than the way society is organised to include people with disabilities.

The dismissal of vision impairment by some 25% of parents of children with multiple disabilities ( is concerning to those who are able to improve quality of life through working on vision impairment.

## Recommendations

The relationship between clients and medical professionals frequently commences before parents become clients of specialist organisations serving children with vision impairment.

There is therefore, a need to:

- 1.1. Inform medical practitioners throughout the State of the importance of considering the needs of parents when a child has been diagnosed with vision impairment.
- 1.2. Seek input to medical students so that future practitioners are sensitised to the needs of parents and family members at the time of diagnosis.
- 1.3. Collect and publish parent and family stories on good practice at the time of diagnosis, the material to become a practical resource for "new" parents.

## 2. Genetic Counselling

After the birth of a child with genetically caused impairment, 15% of parents reported that they were informed by medical professionals such as ophthalmologists, neurologists or geneticists that the condition was inherited. However, there appears to be little opportunity for older adolescents to inform themselves on their condition and whether it is genetically caused. One adolescent commented:

*"They diagnosed me with Stargardt's - there wasn't much they could tell me about it like whether it would be passed on to my children and I'd like to know a lot more about this. But I'm not sure who to ask." (Comments of NE)*

## Implications

Many adolescents with vision impairment will feel uncertain and insecure until they know about the likely genetic impact of their condition. Asking others where they might get this information might be difficult and embarrassing. Although some adolescents will already have some information, developments in genetics mean that earlier information needs to be checked. Moreover, adolescents may be concerned about how they will manage negative information and thus are reluctant to obtain the information.



## **Recommendations**

There is a need to:

- 2.1. Systematically inform parents and adolescents with vision impairment about the purpose and availability of genetic counselling.
- 2.2. Ensure that information on sources of genetic counselling are available at venues where adolescents with vision impairment are likely to visit or congregate, for example, teen camps.

### **3. Needs generated when a baby or child is hospitalised**

Although parents and children benefited from the services of hospitals, the organisation of these services often conflicted with family life, creating problems for 52% of parents.

Parents wanted hospital administrators to appreciate parents' dual obligations to the child in hospital and the family at home. When mothers were away from home at the hospital, problems were created if there were other children. If no adult family was available to help, families had to obtain a carer or fathers took time off work. This situation occurred when new born babies were hospitalised for several months and mothers were required to spend long hours at the hospital or stay in hospital with the child.

When children had to return to hospital for appointments and tests, the care of other children was a problem mentioned by 20% of parents. Families had to solve this problem or else take other young children to the appointment. Although intermittent "occasional" child care is available for such purposes as medical appointments, parents found this care too expensive when more than one child was involved.

Travelling to hospital involves planning and "hard work" for both metropolitan and non-metropolitan parents and was mentioned by 29% of parents. In the metropolitan area, hospitals are usually distant from the homes of many city patients and this caused difficulties for parents of children unable to walk and the parents of children with behaviour problems. For people in non-metropolitan areas, the organisation to visit hospital for services was both complex and costly, particularly when the family business had to be closed for the day. Moreover, not all families were aware of benefit schemes.

Some 24% of parents also disliked the conflicts in care which sometimes arose when a child was hospitalised. When parents' care for a child in hospital did not accord with the views of such personnel as medical registrars, parent care was harshly criticised. On the other hand, if parents experienced repeated stays in hospital, they compared the standards of care their child received and became distressed if they believed standards were deficient. However, parents felt powerless to raise questions about care when the atmosphere in wards is one of tension and lack of "manpower".

When children were undergoing operations parents prepared the child for the experience. As mentioned earlier, parents had to be convinced of the likely benefits of the procedure for the child and evaluating risks and benefits meant decision-making was often difficult for parents.

## **Implications**

The message which parents received from hospital administrators was that such organizational goals of hospital as minimising costs had precedence over the needs of patients. There was an assumption that families had "ways" to manage their affairs. The organisation of hospitals used the belief that it was mothers' duty to care for their child to induce mothers to spend long hours at hospitals which saved on organisational costs. Parents had to recognise their position in the hospital hierarchy as "amateurs" and accept criticism by "professionals". Moreover, care arrangements were not debatable although parents mistakenly viewed the relationship as a "partnership". Allaying a child's fear was definitely viewed as the role of the parent and was expected to be done at home and completed by the time the child was in hospital.

## **Recommendations**

There is a need to:

- 3.1. Increase links between community organisations concerned with vision impairment and professionals in hospitals.
- 3.2. Inform social workers in hospitals of the results of this research.
- 3.3. Seek input into the education of student nurses about the difficulties faced by parents.

## **4. Therapies and early childhood intervention.**

Therapy services traditionally refer to occupational therapy, physiotherapy and speech pathology or therapy. These services, originally supervised by doctors, are based in medicine (Tipping, 1992). The services which children receive emanate from a number of government departments, non-government agencies and private practitioners.

Except for children from non-English speaking backgrounds who had recently arrived in Australia, therapy services were generally accessed by infants or children before starting school. Children with disabilities additional to vision impairment often continued to have therapy services while at school.

When parents believed their child would benefit from therapy, they were enthusiastic for their child to receive these services. All interviewed parents with infants were receiving therapy supports.

In the past, some infants were excluded from services of community blindness organisations because they did not comply with such organisational requirements as the child submitting to an intelligence test. This exclusion meant no access to therapy services at the time, and, in addition, parents have remained angry and reluctant to use the organisation's services.

Access to therapy services for primary school children was complex. The parents of all primary school age children with multiple disabilities, living in non-metropolitan areas, claimed their child had need for therapy services but the services were unavailable to them. The reasons given to parents by government services were that there were either no therapists currently employed or the child did not fit the "criteria" of the providers. Parents perceived the eligibility criteria for therapy from non-government organisations also excluded them.

*"[The local] policy states that Community Health Centres do not service children with high support needs in "special units" [at school]. These are the province of DOCS and DOCS, here in this country town, have no therapists. [Blindness organisation A] although visiting young children in this town also won't see these children. [Blindness organisation A] will see children in mainstream classes but not in Support Units.... [Blindness organisation B] said they wouldn't send someone to our town just for one child." (Parent of CE)*

Parents saw government and non-government organisations each separately drawing up their eligibility criteria for services but not checking that all children and young people were serviced. Parents had received such explanations as, "You're in a grey area" and "the [money] bucket's empty".

The lack of services for non-metropolitan children had several effects. One was that treatment initiated in Sydney at children's hospitals was not pursued on returning home. Thus parents questioned the benefit of trips to Sydney. Another effect was that parents felt a sense of desertion by service providers and blamed other community groups, for example, the elderly and pre-school children, for receiving favourable consideration at the expense of primary aged children.

Parents of primary aged children living in the metropolitan area and from non-English speaking backgrounds had little understanding of "school therapy" and other therapy services, particularly if the parents were illiterate. These parents require assistance from "case managers" and "advocates" to explain and rationalise their access to available services. This need is exemplified by one mother's statements:

*"I'm going everywhere - wherever they tell me to take him. He's hitting me. He was hitting, yelling and screaming. I can't handle it".  
(Parent of CW)*

When parents have observed that "a peaceful controlled environment" benefited their child more than any of the therapies, parents declined therapy and other services for their child.

Over time, parents formed opinions of the services they received. According to one parent, a good service was one where the parent understood the aim, the methods and the time frame. Parents wanted to be able to discuss and question what the therapist did and be given reasons for particular actions. They expected to understand reports and were critical where language used by therapists excluded parents' understanding and participation.

Parents also wanted therapists to regard the child positively. Parents mentioned that it heartened them to hear a comment on the child's abilities, rather than disabilities. Parents were pleased when therapists assessed children at play rather than in formal settings where the child was likely to "under-perform". When therapists gave parents ideas for playing with babies and children and produced a "Service Plan" which monitored children's progress over time, parents understood how their child was being helped.

If children were receiving therapies but the therapists lacked the knowledge and skills to help them, parents felt frustrated. This happened in hospitals and in private practice where physiotherapists admitted that they had little knowledge and experience in paediatric areas. Honesty in admitting that the therapist did not have the answers was appreciated if this was followed up by the therapist referring



to a nearby service or consulting colleagues about appropriate treatment or researching suitable treatments. When, however, staff at early intervention centres, admitted they knew little about particular disabilities and suggested parents drive to other centres, 40 minutes away, parents felt their need for local services were not met.

Parents expected therapists to be interested in helping their child. When assessments were conducted and the results were not given or the therapist never called back, parents became cynical. Parents also appreciated therapists' advice for parents and interest in such local services as kindergarten. Helpful therapists also noticed problems outside their specialised area and brought them to parents' attention.

Many parents were pleased with the regularity of therapy service and treatment from blindness organisations. Moreover, regular visits became a support mechanism for some mothers, which was appreciated.

Many parents were prepared to carry out home therapy programs that were not "overbearing". However, the judgement of "overbearing" had to be made by parents, considering other demands on their time, not by therapists. There was evidence in the project that the amount of time parents had available varied considerably. If the child with vision impairment was the only child in a family, a parent might spend an hour or two daily working with the child. When there were other children, time for home therapy was limited.

The capacity of parents to decline "overbearing" programs was undermined by the fear they might not be giving their child maximum help; hence, a tension was produced.

*"They all meant well but each person gives you a bit more to do: the speech therapist says to do this, the occupational therapist to do a bit of that, the physiotherapist gives a bit too and the early intervention person says go over there for groups and you've got to fit the baby's sleeps and feeds around it. It was really a strain". (Parent of CF)*

When therapists visited the family home, this solved such problems as finding someone to mind other small children or "dragging" them to the therapy centre for parents. Home visits relieved those parents who stated they "spent the first few years in the car going to specialists and therapists".

Parents expected a high quality service from professionals. Therapists who did not respond quickly or continually cancelled appointments or did not bring good quality equipment or toys were criticised by parents. Similarly, when parents experienced therapists who dismissed children as having an "off day" after working with them briefly, parents not only cancelled further therapy but also halted further contact with the agency.

Parents also expected equitable treatment between children and any perceived discrimination discouraged parents from using the therapy services.

*"I always felt that their interest was with capable blind children. My son was a handful and was very delayed and I always felt the service wasn't for him. For example, the OT used to refer to the other children she saw, who were very capable, as her 'stars'. Every time she said it, I and another mother*

*who also had a child with multiple disabilities, reacted the same way - we knew damn well our kids weren't included in it." (Parent of NA)*

Parents raised the issue of complaints mechanisms within organisations, stating they that had no knowledge of where to turn and, thus, when they were dissatisfied with services, they "just stopped going" to therapy. Moreover, parents stated that because it was difficult for them to complain, they wanted to feel "some good will come of it".

### **Implications of missing or inadequate therapy programs**

Parents' belief in therapies stemmed from their strong desire to do all they could to help their child reach age appropriate milestones and to prevent any possible suffering. Thus, some parents called for a clarification of the child's rights with regard to provision of therapy services by agencies.

This belief also explains why the lack of therapy services and the lack of paediatric skills were viewed seriously by parents.

As in other services, parents wanted to be viewed as partners. They therefore wanted to understand the reasons for particular treatments. The relationship between the "partners" thus demanded honesty, respect for the parents' views and basic courtesies. The fact that therapists visited at home was seen by many parents as a welcome acknowledgment of the difficulties they faced.

While many therapists did not confine themselves to their professional role and were emotionally supportive of mothers, the organisational requirements of both therapists' work and the work of many fathers meant that therapists usually interacted only with the child's mother.

### **Recommendations**

There is a need to:

- 4.1. Monitor the "phased implementation" of recommendations of the Review of Therapy Services (Lea Maher & Associates, 1998) for their effect on programs for children with vision impairment, and inform the parents of agency clients of that Review.
- 4.2. Increase links with school therapy teams.
- 4.3. Establish a standard practice that therapists working with children who are about to start school ensure, as much as possible, that their clients are referred to a school therapy team member who is fully briefed on the child's needs.
- 4.4. Ensure that therapists inform parents about school therapy and what steps parents might take if services are not currently available to them.
- 4.5. Consider responding to a call to tender for the provision of therapy services to school students with vision impairment, should there be a decision to organise therapy services for school students on an area basis (Lea Maher & Associates, 1998).
- 4.6. Verify that all funded services have a leaflet in plain English, detailing the entry and exit criteria for therapy and other services, descriptions of the way in which services are organised (i.e., based upon an Individual Service Plan and the "complaints" mechanisms that are currently available). Parents should be encouraged to request this information from all service providers.

- 4.7. Consider the need to play an increased advocacy role on behalf of school students with vision impairment.
- 4.8. Inform professionals on such issues as methods of writing useful "parent-friendly" reports.
- 4.9. Ensure that both parents are informed of the availability and content of therapy programs

## **5. Counselling**

This was not a service about which parents or adolescents directly expressed a need. However, parents sought urgent assistance with behaviour management of children with such conditions as Attention Deficit Disorder (ADD). When referred by schools to counselling at community health centres for their child, parents found that the counselling, in the words of one parent, was "going nowhere" with regard to managing the child.

When mothers who felt very stressed about their pre-school child were able to attend relaxation courses while their child received therapy from mothers described their relaxation course as "very helpful".

### **Implications**

The general public has had little experience with counselling. Thus, the work of counselling, its aims, its methods and its timeframes must be explained and negotiated.

### **Recommendations**

There is a need to:

- 5.1. Advise parents on the role of counsellors, psychologists and social workers and where these services are available.

## **6. Assistance from social workers**

Parents expected social workers in hospitals to "look into everything for [them]", inform them of helpful community organisations and other forms of assistance including government financial assistance. Hospital social workers either did not visit mothers when inpatients or, when they came, did not pass on information which parents, in retrospect, realised would have directed them to appropriate community organisations. However, social workers in community organisations provided more practical information and appeared to fulfil parents' expectations.

### **Implications**

Parents felt that "stumbling" on community support networks some time after hospitalisation could have been prevented by social workers in hospitals. This would have reduced much of parents' sense of isolation.

## Recommendations

There is a need to:

- 6.1. Inform hospital social workers of the role of the major organisations serving children with vision impairment and about the focus of relevant community organisations.

## 7. Aids and equipment

Children and young people used a wide range of aids and equipment. These were for vision impairment and a miscellany of other impairments. The vision aids mentioned were miniscopes, magnifiers, closed circuit television, contact lenses, prescription dark glasses, prescription "ordinary" glasses, lens swimming goggles, white canes, "talking books" and enlarged books. Other aids mentioned were laptop computers, elevated cots, orthotics, adult size nappies, wheelchairs, standing frames and aids related to tracheotomy and gastrostomy care.

Most children and young people had aids to complement their vision. The attitude of parents was to obtain aids, to the maximum of the parents' ability, to help their children. Some parents, however, commented on high costs. After making the expenditure, parents were concerned when their children were not using the aids. One student with a closed circuit television stated that using a miniscope and a magnifying glass slowed his work and that he usually finished the day with a headache if he used them. The main reason, however, for other students not using their aids was because they didn't want to appear "different" from their peers. This peer group pressure started in primary school and continued into tertiary level for one male student. As the consequence of appearing "different" was often teasing, possibly physical bullying, children and adolescents attempted to appear the same as their peers.

Parents sought ways to give their child the benefits from aids and equipment in a manner which reduced their vulnerability to teasing. Parents who could see a role for schools asked for their help, for example, one mother of a beginning primary school student asked the school to consider having a "sun glasses day" to legitimate the regular wearing of sunglasses by her son. Wearing contact lens, although an expensive option, solved the problems of some children and adolescents, those who wore contact lenses, usually had prescription sun glasses and prescription lenses in swimming goggles. Students who were concerned about appearing different kept their more intrusive aids at home, taking them to school only for examinations or other special events. Students used their aids at school if they had accepted their disability and openly talked about the need for the use of aids. Students also felt comfortable in using aids when the atmosphere in the school did not invoke teasing.

Although parents wanted to help their children as much as possible, the use of aids and such appliances as glasses and contact lens often involved parents in hard work. Placing contact lens in the eyes of a baby was regarded as a futile infliction of cruelty on a baby by parents who were nonetheless anxious to help their child. Young children and babies were also wearing glasses and prescription sunglasses to reduce glare and parents found persuading young children to wear expensive glasses and not to lose them a "tiring" task, although the child benefited. The expense was aggravated by the fact that glasses became too small for children.



Wearing prescription sunglasses was also accompanied by the conscientious wearing of hats, application of sun cream and placing ultraviolet protective screening on windows. Children had to be taught to apply sun cream and wear sunhats at school. Where children and young people had more than one disability, other sets of aids and equipment were usually needed. Mobility aids required by six children and young people are discussed further in the section on Mobility.

## Implications

Wearing prescription sunglasses was also accompanied by conscientious wearing of hats, application of sun cream and placing ultra violet protective screening on windows. Children had to be taught the necessity of taking precautions and to apply sun cream while at school.

Where children and young people had more than one disability, there were usually other sets of aids and equipment needed. The mobility aids of six children and young people with mobility problems are discussed in the section on "Mobility".

The cost of orthotics, similarly, fell heavily on parents and they sought ways to minimise the effects, for example, organising that a child's orthotics were obtained through the PADP of a metropolitan hospital rather than from a nearby country city, where *"they are very expensive and you have to pay upfront"*.

When children were denied aids and appliances, parents interpreted the denial as inhibiting the child's development. Lack of aids and appliances also increased the difficulties and workload for both children, adolescents and parents. Parents expected their child to ignore the stigmatising effects of some aids if they were helpful to "learning". However, parents' enthusiasm for infants using aids and appliances was reduced because they saw the infant in discomfort and comparatively little use was made of expensive aids.

The expense of many aids and appliances were a cost to family incomes and parents, who were led to believe there was assistance from the state, were disillusioned when they found the programs of assistance were hedged by eligibility criteria which permitted few families to enjoy their benefits. Moreover, the operation of PADP appeared capricious to parents.

Teasing at school, often related to the use of aids will be discussed in more detail further in the Report.

## Recommendations

There is a need to:

- 7.1. Provide comment to the Commonwealth and State Governments on such services as Continence Aids Assistance Scheme (CAAS) and Program of Appliances for Disabled People (PADP).
- 7.2. Investigate ways in which information on the need for inexpensive, "child friendly" aids and appliances can be conveyed to relevant industries and seek representation on committees providing consumer-related advice to industry.

## 8. Enlarged print and taped books

Secondary and tertiary students used tape text books and also borrowed tape playing machines. Students who used the service were unable to manage with standard texts, although, initially, the service was rejected by those who were reluctant to admit their need.

Most students were pleased with both the taped book and the enlargement of text book services they received.

Taped books and large print books for leisure reading from libraries was a problem for older primary school students and adolescents who felt their age group was not catered for. Suitable large print books also seemed to be unavailable for upper primary and lower high school aged children who had outgrown children's books but were not ready for adult literature. Students generally preferred to choose their own books rather than having librarians make choices for them.

### Implications

Parents were concerned that their child would fall behind or "miss out" by not having access to books or that they would lose the skills they already had. Having "educational skills" are seen as a protection or a weapon in a child's armoury for the future.

### Recommendations

- 8.1. Make copies of this report available to librarians throughout the State.
- 8.2. Agency children's services staff, parents and students should discuss the availability of attractive leisure reading for children with library staff.

## 9. Late onset conditions

The initial need for children and adolescents is confirmation that they have a vision impairment, and then, diagnosis. When problems with vision arose in the primary and secondary years, parents, initially, separately turned to optometrists. However, parents became frustrated and disbelieved their child or adolescent when the diagnosis of vision impairment was very delayed for a number of reasons, for example, due to an optometrist having performed "*six to eight months of light therapy*" before admitting no changes were occurring and referring to "*someone who can look at the back of the eye*", or a family visiting a number of optometrists with the last advising the parents to take their adolescent to a psychiatrist. The feelings of children and adolescents were further insulted when teachers at school doubted students' eye problems and carried out their own tests:

*"He [the teacher] had me in his room and he had this chart of faces and he was saying, 'Is this a smiley face or is this a frowning face?' and I felt like a three year old."* (Comments of NE)

Moreover, after the identification, parents suffered guilt that they doubted their child and blamed themselves for delaying the identification of vision impairment.



## **Implications**

Identification of vision impairment has a traumatic effect on the whole family. These families, like parents of babies, also may not hear of community agencies for some time. The child at school is likely to fall behind in school work and possibly loses capacity to participate in recreational activities. In addition, parents feel guilt about their earlier disbelief.

## **Recommendations**

There is a need to:

- 9.1. Facilitate parent and peer support for adolescents affected by late onset vision impairment

## **10. Parental anxieties**

Various aspects of life for parents and adolescents with vision impairment produced debilitating anxiety and parents identified strategies which helped them reduce anxiety.

Most people associated more information on their topic of concern, with relief from anxiety. This information had to stem from a source regarded as authoritative, for example, an ophthalmologist who gave an opinion on the probability of "sympathetic ophthalmia". However, most parents were not in regular contact with their ophthalmologist or felt it inappropriate to contact them with their questions. Information needed to be expressed in language appropriate to parents' knowledge. Those parents able to access the Internet frequently found that the available information was too technical. An example of a concern which made parents anxious was when their child's eyes moved fast at particular times, for example, after a prolonged session of computer use. These parents believed that they had no one with whom to raise these concerns.

Past experience of helpful services also allayed anxieties when new concerns arose, for example, the birth of a second child with vision impairment. Moreover, professionals were expected to know when parents are anxious and "vulnerable" and to tailor their manner accordingly. Thus, parents expected professionals to understand the apprehension of parents at the start of school or when they were concerned their child might have developmental delay as well as severe vision impairment.

A further source of anxiety was the lack of action to address a child's particular problems. This anxiety was epitomised by the experience of the parents of a child with no speech. The parents were disturbed by the delay in starting a communication program with their child, although professionals explained that they had to wait and be certain that their child would not speak.

Parental anxiety is clearly high when no services will accept a child and the parent experiences a sense of abandonment due to exclusionary criteria and the explanation that "the [money] bucket's empty".

## **Implications**

When parents are given information about their child's impairment and services, they are being given the possibility of developing some order and certainty in life.

Anxiety is the antithesis of certainty and it is disempowering and de-stabilising. Parents instinctively wish to avoid anxiety and one of the ways, they believe, to allay anxiety is to have information from authoritative sources, understanding what services can be provided and ways in which services operate.

## **Recommendations**

There is a need to

- 10.1. Provide more information to parents of children with vision impairment.
- 10.2. Inquire regularly from parents about areas on which they might require further information, particularly where the needs are for information in languages other than English. Alternatively, parents could be informed of ways to obtain this information.

## **11. Relationship between spouses**

The interviews with spouses involved only one parent from each household, in all; 26 women and 6 men. (Some families had only one parent. The question of how many parents were presently with the family was not asked but this information emerged in some interviews).

Of this group, 13 parents commented that they saw caring for the child as a joint responsibility. This meant sharing the physical work and sharing feelings on the emotional impact of the child's disability. Where partners were unable to face their child's disability and had turned away and blocked their feelings, women reported isolation and lack of support which added to the grief.

Discussing such tasks as a home therapy regime were an important element of joint responsibility. When parents had not arrived at a joint understanding of how such work would be accomplished, stress was generated and fathers were interpreted as

*"escaping to work" or "relaxing ...when every minute should be used to stimulate the child".*

Fathers who acknowledged the extra work carried out by their partners tried to help after meeting work commitments. Fathers were also motivated to help if the family had no relatives in Australia and the mother cared for a child with a multiple disability and other children without any relief. If fathers became unemployed, they saw the difficulties of managing a *"hyperactive"* child at home.

The extra financial costs incurred by a child's disability also impacted on the relationship between some spouses. In one situation, the child's mother argued the need for some aid or service while, the father, questioned the necessity for the expenditure. It may be no coincidence that this father was reported to have been *"cut off emotionally"*. (An examination of extra costs and how these are incurred follows in a later section of this report).

## **Implications**

Mothers were likely to feel physically tired and mentally stressed more quickly if they did not share the experience of having a child with disabilities with their partner. Also, important aspects of the child's needs were not understood by the father and this was also a source of friction.

The fact that the father's emotional needs were not addressed was not healthy for the father as well as the child's mother. It may also have affected the child's siblings and their attitudes.

## Recommendations

There is a need to:

- 11.1. Ensure that appropriate referrals for parent counselling are possible
- 11.2. Investigate such strategies as groups or camps to specifically target fathers.

## 12. Parent support

Many parents mentioned the need for more parent support. "Support", from parents' comments, included an acknowledgment of the difficulties of parents' experiences. "Support" was different from information as this comment from one mother conveyed - what she needed was

*"more information, more support, more idea of what the future would be like"* (Parent of CB).

Why parent support was necessary was expressed by a number of parents. Reasons given were that mothers who had babies who were "different" felt "isolated" when surrounded by "normal" babies and children; the series of medical and therapy appointments mothers had to undertake; the tension mothers felt because they had to care for the rest of the family and the fact that no person or service inquired into how the mother felt, which was often depressed.

The need for support also varied over time with the greatest need following diagnosis. What form the support should take also varied. Meeting the social worker at the hospital was not the support which most mothers looked for after her baby was diagnosed. Mothers who stated that they would have liked to have met parents of children with similar disabilities after diagnosis, felt a few years later that this support was no longer important. Mothers who enjoyed reading obtained great support from books and reading about how others had coped. Meeting other mothers at playgroups was a source of support for some mothers - *"we're all on a learning curve together"* - but whether mothers drew support from the group was related to the extent of children's impairments:

*"They did try to have mothers' groups at Early Intervention but they were so depressing. You'd go to those and in lots of cases CF was "better" than most. One mother I've stayed in contact with ... she told me that she resented me because CF. had so little wrong with her, so there's that within the early intervention mothers' group!"* (Parent of CF)

Professionals, particularly those who visited the home, were seen as sources of support for many mothers of very young children and babies, with one mother stating therapists spent half their time listening and talking to the mother.

Mothers looking back on their needs several years ago were inclined to blame themselves for their own lack of support, believing they should have self-talked themselves into a different state of mind or taken some other action:

*"In hindsight, I should have done a lot more for myself mentally."*  
(Mother of CF).

However, at the time mothers felt overburdened, and, generally unable to engage in much self-help.

### **Implications**

Parents wanted understanding by other family members, friends and service providers of their feelings of grief, their need for attention, information and intervention and their doubts about capacity to manage. The source of support for many was another set of parents who were also a source of practical information. Others derived "support" from such professionals as therapists.

Because parents with pre-school children are less able to visit friends and relatives they are more reliant on meeting other parents at such activities as "early intervention programs" for their support and if these meetings are to be supportive, care must be taken in structuring the programs.

Some parents are also more likely to be isolated in the community without "support". Parents of non-English speaking background and parents in rural areas are two groups at risk.

### **Recommendations**

There is a need to:

- 12.1. Facilitate parents supporting each other using a variety of parent support models, for example, family social events.
- 12.2. Become more alert to the difficulties inherent in operating "mother's-only groups" and

### **13. Regaining life control**

This was mentioned by parents of babies and young children who had multiple disabilities. Resuming "normal life", albeit in a different form from before the baby was born, was a major goal in all families. Regaining control meant that, instead of the baby's needs dictating family activity, the needs of other family members would direct activities. Regaining control was possible only after medical problems had been resolved and some basic equipment such as a wheelchair had been obtained. When this occurred, one baby's mother made a positive statement that the baby had to fit in with the family and not the reverse, that is, the family fitting in with the baby.

### **Implications**

If control is not returned to parents, parents feel unable to fulfil their other social obligations and be part of "normal" life. If restoration of normal life does not occur, the family is likely to consider other options such as placing the child in care.

## Recommendations

There is a need to:

- 13.1. Ensure that parents of children or babies with multiple disabilities are informed of sources of home help and respite.
- 13.2. Ensure that social workers and other professionals in contact with families monitor closely those in which there are children or babies with high support needs.

## 14. Sibling needs

Many parents commented that they felt that siblings of the child with vision impairment had missed out on family life because so much attention had been paid to the child with vision impairment. The remarks were usually made about the period when children with vision impairment were at pre-school age and mothers were heavily involved with medical and other services.

Mothers of children with multiple disabilities remarked that there was a need for "more things" for siblings. The current programs run by a community blindness organisations were seen as -

*"geared to vision and we need a broader recognition of disability, and ideas and strategies for siblings on accepting and coping".*

(Mother of CM)

## Implications

Many parents were worried that they had neglected siblings and felt guilty about this. They were concerned that the siblings would resent the child with vision impairment, believing the child with vision impairment has spoilt their childhood lives.

When parents are totally absorbed and the effect on siblings is that they receive little or no age appropriate attention, then the family is likely to declare that it cannot manage the child with vision impairment.

## Recommendations

There is a need to:

- 14.1. Review existing programs that address the needs of siblings
- 14.2. Offer counselling for siblings by appropriately qualified staff.

## 15. Psychological needs

When parents talked about the psychological needs of their infants, two areas of concern were identified. One area of concern was the child who was "clingy", did not enjoy social engagement with others and disliked being touched. The other area of behavioural concern were possessiveness and extreme aggression.

Interactions at school contributed to the negative state of primary school aged children. Children, not keeping up with their peers in reading and writing, were unhappy and subject to aggressive outbursts and reluctance to attend school. Other children, described by their parents as lacking confidence and assertiveness, longed to meet another child with a similar impairment to their own, were affected by teasing, "*frightened to appear different*" and were upset by their inability to play sport.

Comments, some by adolescents themselves or parents, were made about adolescents psychological needs. Adolescents, who had endured severe teasing and bullying and were described by parents as "*lacking confidence*", either changed schools or were reluctant to attend school, leaving early. When adolescents who successfully managed school encountered discrimination in the workforce, the adolescents are "*devastated*" and have "*a damper*" put on them. Not appearing different or conspicuous was also concern of adolescents.

In all cases where children had difficult behaviour patterns, parents sought advice on effective techniques for behaviour management. The advice came from doctors who prescribed medication, counsellors and one child had a consultation with a psychiatrist and a psychologist. Parents in country towns had to manage without the advice of psychologists for assistance with difficult behaviours, if the only psychologist in town did not accept clients under the age of five. For other concerns experienced by children such as lack of confidence and assertiveness, parents advised their child. In adolescence, parental advice dwindled and young people attempted to manage concerns such as their "*difference*", teasing and bullying and discrimination themselves. Parents of adolescents who had attended camps organised by blindness organisations commented on the value of the camps for developing networks and demonstrating that others also have disabilities.

## Implications

The child's psychological difficulties, for example, "*wild*" behaviour or not wanting to go to school very much, concerned parents who felt badly about the unhappy state of their child. In many cases, parents saw the cause as school-related: the child could not keep up with his peers in the classroom, or when teasing was occurring. Other parents wanted children to make the natural progression to independence and adulthood and not to be dependent. These parents were concerned at such qualities as lack of assertiveness.

The problems related to a child "*not keeping up*" educationally are discussed later in the report. The effects of teasing and bullying on children and adolescents have been documented in Australian research (Rigby, 1996). Rigby argues that boys are likely to respond with anger and girls with depression; for both boys and girls, the result is lowered self-esteem because the "*victims have been unable to 'stand their ground'*". This produces a range of consequences such as lack of friends, poor health, inability to concentrate and for some, attempted suicide and in adult life, inability to form relationships with others (Rigby, 1996).

## Recommendations

There is a need to:

- 15.1. Provide parents with information on appropriate behaviour expectations



- 15.2. Provide a wider variety of recreational activities for children and adolescents which stimulate confidence building and assertiveness, for example, camps for primary school aged children.
- 15.3. Draw to the attention of the appropriate authorities the alleged general tolerance of teasing and bullying of students with disabilities in schools which was revealed in this research.
- 15.4. Educate parents on the existence of "anti-bullying" strategies.
- 15.5. Educate parents and adolescents about "discrimination" and the methods available to combat it.

## 16. Respite care

Carers or parents of children with disabilities may have a temporary break from care responsibilities and children can socialise with people other than family through respite care. There are a few types of respite care. It may be provided by a respite care worker coming into the family home and caring for the child or the child may stay at a community group home or large facility or the child may stay with a "host family".

All families whose child had multiple disabilities except one family from a non-English speaking background were aware of respite care. The mother from the family who were unaware of respite care described herself as *"desperate for a break"* and hating the weekends because she was tired of caring. The families using respite care appreciated their break from responsibilities.

*When a parent has experienced respite care in one area , the parent was surprised that none was available when she moved to another area.*

The importance of a choice in the type of respite care was demonstrated by the comments of parents who expressed strong views about the type of respite care they preferred to use. Parents who believed that children's routines would be maintained if they did not leave home wanted respite care, only in the family home. Other parents disliked this form of care and were disappointed that the only form of respite available in their area involved care workers coming into family homes. In this form of respite, parents stated it was difficult for them to provide a bed and food and pay the cost. When parents did not want the care of the child moving outside the family, they organised that another relative provide respite from time to time.

Parents who had not yet used respite care spoke about the difficulty of *"letting go"* and *"trusting"* other people. Parents also saw that respite care benefited the child providing other people in the child's life and recreational opportunities. Parents who used the *"after school service"* at a non-government special school as a form of respite care described the program of activities for children as *"brilliant"*.

When the families of children with high support needs are entitled to less respite care than families of children who have lower support needs, parents of the former group feel their needs are not being recognised. Such anomalies were reported to stem from an assessment by the respite care facility that a child with such high support needs as a tracheotomy required more expensive nursing care, despite the fact that the mother cared for the children at home.

## Implications

Not all families are using respite care. This is, in part, because the current publicity about respite care does not extend to people from non-English speaking background. Moreover, some people are choosing not to use respite care because they are not comfortable with the modes that are offered in their local area. Many parents are concerned about the standard of care and are unable to trust workers with their child.

In addition, some parents of children with high support needs, are prevented from having as many respite care hours as other children with disabilities due to policies of particular centres.

The effect of not using respite care, if a family has no other care arrangements, is to tire and stress the family as carers, to prevent siblings from having attention from parents and to deprive the child of recreation and relationships with their peers and other adults.

## Recommendations

There is a need to:

- 16.1. Check that parents, particularly those from non-English speaking backgrounds understand the nature of respite care and its availability.
- 16.2. Actively support the establishment of a range of respite care options in local areas which are operated according to "best practice".
- 16.3. Actively support a policy of equitable access to respite care in which the costs of caring and the time available does not discriminate against the families of children and adolescents with high support needs.
- 16.4. Inform agencies which perform care services, for example, NSW Home Care, about the particular needs of children and adolescents with vision impairment and their families.

## 17. Holidays

There are two aspects to holiday needs which may be problematic for families with a child or adolescent with a multiple disabilities - the family taking holidays and the care of the child or adolescent during school holidays, especially the long summer vacation.

Parents pointed out that if they included the child with multiple disabilities on family holidays they had no rest. This was because the family had responsibility for all the child's care needs; the only change was the location. The ideal, parents stated, would be some way in which a carer could go on holiday with them.

The school holidays were not welcomed by some parents because of the long hours of care responsibility without the respite that school attendance provided. This was the case where families from non-English speaking backgrounds with children with behaviour problems and hyperactivity were unaware of vacation programs. On the other hand, well conducted holiday programs where children and young people had "a great time" and there was a "good staff ratio" were highly praised by parents.

However, parents commented that there were insufficient day programs in the community during the school holidays for children and young people with disabilities.

## Implications

The issue of families having no holiday themselves when they take their child on holidays with them is a difficult one. It may be possible to take funded care hours in another area but this would be only a small proportion of the hours of care provided by parents.

The issue of vacation care programs and the effect on families is discussed later in the report.. It should be noted activities such as vacation care are also a form of respite care for families.

## Recommendations

There is a need to:

- 17.1. Invite parents to contribute articles for newsletters on the ways they manage holidays so that these various methods can be shared with other parents.
- 17.2. Support proposals to extend quality vacation programs which would cater for children and adolescents with vision impairment.

## 18. Mobility

Independent movement or ability to walk, understand road traffic movements, and negotiate obstructions around home and community is the social norm. Children gradually learn to meet these expectations and have usually attained the norm by adolescence. Thus, children and young people aimed to attain, as much as possible, age appropriate mobility skills.

It might be expected that those with the greatest vision impairment, that is, those who were identified as blind, would experience the most difficulty achieving independent movement. However, of the seven young people identified as blind, four had other disabilities and were not ambulatory. Where a child was described as "*quite mobile*" and used a cane "*quite well*", it was because he had received regular help from Guide Dogs Association.

Younger children were likely to be described as "*very dependent*" on their mothers or other family members and helped at street crossings, although some education on street lights, crossings and bus stops may have been given to them by teachers. The exceptions to the dependent children were those who were extremely active and had "*no fear of danger*" but who also were always closely supervised.

The parents of the non-ambulatory young people with blindness had generally sought support from a variety of agencies for wheelchairs or a "major buggy". All parents had encountered difficulties with PADP. Where the cause of the problem was PADP's income test, mothers either successfully opposed the decision of PADP and demonstrated that there was little left in the family income after the costs for the disability-related expenses were deducted, or, families reluctantly accepted the rejection of their application and its implication that the family income was excessive. When PADP assistance was refused, families had to determine whether to find alternate means to obtain the items or manage without them, and, if the former, whether to seek assistance from service clubs



Although PADP officials approved applications for aids and equipment, some parents and children had to wait excessive lengths of time before these were issued. Receiving equipment from PADP was also delayed if parents were unable to show a Health Care Card due to a problem arising in the processing of the Child Disability Allowance which was linked to the Health Care Card.

Apart from their child being unable to walk, parents also mentioned difficulties they had experienced in picking up, carrying, bathing and other tasks related to their child's care. However, none of the parents seemed aware of any aids or equipment to minimise this work.

When children were slow to start walking, this provoked some anxiety in parents of potentially ambulatory children. Parents who mentioned this problem had been told that if the child did not walk in the next few months, further "intervention" would be necessary.

For many parents, mobility meant constant watchfulness to prevent accidents as children and adolescents tripped or bumped into objects or could not discern the edges of stairs. Most parents commented on their child's "constant bruising" and "scratching". Parents expressed pleasure when workers from a community blindness organisation visited such local venues as a kindergarten and highlighted the need to paint step edges to the director.

The reaction of children to the hazards of the environment was individual. Cautious children moved slowly while "fearless" children were undaunted by heights, water, road traffic and the fact it was night and were a source of great anxiety for parents. The physical act of ambulation with vision impairment compounded the mobility problems of children with such additional disabilities as hemiplegia, which caused a child to trip, and traumatic head injuries, which caused walking to deteriorate to a stagger.

The dangers of road traffic troubled parents. Parents of primary school aged children managed this worry by transporting the child in their car or by escorting the child to school or allowing an eligible child to travel in school transport. Concerns related to traffic were heightened for parents where the child in the past had run into traffic and where the child had deafness in addition to vision impairment.

Accessing public transport caused adolescents uneasiness. The difficulties of travelling were masked by parents and others driving adolescents around and by the ease with which adolescents negotiated their local buses and railway stations, skills assumed by adolescents to be transferable to other locations. Five adolescents who mentioned problems observed once a place and a route became familiar they were confident. However, they needed to seek help with details such as train and bus destinations. For this reason, some never travelled alone. Where requests for information were made to "strangers", rude responses occurred which were discouraging and the thought of travel alone to unfamiliar areas for which no "training" had been received was frightening.

The fact that many sighted adolescents were pursuing a driver's licence distinguished adolescents with vision impairment from their peers and was an emotional disappointment for adolescents to overcome. Three female adolescents claimed it was not worrying them and that they had been prepared well in advance for this. It is likely that the pressures are greater on males to obtain a licence and the inability requires relinquishing such dreams as ownership of a motor-bike, important to one young man. The disappointment was viewed not as a matter solely for the adolescent but as a *"hurdle which the family had to jump"*.

## Implications

Independent mobility is important for accessing education, for participation in the workforce and for everyday social activity. If the mobility needs of children are not met, then they are in danger of not progressing in an age appropriate way. Moreover, lack of mobility restricts access to the community. When a family is unable to afford such equipment as a wheelchair, the family faces a dilemma. Buying equipment may represent foregoing other family expenditures. When the family could not afford to buy equipment, they often approached a service club. In other cases, families went without the item which was likely to result in parents lifting and carrying, which sometimes resulted in back injury.

With ambulatory children, parents experience a tension between fostering independence and concern for their child or adolescent endangering themselves. Adolescents register a similar tension seeing independent travel as part of their emerging adult status but acknowledging they need further training.

Gaining drivers' licence is an important occasion for adolescents, a status symbol. When one adolescent is not involved in this "*rite of passage*" that adolescent feels out of their peer group.

## Recommendations

There is a need to:

- 18.1. Ensure that families understand the nature of referral to such agencies as the Guide Dog Association of NSW & ACT.
- 18.2. Ensure that there is adequate information exchange with agencies providing orientation and mobility services.
- 18.3. Inform agency client families of the equipment and modifications available for caring for children at home and other related sources of technical assistance (for example, the Independent Living Centre at Royal Rehabilitation Centre, Ryde).
- 18.4. Remind client families periodically of the opportunities to continue orientation and mobility training.
- 18.5. Cooperatively with Guide Dogs Association of NSW and ACT, ensure that the community access needs of client families are included in representations to Local Government Access Committees.

## 19. Schooling needs

A significant role of education is to prepare students for participation in the labour force through imparting work-related knowledge and the disciplining of young people in preparation for the organisation of work. In addition, social arrangements assume the accomplishment of literacy and other skills and a person lacking these skills is both disadvantaged and stigmatised.

In New South Wales, children with vision impairment receive their school education from either the government or non-government sectors. Children with vision impairment and possibly other disabilities are assessed for integration into "mainstream" education or for education in special units or special schools. Children in any of these settings may receive support from teachers with specialised training in the needs of students with vision impairment. This support is usually delivered by an "itinerant

support teacher (vision impairment) (IST(V))" who may originate from the State education system, the systemic Catholic education system or RIDBC which serves non-government schools on their request.

In addition to the IST(V) service, the school sectors also conduct specific schools and programs for children with vision impairment, many of whom have another disability, for example, learning difficulties.

### **The students represented in interviews**

The views of 28 children and young people were represented in the interviews. One interviewee who had left school also talked about her school experience so that twenty-nine opinions on needs in relation to education were expressed.

### **Student needs**

All parents and students wanted the education system to offer services which would ensure the learning opportunities of students with vision impairment were equal in quality to other students at the school. Fulfilling this need meant that the school would organise and, in other ways, support students to receive education in alternate modes so that students were compensated for their disability. Parents were assured by education authorities that their child would not be disadvantaged at school and thus parents held strong expectations of different but equal education for their child.

Overall, parents and students were disappointed at how the education system met their expectations. The effort by schools was not systematic and sustained over time. It relied too heavily on the efforts of a particular caring individual teacher rather than the school system solidly backing a student's need. Thus, there was variation in students' experiences over the years.

Expectations of parents and students were met only in a piecemeal way. Parents expected teachers to enhance the learning capacity of students with vision impairment by such efforts as enlarging worksheets, ensuring homework sheets were "dark" and photocopying and enlarging learning materials. Moreover, they expected this attention would be maintained and not curtailed when the itinerant teacher was no longer around or the enthusiasm at the beginning of the school year faded. When the responsibility for tasks such as enlarging school papers was transferred to students to carry out in lesson time and the students missed much of their lesson, an experience of two students, parents were angry.

Parents and students had believed that teachers would understand the difficulties imposed by vision impairment and, if they were uncertain about aspects, they would consult with the itinerant teacher. It was therefore disappointing when teachers interpreted the inability of students to work as "laziness" and "bludging", interpretations which they imposed in students' written and verbal reports.

Parents made simple requests to teachers and received varying responses. Parents considered teachers helpful when they applied sunblock to students, helped children to remember to wear hats and sunglasses and made special arrangements for students to sit for Basic Skills and other tests. But a number of parents were surprised when teachers could not meet simple requests such as moving a student from the back of the room to a classroom position nearer to the board.



The actions of many teachers were interpreted as disinterest in the student with vision impairment. Parents expected to be alerted if a student was not learning or participating in classroom activities - for example, when a student was moved to the front of the room and the student still had difficulties. Students were stunned that they could sit in a classroom and do no work and no teacher inquired or contacted parents - "as long as you were quiet". Moreover, parents expected that learning problems of students in such key areas as reading and writing to be detected early and to be addressed before behaviour and other problems were manifest. If a student had other problems, for example, lack of communication, behaviour problems and attention deficit, parents expected that these would be addressed in addition to vision impairment.

Both parents and students expected the dignity of the student to be preserved. Where a student could not carry out such practical components of their curriculum as chemistry experiments and driving a tractor, parents and students had expected alternate arrangements would be discussed with the student in private. Parents and students anticipated the IST(V) would inform teachers of vision impairment and the need for special arrangements such as the wearing of dark glasses so that teachers would not make incompatible requests of students. Similarly, if a teacher was not informed but wanted further information, parents thought the teacher would request information rather than carry out eye tests which humiliated a student.

The fact that no administrative system had been established in many schools to inform casual or new teachers of students with special needs was viewed by many parents as symptomatic of the attitude of some schools. In the classes taught by these teachers, students with vision impairment were idle and likely to be chastised.

When a student with multiple disabilities enrolled at a school where resources were stretched, principals were concerned that they would not be able to meet the child's needs and attempted to divert the student away, for example, by suggesting the student "belonged" in a hospital, not a school. Parents of students who attended special schools which were well resourced generally praised the caring attitude of teachers and the professional manner in which they worked.

When students were placed in special units, parents expected that any therapy needs would be met by teams from Government sources. However, as mentioned earlier, this was not the case in some areas. In addition, parents observed teachers had no understanding of the medical or therapy needs of students with special needs. Moreover, parents were concerned about the lack of training for teachers' aides in such areas as hygiene which jeopardised the health of their child.

The short term consequences of this educational experience was increased involvement by parents in everyday schooling as parents attempted to remind or help teachers with tasks such as photocopying, enlarging notes and changing classroom positions. Where parents learned of sources of funding they wrote submissions on the school's behalf. If a child had additional disabilities such as hearing or behaviour problems or juvenile arthritis, parents met teachers regularly unless the child attended a school dealing with multiple disabilities. Busy parents looked forward to the time when their child could take over the task of reminding teachers but acknowledged that prior to this happening their child would have to be more assertive. On the other hand, one set of parents who had delegated the reminding work to their child acknowledged that constantly "nagging" teachers placed their child in a difficult position and was no solution to the problem.

It was difficult for parents to watch their child fall further behind in school work. Parents of students in public schools who could afford it moved their child to private schools where it was believed parents had stronger rights. Other parents cast around for such solutions as private coaching in reading and other skills. Students at secondary level who had experienced poor support in their earlier years confirmed that their basic skills such as spelling were now deficient and it would be difficult to pursue higher studies.

After students, parents and principals had met to discuss problems and the problems returned, options for parents and students appeared limited. Students who could move to other schools felt they had little choice but to "blend quietly into the background" and leave school as soon as possible.

### **Implications**

Parents connected obtaining sufficient education with improving the likelihood of employment, normal life and independence for their child. Parents believed children who did not receive good education had reduced life chances. Students were motivated to work to keep up with their peers because falling behind brought shame and, if not addressed successfully, reluctance to attend school which became a source of embarrassment.

Parents believed that they were in a partnership with the school to help the child learn and were bewildered by the careless attitude of schools to their child's learning. Parents had an expectation of individual attention which the teacher and school were unable to deliver. Parents who believed schools were solely interested in teaching and learning were surprised that schools were concerned about the costs some students would incur, for example, those with high support needs..

### **Recommendations**

There is a need to:

- 19.1. Provide opportunities for parents to meet with public and private education authorities in order that parents understand the education system's offerings to students with vision impairment.
- 19.2. Seek opportunities to represent and advocate for students with vision impairment at all levels of the education system.

### **20. Itinerant teacher support**

An expectation of parents of students in the public and Catholic systemic system was that their child would receive regular attention from an itinerant teacher. Of the 13 students with vision impairment attending "state" schools or who had recently attended, nine students received regular "support" from itinerant teachers. This expectation was dashed when students went years without attention such as the student who had been visited in Year 1 but had not seen a teacher in the next four years without parents receiving any explanation. Parents wanted the time between visits by itinerant teachers to be less than a year which was the case for students in a "special unit". These students received an annual visit from a "team from the Department of Education which has specialist vision impairment knowledge" which the parent described as "useless". Moreover, unless parents from non-English speaking

backgrounds, are given careful explanations, they are uncertain what the role of the itinerant teacher is and whether their child receives any support.

Apart from being a source of expert information for classroom teachers, parents saw the role of itinerant teachers as to *"help the student learn"*. If a student was not progressing, parents felt the amount of support was not sufficient or that the teacher was *"spread very thinly"*. An itinerant teacher who came for four periods in a 40 period week and copied writing from the board in a format which the student could not read was rated as *"hopeless"* by the student.

Secondary students expected itinerant teachers to play an advocacy role. Itinerant teachers were regarded as *"good"* when they pointed out student needs such as enlarging of materials, *"kept on their [teachers'] backs"* and also made sure examination papers were enlarged on time. Moreover, secondary students expected the itinerant teachers to consult them rather than tell them what to do.

The fact that there were many changes in staff and long intervals when no service from an itinerant teacher was available suggested to parents that the educational future of students with vision impairment was not a high priority.

Where parents believed a skill such as *"touch typing"* would benefit their child, they looked to the itinerant teacher to help their child obtain the skill. In addition, itinerant teachers were a source of information and support for parents but the parent of a student who was *"academically very able"* considered itinerant teachers concentrated their attention too much on students with *"severe problems"*.

In the non-government sector, students were not supported by a regular itinerant service although this is available. Parental vigilance on student progress was the main factor in ensuring that schools paid attention to issues related to students' vision impairment.

However, parent vigilance could not produce special services which a child might require, such as learning braille and other vision related skills which could only be taught by a teacher with specialised skills. This means non-government schools which do not use the regular services of a vision support teacher can be restricted in the skills they can impart to a student.

## **Implications**

It took parents some time to realise that schools were unable to deliver the individualised teaching and support for their child that parents were expecting. Parents were hindered from monitoring their child's support and advocating on the child's behalf by a lack of knowledge of the *"ideal"* support for the child with vision impairment at school and thus unable to raise questions with regard to their child. Parents had no sense of *"rights"* in this area and no parent mentioned *"discrimination"* with regard to equity in education opportunities. It is noteworthy that parents from non-English speaking backgrounds knew very little about such supports as the *"itinerant teacher"* service.

What parents did realise, however, was that their child was falling behind educationally and that this would spell difficulties later for employment. The lack of knowledge about the education system left parents with a sense of frustration and powerlessness.

## Recommendations

There is a need to:

- 20.1. Support parents with information about educational possibilities for students with vision impairment through provision of guest speakers at family workshops and by making available informative reading material.
- 20.2. Encourage parent groups to write booklets for other parents based on their experiences with schools.

## 21. Interaction with peers

Parents expected that teasing would occur at school and parents, selecting a school for their preschooler, mentioned that their criteria included not only educational "help" for students but also avoiding a school *"which did not have a compassionate feel"*. All students except those attending special schools or special units or who had kept their impairment secret had experienced teasing. The teasing, defined as verbal harassment, took various forms - *"picking on"* students, comments on wearing glasses, being called *"blind"* and other names. In addition to verbal harassment, male students in state schools mentioned *"bullying"* or physical acts such as fighting and stealing of personal aids such as sun-glasses and wide-brimmed hats.

All students who endured teasing and bullying sought ways to prevent it. Primary schools students were consoled by their mothers who tried to teach strategies. Two male students who had become proficient at martial arts and boxing used these skills to protect themselves from physical threats. As mentioned earlier, students instinctively tried to minimise their differences from others students to lessen teasing by wearing contact lenses at all times, declining offers of laptop computers where they would be the only user in the classroom and not using other pieces of equipment in the classroom.

Schools showed a variety of attitudes to teasing. Some teachers in primary schools told their classes not to tease. In other schools, principals ignored both teasing and the violence that followed. Ignoring the teasing, one principal explained, would give the student time to develop methods of dealing with it and any protective mechanism, such as the watchful eye of an older brother, should be withdrawn. When principals believed the presence of students with visual impairment created the problem of teasing and bullying, then the students had to make changes. One parent reported:

*"He [the principal] said my son had to have a special place to keep his bag, a special toilet to go to - 'If he didn't leave himself open, then nobody could take anything and nothing could happen to him'".*  
Comment of CN

When a child's teasing continued after parents had met with the principal, the solution for one student and his parents was another school where the principal stated at a pre-enrolment meeting she did not tolerate *"discrimination"*.

The parents of two students contemplated using the Disability Discrimination Act but felt uncertain about its application to schools and how to call on the Act.

When a teasing atmosphere at school was combined with inadequate support and little understanding from teachers, students had no enthusiasm for school.

*" School was really shocking: one, I never had any help from the teachers - and two, the kids picked on me - every lunch hour - fighting and that. I used to wake and think 'Oh no' and I'd try and chuck sickies to get out of school."..* Comment of CA

## Implications

The implications of teasing and bullying on equality of educational opportunities are straightforward. Teasing and bullying detract from students' ability to avail themselves of both the formal aspects of schooling and the informal aspects such as socialising in the playground.

## Recommendations

There is need to:

- 21.1. Press education authorities to become more accountable for the implementation of policies directed at student harassment and discrimination.
- 21.2. Continue to work with children and parents on the problems associated with teasing and bullying at school.

## 22. Beyond school

Although there were Disability Support Officers at TAFE, the two TAFE students interviewed had not met this person and had organised their own ways of coping.

*" I went to the teachers and asked them to make sure that everything they hand out is clear and to photocopy their overheads for me and any notes and handouts. They forget and I have to remind them."* Comments of CO

*'I think I'll end up getting someone to put carbon under their notes and we'll print them out at home - my mother will type them up.'* Comment of CA

Parents and students felt apprehensive about studying at university because they knew little about what support systems were available and how to tap into them. Neither schools nor universities appeared to bridge this information gap. The one university student in this study, like the TAFE students, organised her own support from university staff.

## Implications

The students in this study were able to make their own arrangements at tertiary level. How well this worked over time and whether they were also accommodated in other student activities, for example examinations, is not known. Moreover, how students with more severe vision impairment would fare is not clear.

This is an area in which more research on students' experiences is required.



## Recommendations

There is a need to:

- 22.1. Invite representative of tertiary institutions to publicise their support role for students with vision impairment who are entering tertiary education.
- 22.2. Conduct further research on the experiences of students with vision impairment in tertiary level education and beyond.
- 22.3. Invite students with vision impairment studying at tertiary level to talk to adolescents and parents about their experiences at tertiary level education.

## 23. Recreation

This term encompasses activities enjoyed outside formal schooling which are sufficiently structured to distinguish them from play. In this discussion, sport, dancing, playing a musical instrument, making things are forms of recreation. The term is distinguished from passive pursuits such as watching television and listening to music.

An examination of the comments of parents shows "recreation" appears to emerge as a need at approximately eight years of age. The value of recreation according to the comments of adolescents and parents is its interactive aspects, its contribution to fitness and to better movement and co-ordination, its opportunities to enhance self-esteem, the enjoyment of physical energy and its mental challenge.

All parents except two, who were very involved in finding suitable recreation for their children with severe disabilities, were concerned about participation in sport. The main reason for non-participation, if sport was available, was inability to see balls, the effect of movement on eyes and the inability to see into the distance, for example when running. Glare in some sports, for example water polo, also made participation difficult but not impossible for an adolescent with oculo-albinism. In some cases it was another disability, not vision impairment, that affected participation - for example, a child's behaviour made co-operation in team sports difficult; the tripping gait of a child with hemiplegia prevented running more than short distances.

Parents worked hard to find activities in which their child could participate. Their efforts were also helped by those schools who took a wide interpretation of sport and counted aerobics, yoga and other non-competitive activities as sport. Hence, children and adolescents participated in a wide range of activities: these are listed in the Appendix.

Parents of children with disabilities may look either to "mainstream" sport and recreational activities, or they may turn to activities specifically for children or young people with disabilities. Families of adolescents with multiple disabilities used recreational services for young people with disabilities provided by community organisations. Parents whose adolescents used recreational services for young people with disabilities argued there are a number of problems with these services: there are insufficient opportunities to participate and adolescents wait for months for particular activities. Moreover, the quality of care from workers is "worrying" and parents and adolescents were "uncomfortable" about some workers. The choice of activities was described as "limited" and there is little recreation available during school holidays. Parents noted that some activities, such as swimming

at council pools, was prevented because of the lack of physical access to the facility and to the pool itself for people with wheelchairs. The rigidity which existed in services also caused problems. One parent stated:

*"M's friend lives in [suburb X] and goes to a recreational service in X and we go to one in [suburb Y]. But M can't cross boundaries and take a friend along to the service. If M wanted to take her friend she can't because that position has to be kept for someone in Y. So we don't use the service much and we, the parents, make another arrangement to get around this - ... We wouldn't like to break the friendship up."*

Parents of young children other than those with multiple disabilities were experimenting with various mainstream activities for their child.

Finding suitable sport meant parents and the child accepted that there were activities the child would not do. This realisation was an emotional experience for some parents and the child. The judgments of parents were sometimes fiercely contested by children - for example, the parents of a child who had been knocked out at football because he had not seen other players, experienced "some friction" when they stated football was not an appropriate sport. Then, the task of finding alternatives which were agreeable to both parties had to begin. Acceptance of sports such as martial arts, took some time for children socialised to play such popular sports as football.

Recreation also meant non-sport activities such as playing musical instruments and dancing. Learning these activities depended on teachers who understood students' needs and were willing to adapt their practices to meet the student's need. If a teacher refused to accommodate a student's needs, parents ended such activities as dancing. This occurred when a teacher who rotated students around the room refused to make an exception to her practice for the student with vision impairment, despite the parent's request.

Even if teachers were helpful, parents felt the onus for ensuring the child learnt, fell back on parents. Two parents talked about how they were seeking ways to enhance their children's learning of music and whether there were *"easier ways and little tricks"* for handling particular problems.

The degree of vision impairment did not prevent participation in recreation although it involved parents in looking around and trying various activities. One blind child "made things", loved camping and was an avid player of a music organ; others participated in horse riding, swimming and gymnastics. Children and adolescents living outside the metropolitan area were not disadvantaged and participated in recreational activities as much as metropolitan children and adolescents.

## **Implications**

Participation in recreational activities is clearly important to parents, children and young people. To be participating in recreation was considered "normal" and a mark of inclusion in society. Moreover, recreation is considered to provide a number of benefits to individuals such as providing opportunities for having positive relationships with others and for breaking down stereotypes.

The lack of well managed recreational opportunities for children and young people using "disability services", especially in school holidays has serious implications. Apart from missing recreational

opportunities enjoyed by other children, children became bored, often regressing on important social and personal skills. Moreover, when there were no vacation care programs some parents had to leave paid employment to care for children in this period.

## Recommendations

There is a need to:

- 23.1. Publicise, for the information of parents and those working with children and adolescents with vision impairment, the variety of sports and recreational activities for children and adolescents and sources of community and government assistance.
- 23.2. Lobby for increased funding for recreational activities and holiday programs with a view to supporting these efforts.
- 23.3. Prepare parents, children and adolescents, when dealing with the emotional component of vision impairment, for the disappointment that is experienced when it is realised that particular sports cannot be played. Information on the range of activities which children and adolescents with vision impairment successfully undertake should be readily available

## 24. Employment matters

The work context in which young people seek employment is a complex one. In the "mainstream" workforce, unemployment of young people who leave school without further qualifications is high. Among the employed workforce, women have been accepted as part of the workforce and contract, part time and casual work are increasing trends. Employers seek the most "efficient" labour units and potential employees are aware of the need for experience, skills and attractive personal qualities.

Job applicants with disabilities may compete with non-disabled applicants or they may consider some form of employment assistance, available from government sponsored support programs after assessment. In addition, a Post School Options Program is available which aims to *"bridge the gap for school leavers between departure from school and participation in the wider community and assuming adult life roles"* (ADD, 1998).

All young people involved in integrated schooling, and their parents had high expectations of work. Work to young people meant "financial independence" from parents and symbolised adulthood. Of the 12 young people in this study, one was working full time as a clerk in a government department, two were TAFE students, one was a university student and the remaining eight were at school. Two had worked part time in food services and a third student was about to apply for part time work.

A worry for young people contemplating work or in the workforce was the stage at which they felt it necessary to inform employers of their disability. Two young people felt it was better to *"discuss the sight problem up front"*. One of these young people felt he could argue at his job interview that he could perform in his chosen area with his disability although he admitted it was a *"hurdle"* to be overcome. Two other young people had accepted jobs and their employers had discovered their impairment while they were working. Both of these employers saw no reason to take any further action. However, one of these young people applied for another job, succeeded and went on a training program. Before this young person could work on the job, the employers contacted the young person



and terminated the employment. After giving one reason for the termination, the employers then stated the real reason was they thought the employee could have an accident in certain areas of the work.

A further dilemma for young people was whether to maintain their career ideals or to modify them because of their impairment. Three young people who had specific occupations in mind had changed from their original choice to another career which they considered less demanding.

When students and their parents were uneasy about job choices, they were unsure of where to turn for further information. Both of the areas of uncertainty related to ability to practise particular professions. In one case, a student was concerned that a professional association might have some requirements about vision, and in the other case, a student wondered if there was helpful software in his area of interest.

Two parents commented on the role of itinerant teachers in occupational choice. Where an itinerant teacher contributed information, the student and parent received this gratefully. But if a parent felt an itinerant teacher did not share the aspirations of the parent and student, the parent was critical of the role of the itinerant teacher, seeing the teacher as limiting the potential of students with vision impairment.

Where there was no itinerant teacher attending the private school of a student, the parents and student pinned their hopes on *"vocational guidance"* at school to help in the choice of occupation.

A further area of difficulty was finding information on whether employers would provide special equipment to enable an employee to do the job if a young person's application for a position was successful. One parent stated that it seemed unlikely that *"small business"* would spend money on equipment for an employee with vision impairment but the parents had heard about *"government assistance"* and wanted information about this and possible entitlements for an employee.

The attitudes of parents and students to obtaining successful employment ranged from pessimism to cautious optimism. The students and parents who seemed least concerned were those who were considering professions such as medicine and were considering university or were already there. This optimism stemmed from a demonstration of the student's capacity at school. Where school had been difficult or was currently difficult, then there was an expectation of job difficulties.

The parents of a student not entering competitive employment felt pessimistic about the future activities of their daughter. The pessimism related to whether such programs as *"Post School Options Program"* would be continued and obtaining a place in a program, a concern vindicated by the estimate that only 40 per cent of people eligible for Disability Services Programs were placed in them (Baume and Kay, 1995). If a student was not placed on a program, then parents foresaw radical changes in their own lives. As one mother commented:

*"She'll leave school at 18. She's now 14. In another 4 years what will I do? I'm starting to think now about how I'll have to give up my job to mind her because we couldn't afford to have someone come in and do it. It just means a whole change of life."* (Parent of CM)

## Implications

Whether a young person will be successfully occupied in employment or a suitable day program is an important issue to parents for several reasons. If successfully employed and earning a "living", then parents view their child as "independent" and they are less anxious about how the future needs of their child will be met. If a young person is accepted into a full-time well-organised day program or form of supported employment, parents are similarly relieved of anxiety for the child and for themselves regarding their care responsibilities.

While still in the school system, the main need of parents and young people is making contact with sources of information related to future employment. While still at school or at tertiary education, young people and their parents want to learn how others with vision impairment have succeeded in employment. They want to hear stories of how their peers have managed in such matters as job interviews and telling employers they have an impairment. Information from peers would also help with uncertainty about ability to do jobs and to what extent young people should modify their ambitions.

In addition, young people have no strategies for plugging gaps in information about the contents of particular jobs, both the official requirements and the more informal aspects. The assistance that employers might provide to employees with disabilities and government assistance should also be part of the "story" which employed people could provide.

The lack of places for students from special school in employment or day programs is not only a worry for parents. For the young person it can mean separation from the community back to a form of segregation, living at home. Without continuous stimulation the skills learned at school are often lost and the young person is bored without social contact with others.

## Recommendations

There is a need to:

- 24.1. Provide the best quality educational experience and careers advice for children and adolescents with vision impairment, so that their chances of employment are maximised.
- 24.2. Facilitate sharing between adolescents and employed people with vision impairment in which the latter group talk of such experiences as obtaining work, working and the types of equipment employers have provided.
- 24.3. Sponsor a project in which stories of people's employment experiences are collected and published in appropriate formats and which serve to inspire and inform other young people and parents.
- 24.4. Familiarise itinerant support teachers and career advisers with the concerns of parents and adolescents in relation to careers and employment for people with vision impairment.
- 24.5. Monitor the post-school experience of adolescents who leave special schools/units and, where necessary, advocate for the expansion of post-school options programs and employment support programs.



## 25. Extra costs of disabilities and government assistance

In the preceding sections, various items which parents and adolescents have viewed as extra costs stemming from disability have been mentioned. Briefly, these were medical costs, wheelchair and other mobility aids, continence aids, travel costs (local and travel from country to the city), vision aids, respite care and, for some, the cost of contributions to private health funds.

The consequences of the extra costs meant adjustment in family expectations. Women, who had not intended to work, identified the extra expenses related to disability as the "pressure" which forced their return to work to supplement family incomes. Families who wanted their child to have the social and educational benefits of child care found the cost was too high for them and made alternate, less expensive arrangements for their child. Expenditures which could be delayed, for example, the child's visit the dentist, were postponed indefinitely because the family's finances were stretched.

Given these costs, parents were pleased to receive any support, financial or in kind, from government. The "Health Care Card" often meant doctors "bulk-billed" and pharmaceuticals listed under the Pharmaceutical Benefits Scheme (PBS) were paid at concession prices. But medications not on the PBS list were an expensive item for families, although some families obtained expensive medications through hospitals. Nappies for older children were another expense mentioned by the families concerned. As mentioned earlier, PADP benefited few families due to its income test and other restrictive policies. Similarly, the NSW Government Spectacles Program was means-tested. None of the families interviewed were eligible for any assistance. (Two families were unaware of the existence of the Program).

All families except two from non-English speaking backgrounds were aware of the Child Disability Allowance (CDA) from the Department of Social Security. The consensus on the amount paid was that it was too "small", particularly considering the application form which was considered a "hassle" and "all double Dutch". However, parents welcomed the entitlement to a "Health Care Card" which went with receiving CDA for the benefits mentioned above.

The medical certification which was required for application to CDA was the site of difficulties for parents whose certifying doctors did not know the child and parent and wrote scant and dismissive information on the application form. This caused parents to worry about losing the money from CDA and their Health Care Card. When the CDA application forms of parents were lost, either in Social Security or in the hospitals certifying the forms, parents, especially those who were unfamiliar with Australian institutions, were perplexed and worried by the ensuing delay which affected the child's access to other benefits, for example, PADP.

Parents who believed that claiming CDA would label and stigmatise their child had not claimed.

Both parents and adolescents were confused about the income support available for adolescents who were studying. The parents of some adolescents were still receiving CDA. Other parents stated that the Disability Services Pension (DSP) would not be paid until their child left home to go to university. However, some university students were living at home and receiving DSP. Secondary students who Social Security judges are likely to find employment for 30 hours per week were not eligible for the DSP, despite the seriousness of their impairment.

The existence of the Isolated Patients and Travel Accommodation Assistance Scheme (IPTAAS) was not known by all non-metropolitan families. However, other parents claimed that the way in which IPTAAS operates means that it helped only families with surplus cash. This was because families had to pay for the initial costs of a trip and claim back their costs which often took up to three months to process.

The organisation of hospital beds further complicated finances for parents, as explained by one parent:

*"If you get a cheap air fare and they [the hospital] can't fit you in that day you either lose your money or you have to upgrade the ticket which means paying the full fare."*

The solution, according to this parent, was the "QANTAS Carer's Card" which cost \$20 but lasted "four or five years", allowed the child's carer to travel at half price, saved "upfront money" and allowed parents to travel on the day the hospital bed was available.

If young people were unable to travel on public transport or parents were unavailable to drive them, they found the costs of travel within the metropolitan area expensive when they had to use taxis. Although taxi fares were discounted 50% with a voucher from the Taxi Subsidy Scheme, the remaining payment (also 50%) was still a high expense for a student to meet when long distances were involved.

### **Implications**

The extra costs of disability constitute a pressure on particular families in the community which many consider inequitable. The structure of such programs as PADP and the NSW Government Spectacle Program benefit comparatively few families because benefits are designed for award only to those on incomes as low as Social Security payments. The Continence Aids Assistance Scheme (CAAS), while not income tested, excluded those under 16 years of age. This meant the only assistance which many families received was the CDA which parents described as "meagre" despite the cumbersome application form preceding payment.

In addition, people from non-English speaking backgrounds were least likely to know of such government welfare programs as Child Disability Allowance and NSW Government Spectacles Program. However, all parents were becoming confused by the continuing name changes and "rationalisations" of government welfare programs.

### **Recommendations**

There is a need to:

- 25.1. Lobby for extra financial assistance for families of children and young people who incur extra, unavoidable costs due to disability.
- 25.2. Examine the Review of PADP when this is released by the Department of Health and the Ageing & Disability Department and inform client families of its implications.
- 25.3. Check that parents from a non-English speaking background have been given information on community services and assistance in appropriate languages and formats.



- 25.4. Discuss with such personnel as ethnic community workers, ways in which they might work together to ensure that services reach people of non-English speaking background.

## 26. Information

Sprinkled throughout the comments of parents and adolescents were comments about the need for more information.

Parents had a strong need for information following the diagnosis of their child's impairment. This need for information on medical aspects faded if families found sufficient information to satisfy their needs but continued if parents received insufficient information. The medical profession was seen as the source of medical information although parents acknowledged they had received helpful, understandable information from orthoptists employed by blindness organisations.

As mentioned in the section on genetic counselling, the need for medical information was also future-oriented. Both parents and adolescents contemplating their futures wanted information on where the impairment "*came from*" - what caused it, whether it was inherited and "*how it will all end up*".

When interviewees, who spoke about their need for more "more information", were asked on what topics, their replies had two characteristics: one, they felt "*out of touch*", that they didn't know what was happening with regard to "*any medical breakthroughs*"; and two, their needs related to technologies such as "*new inventions*", "*what's available through computers and other assistance*" and whether any "*high tech devices*" had been invented which would make life for their child easier. Implicit in these statements was the question of how they would be informed if any developments had occurred as no mechanism appeared to exist.

As mentioned earlier, parents were hungry for information on community services and other social supports at the time of diagnosis. This need faded over time as parents became experts on community services in their area.

The most specific area of information which parents mentioned was behaviour management: should certain behaviours be ignored or dealt with in some way and who could advise parents on these matters. Parents who had tried to obtain information and guidance from counsellors and early intervention workers found they were unable to help. Thus, parents stated they did not know who could provide guidance on behaviour management which remained an area of unsatisfied need with no identifiable agency to which parents could turn.

Parents also mentioned a need for further information on education matters. This need grew out of concerns for their own child. For example, a parent wanted to know about the organisation of itinerant support teachers and "*whether it [the service] was doing enough*" for his child. Similarly, parents who were concerned about their child being bullied at school wanted information on "*discrimination*" legislation and which community organisations could help with this topic.

As mentioned earlier, adolescents and their parents had some specific information needs on their careers and employment matters.

Parents used many sources of information: at first medical professionals, then, professionals in community organisations were helpful sources. Some parents found their child's itinerant support teacher a source of information. Parents of non-English speaking background, who were recent arrivals to Australia, stated that they would have appreciated information in their own languages. One father had acquired a computer program to translate English into his own language which he applied to information on his child's vision. Parents with access to the Internet searched for information related to their child's vision impairment. Most had not found the information from the Internet very satisfying and no parent mentioned contacting other parents of children with vision impairment via the Internet. Parents who enjoyed reading about aspects of their child's impairment questioned if they could access libraries of disability and blindness organisations.

## **Implications**

The need for information is related to parents need to feel in control of family affairs and to have some autonomy about how these will be managed. This need is manifested in how decisions about their child are made: parents want to be "partners" with service providers and professionals, and do not want decisions imposed on them. The fact that information needs on behaviour management and sources of help are not met is a serious gap because families who cannot manage a child may seek to have the child placed in care.

The need for information on school education policies is related to the child's long term future in society. Awareness of how schools should operate allows parents to recognise "gaps" and negotiate solutions. Moreover, parents lack a clear picture of what occurs in schools and what "*best practice*" for their child is.

The Internet offers opportunities for parents to obtain information from both community organisations and such informal sources as other parents. However, the Internet is not available to all families. Also, much of the current information parents obtain is technical underscores the point that parents need "*understandable*" information.

## **Recommendations**

There is a need to:

- 26.1. Investigate means by which agency information can be made available to client families.
- 26.2. Develop reading lists of books and articles on topics which are identified by parents and adolescents. These could be made available through the Internet.
- 26.3. Make lists of recent articles and books, prepared by library staff, available to parents who request this service. These could be made available on Websites.
- 26.4. Encourage parents to exchange information with each other and, where possible, to resource each other.
- 26.5. In conjunction with ethnic community organisations, community organisations and government departments, provide information on eye conditions and community resources in community languages for individual clients.

## **27. Needs arising from child's family status**

Three of the children contacted in the project were fostered by the parents who participated in the project. One foster parent raised a problem which stemmed from the child's foster status. She mentioned that obtaining respite care was difficult for the fostered child when one of the other children, and thus the mother, went into hospital. The fostered child was not allowed to be taken to another carer and the mother had to organise for a carer to come into the house. The foster mother thought there should be more flexibility in the care arrangements to allow for family emergencies.

One family had adopted a child from a nursing home. The adoptive mother was surprised that she has received no help, that she has been alone and no one explained to her what her social entitlements were. In this respect, this mother's experience was similar to those of natural mothers.

### **Implications**

Fostering has provided non-institutional care for children and young people when a break from their natural family has been necessary. This option will be maintained if the difficulties of carers are known and sympathetically considered.

Adoptions also play a valuable role in the care of children with disabilities. Again, this alternative needs to be nurtured by having the best possible systems in place.

### **Recommendations**

There is a need to:

- 27.1. Take account of the needs of foster parents regarding respite care.
- 27.2. Offer information on the services of the major organisations serving children with vision impairment to adoption agencies.

## **28. Conclusions**

In many areas of development, parents were aware that their child was not advancing in skills or knowledge but they found it hard to say what the problem was. This underlines a difficulty in asking people about their "needs". Unless people have been given some pictures of "ideal services" they are unable to say what is missing. For example, many parents did not know whether their child should be having orientation and mobility training because they were unsure whether children needed it or whether it was done later in adolescence.

Education was also an area in which parents had little idea of what kinds of inputs their child might have and who should provide them. Moreover, when parents were receiving many of their services they found it hard to comprehend the service because the Individual Service Plan had not been shared with them or a written copy had not been given to them. Further, parents did not understand the role of many professionals such as counsellors, social workers and optometrists and lacked sources of information on practical elements of service provision.



Certain social groups are more vulnerable to lack of services and not understanding : children from non-English speaking backgrounds, children whose parents are illiterate and children who have high support needs. In addition, children crossing the boundaries of such major systems as hospital to life at home or from pre-school to school are in danger of *"falling into a hole"*.

Throughout the conversations with parents and adolescents it became clear that they wanted to be in control of their own affairs. Information pitched at the right level was perceived to help people and give a higher degree of certainty. Similarly, professionals who worked empathetically encouraged and legitimated parents in their actions. However, in situations where parents feel overwhelmed by the complexity of their situation and lack someone to listen sympathetically to their account - for example, when facing discrimination, there is a need for advocacy.

Where the needs of children and adolescents stemmed from government policies such as the ages at which the CAAS scheme operates, parents needed to be informed of the difficulties in changing policies and where decisions in these areas were made. Parents and adolescents could be invited to comment and explore these sorts of policy issues further.

It is reiterated that the needs of Aboriginal people, as a community, have not been addressed in this study. From the literature and the work of the researcher in this area (Hogan, 1998) it is clear that this research should be done with the Aboriginal community and that it should have direct tangible benefits to the community.

### **General recommendations**

There is a need to:

- 28.1. Continue to model exemplary Individual Service Plans and other forms of quality practice.
- 28.2. Ensure that client families understand the role of the various professionals they encounter.
- 28.3. Undertake research with selected communities from non-English backgrounds.
- 28.4. Record or videotape information sessions and make these available to families in appropriate formats and through the Internet.
- 28.5. Further investigate models of co-operative research and ways of working with Aboriginal communities.

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## Appendix 1 Project methodology

The project entailed two research tasks that were derived from its Terms of Reference-

*[1] Provide a comprehensive picture of the child and family characteristics of those in the sample, particularly ensuring adequate coverage of Aboriginal and people of non-English speaking background; and*

*[2] Examine and analyse the ways in which needs of the State's population of children with vision impairment (and their families) are currently being met from disability and health agencies and other sources. Produce evidence of any unmet need.*

In this report the tasks will be treated separately. Before embarking on both tasks, literature pertinent to the area was sought including information on similar research which had been conducted elsewhere in the world. Reading on these topics relating to the research (a) sensitised the researcher and (b) provided the list of topics which were later used as "interview prompts" in the survey.

### 1. Provision of a comprehensive picture of child and family characteristics

The purpose of this task was to obtain a "snapshot" or profile of the children and their family situation. As clients listed on the RIDBC database overlapped clients on the RBS database to a considerable extent (60 per cent), it was decided to use the latter, which was consequently "cleaned" of repetitions and redundancies.

The project's Steering Committee then decided that data should be collected with a "simple" two-sided sheet which would take little time for clients to complete. In addition to asking basic Census-like questions, it was decided to ask families to indicate what where their current needs and what future needs they anticipated. Also, in preparation for the second research task, clients were asked about their willingness to be interviewed.

Almost 2000 clients were mailed a survey form with an explanatory letter and a "reply paid" envelope. The initial return was 307 forms (15 %). The Committee decided that the return rate should be enhanced if possible, and reminder postcards were sent to clients. The final number of responses was 496, (25%).

Most of the data on the survey forms did not require complex coding. In those areas which did require coding, this was done by the same person so consistency in coding decision could be maintained. The coding was then entered on to computer and processed using SPSS software to produce frequencies and cross-tabulations.

It is difficult to know how representative this sample of clients is of all clients of the organisations. The representation of metropolitan and non-metropolitan clients is balanced and gender representation is as expected with slightly more than half the children represented male. It is possible that the survey under-represents children from non-English speaking backgrounds as only an English version was sent out. However, this would depend on the number of clients who cannot read English and required translations which from experience in the second research task is a very small number. The survey form was returned by some people from a non-English speaking background but these clients completed the question on "languages spoken at home" as their first language and English. Similarly, the number of Aboriginal clients who returned a survey form was extremely small while the number of clients is known to be larger, though still a small number.

Some of the questions on the survey form were answered in unexpected ways, despite piloting the form. One of these questions had to do with the effect of vision impairment on the child and some example answers were provided, but nonetheless some parents wrote such comments as "*She can't see too well*". Questions about future and current needs were answered at varying levels of abstraction although examples were provided - for example, some parents wrote "health and happiness" while other wrote more specific needs such as "that she is able to get a job". When asked about willingness to participate in an interview, a small number replied "*uncertain*". An orthoptist helped in the classification of medical diagnoses of eye impairment; moreover, a number of children had more than one impairment.

Despite the "broad" picture of needs given by a few families, an indication of needs for each age group emerged (infants, primary school age and secondary and beyond) which indicated schooling" as the area of greatest concern.

## **2. Examination of ways needs are met with evidence of unmet need.**

The purpose of this task was to yield information for service providers. The aim was to provide a picture from a wider group - all children and adolescents with vision impairment in New South Wales (NSW) and the Australian Capital Territory (ACT), clients and non-clients of RBS and RIDBC. In addition, strong representation from Aboriginal people and people of non-English speaking background was required.

Data for this task were obtained by structured interviews, aided by a list of prompts derived from issues revealed in the literature review. Interviews were conducted over the telephone, recorded and transcribed. Names were derived from the survey forms, as outlined above. Participants were contacted by telephone to ascertain their willingness to participate, their role in relationship to the project was explained. They received assurances of confidentiality and anonymity and a suitable interview time was arranged. Client names were organised into the following age groups; infants, primary and secondary and beyond, and clients were randomly selected from these three groups.

It is remotely possible that selection of participants from those who returned survey forms and were prepared to be interviewed biased selection towards those who were comfortable talking about their experiences and had experienced reasonable outcomes. A number of people wanted to be interviewed because they were angry about the provision of services and wanted their stories told.



Most of the participants were parents and most were mothers. This factor raises the issue of how well a parent can represent the needs of a child or adolescent. In the case of the latter, this will vary and the better interview method is possibly, to speak directly to adolescents.

A further assumption is that those parents who returned survey forms and agreed to be interviewed are not different in any way from those who did not return forms or did not agree to be interviewed. The results of the research may, therefore, be biased toward a group of people in the community who habitually return survey forms

### **Seeking the views of people with non-English speaking background**

Representation of people with non-English speaking background presented difficulties. It was thought that those who indicated on the survey form willingness to participate in an interview, and who spoke another language at home would be a source of people from non-English speaking backgrounds. However, many of these people spoke good English and had little trouble with information or in understanding English-speaking professionals. The decision was made that these people did not experience the difficulties which a person who speaks no English probably encounters, so both organisations were asked for lists of clients for whom interpreters had been used and these people were asked if they would participate in an interview. (None of these people had returned a survey form).

Three interviews using interpreters were conducted. These interviews were qualitatively different from the other interviews in that the use of an interpreter reduced the open, flowing nature of the dialogue and the conversation was structured into a question and answer session. The researcher also suspected that the interviewees were trying to say the "right" answer and trying to be pleasing.

### **Seeking the views of Aboriginal people**

There were also difficulties in obtaining representation from Aboriginal parents in interviews both as clients and non-clients. Only one Aboriginal person had returned a survey form. This matter is discussed further below

### **Seeking the views of agency "non-clients"**

Attempts were made to contact non-clients of RBS and RIDBC and to interest them in participating. Advertisements were placed in metropolitan and non-metropolitan newspapers and notices calling for appropriate participants were sent to all Early Intervention programs in NSW. This process yielded six participants, some of whom had been in contact with the two sponsoring organisations some years ago but had since considered themselves ex-clients.

Advertisements were also placed in the press and on the local radios of 11 major non-English speaking communities. Contact was made with community workers for each community to act as a "go betweens" and answer questions. However, this method did not yield any non-clients. Some community workers thought that due to strict application of the Immigration Act there were few people with disabilities in their community; others believed that people did not answer advertisements in the newspapers but acted more on "word of mouth" or through personal recommendation. Thus, there is no representation of non-English speaking people in the non-client group.



## **Representation of Aboriginal people in the project**

The Terms of Reference required that the needs of Aboriginal Australians be included in the description of people in NSW. Through the North Coast office of RBS, the researcher (Hogan, 1998) was introduced to an Aboriginal person (UV) with whom the project was discussed. UV pointed out that it would be difficult to carry out the research for several reasons. One reason was that a white researcher needed a "liaison person" when contacting non-client families. Another difficulty was the time dimension which clashed with Aboriginal notions of time. Moreover, Aboriginal people considered themselves "over-researched" with most often, little benefit of the research flowing to them. Relationships between Aboriginal and non-Aboriginal Australians were characterised as "mistrustful" because of historical injustices the former had experienced. Aboriginal Health Workers were overwhelmed in their work by "survival issues" (for example, heart disease, injuries from domestic violence and alcohol intake, malnutrition, diabetic complication) and did not have the time to identify children with vision impairment or carry out preventative work, although three workers said they would ask families about children with vision impairment..

The researcher decided to contact Aboriginal Health Workers throughout NSW. Only one Worker knew of a child who was a client of RBS. The Workers pointed that the Aboriginal attitude to disability was likely to mask the presence of vision impairment as most indigenous people managed disability as part of the everyday adversity of life, unless the disability was multiple. Moreover, not to manage disability within the family and Aboriginal community meant turning to a large bureaucracy, either government or non-government. These were regarded with suspicion and often strenuously avoided. The general opinion of Aboriginal Health Workers was that non-government agencies such as RBS and RIDBC would not be used by Aboriginal people unless they demonstrated that they understood the needs of Aboriginal people by employing them and offering their services in a culturally sensitive manner.

Two interviews only were held with Aboriginal clients from the RBS database and no Aboriginal non-clients were discovered.

## **Data analysis and interpretation**

Interviews were conducted by phone and were tape-recorded with respondents' permission, to ensure that the data were accurate. Where permission was not given for recording, the transcript was sent to the respondent for verification.

Data from interviews were then analysed qualitatively. This process consisted of identifying and labelling themes of "need" in each of the transcripts. Many themes were analysed in sub-theme sections. Texts with a corresponding theme were then examined and compared so that a particular need theme became clearer. Part of the examination involved exploring circumstances which had generated the feeling of need and also the ways in which people managed when the need was "unmet". The results of this process were then interpreted in the light of current social theory on social causes of disability as marginalisation from active societal participation .

## Appendix 2 Acronyms used in this Report

CDA	Child Disability Allowance
ADD	Ageing and Disability Department
AIHW	Institute of Health and Welfare
CAAS	Continence Aids Assistance Scheme
CSDA	Commonwealth/ State Disability Agreement
DOCS	Department of Community Services
IPTAAS	Isolated Patients and Travel Accommodation Assistance Scheme
IST(V)	Itinerant support teacher (vision impairment)
MDS	Minimum Data Set
PADP	Program of Appliances for Disabled People
PBS	Pharmaceutical Benefits Scheme
RBS	Royal Blind Society
RIDBC	Royal Institute for Deaf and Blind Children

### **Appendix 3 Letter to parents**

9 December 1997

Dear Parent,

I am writing to introduce myself. I have been contracted by Royal Blind Society and Royal Institute for Deaf and Blind Children to undertake research. However, I am not an employee of either organisation and work independently.

The research is an inquiry into the needs of children and young people under 19 years of age with vision impairments and their families. The aim of this research is to allow both organisations to understand the needs of their clients and to tailor services better to meet those needs.

This research will have a number of parts. One part consists of a simple survey. The survey form is enclosed. I would be grateful if you complete this and return it in the stamped addressed envelope included with this letter. The form should be returned by 19 January, 1998.

Another part of the research is "in depth" interviews with a small number of parents and young people. The "in depth" interviews will be conducted by telephone in most cases and these interviews will be conducted early next year.

The research will include interviews with people from non-English speaking backgrounds and Aboriginal and Torres Strait Islander people to learn about their particular needs and how services could better meet these. Special arrangements will be made to talk to people who feel the telephone is not suitable for their interview.

It is important that you understand that any comments you make to me will remain confidential. Your name or any other reference you make will not be used in any way which would identify you or any person or place you mention. After the research has been completed all confidential material will be destroyed.

I hope you will be able to participate in this project. However, if you choose not to participate, please feel assured that your services from the above organisations will not be in any way affected.

Yours sincerely,

Marilyn Leeds

## Appendix 4 Parent questionnaire

# POSTAL SURVEY OF NEEDS OF CHILDREN AND YOUNG PEOPLE WITH VISION IMPAIRMENT

1. NAME OF YOUNG PERSON OR CHILD (Please print).
2. RELATIONSHIP TO CHILD OR YOUNG PERSON (e.g., mother).
3. AGE:                                  DATE of BIRTH:
4. TELEPHONE NUMBER : (         )
5. MEDICAL NAME OF EYE CONDITION (e.g., cataracts).
6. EFFECT OF EYE CONDITION (e.g., blindness or partial sight in one or both eyes).
7. WHAT LANGUAGES ARE SPOKEN AT HOME?
8. PLEASE TICK IF ABORIGINAL OR TORRES STRAIT ISLANDER.      \_\_\_\_\_
9. DOES THE CHILD OR YOUNG PERSON HAVE OTHER DISABILITIES IN ADDITION TO VISUAL IMPAIRMENT? (e.g., hearing problems)
10. If YES, BRIEFLY, WHAT ARE THESE?
11. PLEASE NAME THE EDUCATIONAL INSTITUTION OR WORKPLACE ATTENDED IN 1997.
12. WHAT EDUCATION LEVEL HAS THE CHILD OR YOUNG PERSON REACHED AT THE END OF 1997? (e.g., just finished 1st year, TAFE)

Please turn over

13. WHAT VISION-RELATED SERVICES HAS THE CHILD / YOUNG PERSON RECEIVED IN THE PAST (Briefly)? WHO PROVIDED THE SERVICES?

Services  
(e.g., Attends playgroup)

Provided by  
(e.g., Royal Blind Society)

14. WHAT DO YOU CONSIDER ARE THE NEEDS AT THE MOMENT OF THE CHILD OR YOUNG PERSON?

15. WHAT DO YOU THINK ARE THE FUTURE NEEDS OF THE CHILD OR YOUNG PERSON?

16. WOULD YOU BE WILLING TO PARTICIPATE IN AN IN DEPTH SURVEY ABOUT THE NEEDS OF THE CHILD OR YOUNG PERSON ?

THANK YOU. PLEASE PLACE THIS SHEET IN THE STAMPED ENVELOPE.



## Appendix 5 Results of parent survey

Table 1: Responses to survey (N=1930)

No. of survey forms sent out	1930
• Envelopes returned - "wrong address"	136
• Parents saw survey as "inapplicable" to them	3
• Child / young person deceased	3
• Forms returned blank	5
• Forms returned completed	512 (26.5%)
• Forms not returned	1271

Table 2: Gender of child or young person represented in survey (N=512)

	Frequency	Percent
Female	214	41.8
Male	285	55.7
Unable to be deduced from name	13	2.5
Total	512	100.0

Table 3: Age groups of children and young people represented in survey, (N=512)

	Frequency	Percent
Infants, before school	137	26.8
Primary school age	213	41.6
Secondary and older	162	31.6
Total	512	100.0

Table 4: Residential address of 512 children and young people surveyed

	Frequency	Percent
Sydney metropolitan	208	40.6
Outside metropolitan	298	58.2
Left blank	6	1.2
Total	512	100.0

Table 5: Number of other disabilities in addition to vision impairment (N=512).

	Frequency	Percent
No other disabilities	247	48.3
One other disability	91	17.8
More than one other disability	169	33.0
Don't know	1	0.2
Unclear	2	0.4
Left blank	2	0.4
Total	512	100.0

Table 6: Medical diagnosis for vision impairment of 512 children and young people.

Medical Diagnosis	Frequency	Percent
Cataract	73	14.3
Congenital Nystagmus alone	62	12.1
Albinism	60	11.7
Cortical visual impairment	52	10.2
High myopia	30	5.9
Optic atrophy	28	5.5
Retinal dystrophy (cone, cone-rod, rod-cone)	27	5.3
Glaucoma	20	3.9
Retinopathy of prematurity	16	3.1
Squint	14	2.7
Leber amaurosis	13	2.5
Retinoblastoma	12	2.3
Coloboma	11	2.1
Optic nerve hypoplasia	11	2.1
Visual field loss	10	2.0
Retinitis pigmentosa	9	1.8
Pierre Robin/Stickler Wagner syndrome	9	1.8
Tumour	9	1.8
Chorioretinitis from toxoplasmosis	8	1.6
Kerataconus	8	1.6
Aniridia	7	1.4
Lens dislocation/Marfan syndrome	6	1.2
Anophthalmia	5	1.0
Macular malformation	5	1.0
Uveitis	5	1.0
Duane syndrome	4	0.8
Neurofibromatosis causing optic glioma	4	0.8
Anterior chamber problem	3	0.6
Corneal decomposition	3	0.6
Ehler-Danos syndrome	3	0.6
"Medical condition"	3	0.6
Microphthalmia	3	0.6
Optic nerve dysplasia	3	0.6
Retinal abnormality	3	0.6
Retinoschisis	3	0.6
Retinal abnormality	3	0.6
Retinal detachment	2	0.4
Behcet syndrome	1	0.2
Part of Goldenhar syndrome	1	0.2
Monocular vision	1	0.2
Refractive error alone	1	0.2
Rod monochromatism	1	0.2
Don't know/uncertain/unsure	2	0.4
Left blank	18	3.5
Unclear meaning/writing	32	6.3

**Table 7: Vision impairment of children and young people, reported by 512 respondents**

	Frequency	Percent
Blind	61	11.9
Blind-monocular	2	0.4
Partial	429	82.4
Normal	3	0.6
Unclear	16	0.4
Total	512	100.0

**Table 8: Languages spoken at home, as reported by 512 respondents**

	Frequency	Percent
English or "Australian" only	464	90.6
English and another language	40	7.8
No English	8	1.6
Total	512	100.0

**Table 9: Main activities in 1997 of 512 children or young persons**

	Frequency	Percent
Day care	11	2.1
Day care & early intervention	2	0.4
Early intervention including RBS playgroup	33	6.4
Preschool/kindergarten	19	3.7
Preschool & early intervention	4	0.8
State primary school	126	24.6
State high school	77	15.0
State special	28	5.5
Catholic primary	34	6.6
Catholic high	22	4.3
Catholic special	5	1.0
Royal Institute for Deaf and Blind Children	17	3.3
Other non-government primary	8	1.6
Other non-government high	16	3.1
Other non-government special	5	1.0
Home school - primary	1	0.2
Post school Options Program	1	0.2
TAFE	7	1.4
TAFE & employment	3	0.6
University	4	0.8
Employment	9	1.8
At home (includes babies, infants)	23	4.5
Institution/nursing home	2	0.4
Left blank	55	10.7
Total	512	100.0

Table 10: Services received in the past, reported by 512 respondents

Services	No. of responses (multiple responses) N=512	Most mentioned service providers
Assessments	137	<ul style="list-style-type: none"><li>♦ Royal Blind Society</li><li>♦ Guide Dog Association of NSW</li></ul>
Early Intervention	151	<ul style="list-style-type: none"><li>♦ Royal Blind Society</li><li>♦ Royal Institute for Deaf and Blind Children</li><li>♦ Early intervention centres</li></ul>
Equipment	70	<ul style="list-style-type: none"><li>♦ Royal Blind Society</li><li>♦ Dept of School Education (DSE)</li></ul>
Education Assistance e.g. advice on learning environment for student, enlarging materials	89	<ul style="list-style-type: none"><li>♦ Royal Blind Society</li><li>♦ DSE</li><li>♦ Royal Institute for Deaf and Blind Children</li></ul>
Community Access e.g. mobility training	45	<ul style="list-style-type: none"><li>♦ Guide Dog Association of NSW and A.C.T.</li><li>♦ Royal Blind Society</li></ul>
Medical	35	<ul style="list-style-type: none"><li>♦ Hospital/medical providers</li></ul>
Professional Services e.g. therapy, counseling	185	<ul style="list-style-type: none"><li>♦ Royal Blind Society</li><li>♦ Community Health Centre</li><li>♦ DSE</li><li>♦ Dept of Community Services (DOCS)</li><li>♦ Royal Institute for Deaf and Blind Children</li></ul>
Itinerant Teacher	129	<ul style="list-style-type: none"><li>♦ DSE</li><li>♦ Royal Institute for Deaf and Blind Children</li><li>♦ Catholic Education</li></ul>
Social/personal e.g. sport, camps	27	<ul style="list-style-type: none"><li>♦ Royal Blind Society</li><li>♦ Disability organisations</li><li>♦ Blind Sport Association</li><li>♦ Service providers</li></ul>
Vocational	5	<ul style="list-style-type: none"><li>♦ Royal Blind Society</li><li>♦ Disability organisations</li><li>♦ Community Health Centre</li></ul>
"Nil/nothing/none" - written on form	16	
"Uncertain /unclear/not sure" - written on form	11	
Left blank	38	



# 11. Current and future needs of 512 children and young people

Table 11.1: Pattern of response to questions on needs (N=512).

	Current needs		Future needs	
	Frequency	Percent	Frequency	Percent
Responses	470	91.8	397	77.6
Respondents wrote "Nil / none"	13	2.5	11	2.1
Respondents wrote "Don't know"	9	1.8	67	13.1
Respondents wrote "Not applicable"	1	0.2	0	0
Left blank	19	3.8	37	7.2

Appendix 7  
**Table 11.2 Current and future needs of 512 children and young people**

Categories of need	Current need (Multiple responses) N=512		Future needs (Multiple responses) N=512	
	Frequency	Percent	Frequency	Percent
Motor skills				
	33	6.4	17	3.3
Personal/social skills	74	14.5	78	15.2
Access to community	43	8.4	34	6.6
Broad needs	81	15.9	73	14.2
Education needs	193	37.7	161	31.4
Parent/family needs	11	2.1	10	1.9
Accommodation	4	0.78	10	2.0
Medical	53	10.4	45	8.8
Change in community attitudes	7	1.4	8	1.6
Equipment	58	11.3	67	13.1
Specific service needs	83	16.2	59	11.6
Employment	16	3.1	64	12.5

Appendix 6 Interview prompts

CHECK DEMOGRAPHIC DATA:

NAME:                      DATE OF BIRTH / AGE NOW:

SEX:                      METROP./ NON-METROP.:

MEDICAL NAME OF EYE CONDITION                      EFFECT

ONSET                      OTHER DISABILITIES                      EFFECT

MOST CONCERNING

COUNSELLING / SOURCES OF ADVICE—INITAILLY/LATER

SERVICES, THERAPIES

CONTACT WITH OTHER PARENTS

MOBILITY                      ABOUT THE HOUSE

DAILY LIVING SKILLS

SCHOOL                      FRIENDS                      TEASING

READING, WRITING                      EQUIPMENT

EXAMS AND OTHER SPECIAL CONSIDERATION

COSTS                      SOCIAL SECURITY - OTHER ASSISTANCE.

SPORTS                      INTERESTS, HOBBIES

HOLIDAYS                      RESPITE

INFORMATION SOURCES                      OTHER

Appendix 7 Characteristics of 37 participants

Parents	N=32
♦ Mothers	26
♦ Fathers	6
Adolescents	N= 5
• Female	2
• Male	3
Total No. of interviewees	37

**Note:**  
In two families, there were two children with vision impairment. Thus although there were 37 interviews the experiences of 39 children and adolescents were represented.

# Appendix 8 Characteristics of 39 children and young people

Characteristic	AGENCY CLIENTS (RBS database)			NON-CLIENTS			TOTAL N=39
	Infants N=10	Primary N=12	Second ary and beyond N=11	Infants N=1	Primary N=4	Second ary and beyond N=1	
Females	4	4	6	-	1	1	16
Males	6	8	5	1	3	-	23
English Speaking background	6	5	8	1	4	1	25
Non Eng. Speaking background	3	6	3	0	0	0	12
Aboriginal	1	- 1	0	0	0	0	2
Metropolitan address	6	6	9	0	1	0	22
Non- metropolitan address	4	6	2	1	3	1	17
Disabilities in addition to vision impairment:							
- Nil	1	5	10	1	1	1	19
- One other	4	4	0	0	0	0	8
- More than one	5	3	1	0	3	0	12
Vision:							
- Blind	1	4	1	0	1	0	7
- Partial	9	8	10	1	3	1	32



**CHILDREN AND YOUNG PEOPLE INTERVIEWED,  
BY AGE GROUP (N=39)**

Group	Numbers		
	Clients	Non-clients	Total
Infant	10	1	11
Primary	12	4	16
Secondary, tertiary	11	1	12
<b>TOTALS</b>	<b>33</b>	<b>6</b>	<b>39</b>

**CHILDREN AND YOUNG PEOPLE INTERVIEWED  
School Attendance at time of interviews (N=39)**

Not at school yet (infants)	10
<b>At primary school or special school</b>	<b>17</b>
• State primary	9
• Catholic	2
• Other non-government	1
<b>At special schools/units</b>	<b>6</b>
• State	4
• Catholic	1
• Non-government	1
<b>At secondary school</b>	<b>8</b>
• State secondary	2
• Catholic	2
• Other non-government	3
<b>At tertiary education</b>	<b>3</b>
• University	1
• TAFE	2
Left school	1
<b>Total</b>	<b>39</b>

**Appendix 9 Aboriginal and non-Aboriginal children in the Northern Territory Education Department's Advisory Service (N=66)**

Condition	Non-Aboriginal N=25			Aboriginal N=41		
	Female	Male	Persons	Female	Male	Persons
Congenital cataracts	4	2	6	6	2	8
Traumatic cataracts	1		1			
Cortical vision impairment	1	6	7		1	1
Optic atrophy		1	1	2	2	4
Retinopathy of prematurity	3	1	4		1	1
Myopia	1		1	1	2	3
Congenital glaucoma				1		1
Kerataconus		1	1		2	2
Retinitis pigmentosa					1	1
Retinoblastoma				1	1	2
Congenital dislocated lens				1		1
Coloboma	1		1	1	1	2
Nystagmus				1	5	6
Aniridia					1	1
Ocular albinism				1	1	2
Hypermetropia					1	1
Bilateral-microphthalmia				2		2
Central scotoma (traumatic)	1		1			
Delayed visual maturation					1	1
Exotropia, astigmatism	1		1			
Accommodative esotropia				1		1
Heminopia	1		1			
Marfans					1	1

Source: Mason and Gale, 1997: 56.

## **Appendix 10 Recreational activities of children and adolescents**

Windsurfing  
Rock climbing  
Yoga  
Swimming  
Aerobics  
Bushwalking  
Martial arts  
Karate  
Boxing  
Gymnastics  
Horse riding  
Trampolining  
Running  
Playing a musical instrument  
Dancing  
Working out at the gym  
Making "things"