

REPORT
APRIL 1997

National
Children's
& Youth
Law Centre

written by
Christine Flynn



DISABILITY DISCRIMINATION IN SCHOOLS

students
and parents
speak out





National
Children's
& Youth
Law Centre

written by
Christine
Flynn



DISABILITY DISCRIMINATION IN SCHOOLS

students
and parents
speak out

CONTENTS

PAGE

1. INTRODUCTION	5
2. MAJOR FINDINGS	6
3. OBJECTIVES AND SCOPE OF THE PROJECT	7
4. BACKGROUND	8
4.1 International law and rights of people with a disability	8
4.2 Anti-discrimination and disability law in Australia	9
4.3 Education policies for students with a disability	12
5. RESEARCH METHODS AND RESULTS	13
5.1 National peak & key advocacy organisation meetings	13
5.2 Focus groups	13
5.3 Questionnaire	14
5.4 Phone-in	14
6. KEY ISSUES	15
6.1 Enrolment	15
6.2 After enrolment	16
6.3 Personal support needs	18
6.4 Access	19
6.5 Resources and equipment	20
6.6 Participation and belonging	21
6.7 School staff: attitudes and training	22
6.8 Students' and parents' attitudes	25
6.9 Discipline, behaviour and school exclusion	27
6.10 Home schooling or dropping out	28
6.11 Senior years and transition	28
6.12 Gender issues	29



	PAGE
7. DIFFERENCES BETWEEN SCHOOL SYSTEMS	30
8. DIFFERENT DISABILITIES, DIFFERENT BARRIERS	33
9. DOUBLE-DISADVANTAGE	37
9.1 Indigenous students and parents	37
9.2 Non-English speaking background students and parents	38
9.3 Geographical disadvantage	39
10. COMPLAINTS AND COMPLAINT PROCESSES	40
11. PARENTS' AND STUDENTS' RIGHTS	43
12. CONCLUSION	44
RECOMMENDATIONS	45
REFERENCES	51
APPENDICES	52
Appendix 1 Access strategies	52
Appendix 2 Statistical results	54
Appendix 3 Preliminary consultation meetings	63
Appendix 4 Focus groups in detail	64
Appendix 5 Questionnaire in detail	66
Appendix 6 Phone-in details	67
Appendix 7 Project team acknowledgments	68



INTRODUCTION

1

Discrimination against children and young people with a disability occurs despite the existence of federal and state / territory legislation (except in Tasmania) making disability discrimination unlawful. Some children and young people with a disability are seriously disadvantaged in their efforts to gain equal access to education. This report outlines the experiences of a sample of Australian students and their families derived from consultation research conducted by the National Children's and Youth Law Centre (NCYLC).

Few complaints are lodged formally using anti-discrimination law and most complaints handled by anti-discrimination bodies are settled through conciliation after a lengthy process. The terms of conciliation agreements are confidential. As a result, the systemic problems are not easily identified and solutions are only achieved on an individual basis. This reflects the nature and objectives of anti-discrimination legislation.

Through its legal practice the NCYLC has identified the issue of discrimination against students with a disability in schools as requiring immediate attention. Many parents of students with a disability had sought legal advice and, in some cases, been represented by the NCYLC in their attempts to solve school-related problems.

A research project brief was developed jointly with the Human Rights and Equal Opportunity Commission (HREOC) and funding was obtained from the Australian Youth Foundation. The NCYLC anticipated that, through the project, the extent of the disability discrimination could be quantified and recommendations made addressing systemic problems.

The Project has been conducted in three stages from May to February 1997:

- PART 1 Data was collected on disability discrimination from education complaints to anti-discrimination bodies and the Human Rights and Equal Opportunity Commission (HREOC), and background research on disability issues, education issues, and legislation;
- PART 2 National consultations and report;
- PART 3 Research findings to be made available to policy makers and strategies proposed by HREOC to reduce disability discrimination in education.

MAJOR FINDINGS

2

Focus group, questionnaire and phone-in research methods involved 784 people, including 461 parents / carers, 144 young people and 70 parents & 70 students together and 39 others. Further, 30 key organisations were involved in consultation meetings. The majority¹ of parents and students who participated in the research said they had experienced discrimination, such as:

- refusal of enrolment;
- different conditions of enrolment;
- denial of or limited access to school services, facilities and programs;
- differential application of discipline policies; and
- failure of schools to sufficiently address bullying and harassment against students with a disability.

This evidence of discrimination was found despite:

1. access to education being the law (both state and federal); and
2. the inclusion for students with a disability being explicit in the policies of all government state and territory education providers of compulsory school education.

Attitudes have moved a long way in the last decade, but continuing improvement in the situation for students with a disability will require a renewed emphasis on ensuring equitable access to education. Many respondents reported that the negative attitudes of both staff and students were still a major problem. Attitude change often follows from behaviour change, so the implementation of inclusive education practices could have the effect of improving attitudes. Inclusive educational policies and practices have been introduced successfully in many areas of education.

The research found that little use was made of formal, external complaint mechanisms. Most complaints by parents or students were made to a teacher or to the principal. The lack of complaint mechanisms within education systems, the absence of knowledge about any systems and the perception of non-responsiveness and fear of consequences, deterred people from formal and higher level complaints. Those who did complain to anti-discrimination bodies were frustrated by the time the process takes, the protracted correspondence, the nature of conciliation and the lack of long term systemic change. The needs of students were usually urgent and complaints systems were insufficiently resourced to respond quickly enough to the problems.

Recommendations are made later in this report which call on governments and education authorities to take immediate preventative and remedial action to eliminate discrimination against students with a disability at school.



1. 75.5% of phone-in and questionnaire respondents said they or their child had experienced discrimination. Focus groups were not statistically analysed but most participants said they had experienced discrimination at some time.

OBJECTIVES & SCOPE OF THE PROJECT

3

The project aimed to document:

- the existence, if any, of discrimination in education experienced by students with a disability;
- the knowledge of young people with disabilities of their right to non-discrimination and of avenues for recourse against discrimination;
- whether/ what legislative reform or other measures are required to overcome the problems identified; and
- barriers to the use of federal, state and territory anti-discrimination agencies and other forums for dealing with discrimination within education systems.

The experiences of school age students, from pre-school through to the end of secondary school, in public, private, Catholic and other church-based schools were canvassed.

While children and young people constituted the main focus of the research, the majority of people who participated were parents. Parents of students with a disability often have to negotiate with education providers to uphold their responsibility to ensure their children are educated. Consequently, their experiences were important and their participation in the project was essential.

The project was publicised through disability organisations and some schools. Respondents were self-selected and tended to be people with complaints about discrimination, rather than those with good experiences. This may be an accurate reflection of the experiences of a majority of students with a disability or it may be a minority view. The representative nature of the research is not relevant, as the number of the responses indicates there is a problem, and it exists throughout Australia.

Advocacy workers and disability organisations were consulted to assist in the identification of significant areas of education discrimination against students with a disability. They also provided valuable information on the best ways to contact parents and children with a disability.

The project did not provide counselling or try to solve individual problems. Referrals were made when necessary. Details of particular schools or teachers were not collected, as confidentiality was assured to all participants.

The tertiary education sector, early intervention programs, employment and training programs, health and community service provision, social security and housing were not within the scope of this research.

The project did not consult education providers. HREOC simultaneously conducted consultations with a range of education providers about barriers which they experienced in providing access to education for children, young people and adults with a disability. These consultations were undertaken to better inform HREOC's complaints procedures and also to provide information relevant to the development of education standards under the Disability Discrimination Act.



BACKGROUND

4

4.1 INTERNATIONAL LAW & THE RIGHTS OF PEOPLE WITH A DISABILITY

Australia has obligations to people with disabilities under international law. The United Nations Declaration on the Rights of Disabled Persons 1975, to which Australia is a party, commits Australia to non-discrimination against people with a disability and to provision of support services and education which enable self-reliance and social integration.

The United Nations Convention on the Rights of the Child, ratified by Australia in 1990, covers the rights of children under the age of 18 years. Articles 2, 23, 28 and 29 relate to children with a disability and to education.

ARTICLE 2	provides for protection against discrimination on various grounds, including disability.
ARTICLE 23	recognises the right of disabled children to a full and decent life, to special care and resources, free of charge whenever possible, and "effective access to education ... in a manner conducive to the child's achieving the fullest possible social integration and individual development...".
ARTICLES 28 AND 29	cover the child's right to education and the nature of that education. Especially relevant to this project is the requirement that "... school discipline is administered in a manner consistent with the child's human dignity..." and that education "be directed to development of the child's personality, talents and mental and physical abilities to their fullest potential".

The Disability Discrimination Act is one part of Australia's implementation of its international obligations.



ANTI-DISCRIMINATION & DISABILITY LAW IN AUSTRALIA

4.2

COMMONWEALTH ANTI-DISCRIMINATION LEGISLATION

The Commonwealth Disability Discrimination Act 1992 (DDA) commenced on 1 March 1993. Education is one of the areas of unlawful discrimination about which a complaint of discrimination can be made:

- s22 (1) *It is unlawful for an educational authority to discriminate against a person on the ground of the person's disability or a disability of any of the other person's associates:*
- (a) *by refusing or failing to accept a person's application for admission as a student; or*
 - (b) *in the terms or conditions on which it is prepared to admit the person as a student.*
- (2) *It is unlawful for an educational authority to discriminate against a student on the ground of the student's disability or a disability of any of the student's associates:*
- (a) *by denying the student access, or limiting the student's access, to any benefit provided by the educational authority; or*
 - (b) *by expelling the student; or*
 - (c) *by subjecting the student to any detriment.*

WHAT IS DISABILITY?

The DDA defines disability as:

- total or partial loss of physical or mental functions; or
- total or partial loss of part of the body; or
- the presence in the body of organisms causing disease or illness; or
- the presence in the body of organisms capable of causing disease or illness; or
- the malfunction, malformation or disfigurement of a part of a person's body; or
- a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction; or
- a disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgement or that results in disturbed behaviour. (s4)

It covers a disability which presently exists, previously existed but no longer exists, may exist in the future, or is imputed to a person even if the person does not have a disability.

Not all discrimination is unlawful. Sometimes being treated differently can be done to assist a person or provide access to special services. For example, discrimination is not unlawful when an educational institution is established wholly or primarily for students who have a particular disability (s22(3)). Nor is it unlawful when a special measure is provided to meet special needs of a person with a disability (s45(a - c)).

"Adjustments" are changes and alterations designed to enable the person with a disability to have opportunities equal to those of a person without a disability. Adjustments are not necessarily just physical, but can include such matters as modification of tasks or the way in which work is done, provision of support services or extra time.

There is provision in the DDA for schools or other educational establishments to argue that to make the adjustments for a student with a disability would pose an "unjustifiable hardship", which means more than simply expense or inconvenience. The effect of making adjustments has to be considered. Educational authorities could use "unjustifiable hardship" as a defence for their actions. The full extent to which this may be a defence, in whole or in part, to a complaint of disability discrimination in the area of education has still to be tested at law.

The DDA provides for the Minister (the Federal Attorney-General) to make Disability Standards in the areas covered by the Act. Education Standards, if adopted, have the potential to expand on and clarify the provisions of the DDA in the area of education. A process is underway to develop Disability Standards in Education, under the auspices of a Taskforce of the Ministerial Council on Education, Employment, Training and Youth Affairs. This project is intended to help inform that process.

Any service provider may decide to work pro-actively to promote equal opportunity for people with a disability by developing an Action Plan, which will be registered with HREOC. Only one school has registered an Action Plan since the commencement of the DDA in 1993.

STATE / TERRITORY ANTI-DISCRIMINATION LEGISLATION

All states /territories, except Tasmania, have equal opportunity or anti-discrimination laws which provide protection against discrimination on the ground of "impairment" or "disability".^{2,3}

Education is an area covered by the laws in all jurisdictions and the methods of handling complaints are similar throughout Australia. Variations occur in the remedies available, the time taken to deal with complaints and the potential cost to complainants. Complainants have a choice of whether to lodge a complaint under Commonwealth or the relevant state /territory laws.

COMPLAINTS TO THE HREOC & OTHER ANTI-DISCRIMINATION BODIES

Annual reports were examined and data was requested from all states/territories to compile the table below of formal complaints to HREOC and state/territory anti-discrimination bodies about disability discrimination in education.

2. A table of legislation appears in the References section.

3. Main differences lie in the definition of impairment or disability. New South Wales, Victoria, Queensland, the Australian Capital Territory and the Northern Territory have similar definitions to that in the DDA. South Australia and Western Australia have narrower definitions. In South Australia, mental illness is not covered and coverage of learning disabilities has not yet been tested at law.

**TABLE 1 FORMAL COMPLAINTS ON DISCRIMINATION IN EDUCATION
ON GROUNDS OF DISABILITY OR IMPAIRMENT**

JURISDICTION	1993/94	1994/95	1995/96
DDA	22	100	57
ACT	5	1	5
NSW	20	→ 5	→ 20
NT	1	0	0
Qld	7	21	19
SA	→ 6	→ 2	→ 1
Vic	5	7	15
WA	6	7	3

→ SCHOOL ONLY COMPLAINTS, EXCLUDING TERTIARY AND ADULT EDUCATION

The DDA figure represents both central and state registered complaints under the Disability Services Act. Complaints under state and territory legislation are listed in the table against States or Territories initials. There is no relevant state legislation in Tasmania.

Interpretation of the data is difficult because definitions differ. Detail is lacking on complaints specific to schools as the statistics usually include all types of education, including tertiary and adult education.

The table shows a relatively small and fluctuating number of education complaints overall, given that there are over 470,000 people under 25 years with a disability in Australia and an estimated 62,000 students with a disability in schools.⁴ The possible reasons for the recent decline in DDA complaints and the low number of registered complaints in other jurisdictions will be explored in section 10 of the report.

DISABILITY SERVICES AND OTHER LEGISLATION

The Commonwealth and state / territory governments have also passed laws which cover disability services such as employment and accommodation services. They will not be discussed in detail, however their principles are consistent with Australia's international obligations and are largely based on the concepts of normalisation and integration, with services being provided in the least restrictive environment possible.

The stated emphasis of Commonwealth income support provisions for people with a disability is on maximising community involvement and employment participation and minimising reliance on social security pensions or benefits.

⁴ ABS, 1993; de Lemos, 1992.

4.3 EDUCATION POLICIES FOR STUDENTS WITH A DISABILITY

State and territory Departments of Education have policies which relate to the provision of education for students with a disability.⁵ The policies are varied and often complex. Most policies contain a key statement which qualifies enrolment in the local regular school in terms such as "when this is in the best educational interests of the student and other students in the school and is within the Department's overall resource capacity."⁶ South Australia frames local enrolment more strongly. "The Department acknowledges that the neighbourhood school is the first point of contact for the initial enrolment of all students. Upon enrolment, a child with a disability becomes a student."⁷

All policies examined affirm that a range of services and settings will be provided including special schools, special units in regular schools and support for placements in regular classes.

The involvement of parents in discussion of enrolment options and in curriculum and support planning is encouraged in most policies, but enrolment decision-making power usually rests with the principal.⁸ The right of parents to have an advocate present is explicit in some policies.⁹ Student involvement is mentioned less often.¹⁰

Policies are regularly under review and it is interesting to note changes in language and emphasis. In Victoria, the 1987 *Integration Support Group Procedures for Regular Schools* policy had as a key principle that the student with a disability had a right to be educated in a regular school. The current policy *Programs for Students with Disabilities and Impairments* (1995) acknowledges the neighbourhood school as the first point of contact. The Queensland policy of *Integration - Mainstreaming of students with special needs* (1986) was replaced with the *Educational Provision for Students with Disabilities Policy Statement and Management Plan* 1993 which states it avoids the terms integration and mainstreaming as they were confusing and the policy substitutes "inclusive schooling" which "acknowledges the students' right to an appropriate education through the design, development and coordination of services to meet their needs".

General policies such as those relating to school discipline, curriculum and examination also impact on students with a disability, but will not be discussed in detail. One notable point is that, in the policies examined, only the Victorian discipline policy contains specific references which give special consideration to students with a disability in the application of the policy¹¹.

5. Those examined by the researchers are listed in the References section.

6. ACT Department of Education Policy for Services to Students with Special Needs 1992

7. SA Students with Disabilities Policy Statement 1991

8. In WA parents are to receive appropriate advice to make informed decisions and have to give permission for placement, but the Minister for Education retains the right to direct the placement of any student. Reg part X1B 262H-262L pert. to s20 of Education Act.

9. South Australia, Victoria, New South Wales and Western Australia

10. Victoria, New South Wales and Queensland

11. Guidelines for Developing the Student Code of Conduct 1994.

Section 4.15 of the Guidelines states that the principal needs to ascertain whether a student with a disability over 18 years is able to represent him or herself at an exclusion meeting, as a parent does not have to be present. Section 4.2.5 (3) states that, in considering suspension the principal must take into account, in favour of the student, any special needs of a student with an impairment.

RESEARCH METHODS AND RESULTS

5

Focus group, questionnaire and phone-in research methods were used to maximise opportunity for involvement and strengthen the validity of research results. 784 people were involved, including 461 parents / carers (59%), 144 students or recent former students (18%) and 70 parents & 70 students together (18%) and 39 others (5%). For statistical purposes, the parents and students completing the questionnaire together were counted as 70 responses only.

TABLE 2: WHO PARTICIPATED IN THE RESEARCH ?

CATEGORY	PHONE IN	Q'NAIRE	FOCUS GROUP	TOTAL	PERCENTAGE %
student	17	94	33	144	20
parent / carer	231	163	67	461	65
parent & student	n/a	70	n/a	70	10
other	14	14	11	39	5
TOTAL	262	341	111	714	100

Particular effort was made to enhance participation by specific groups. These access strategies are outlined in Appendix 1. Statistical results not included elsewhere in the text appear in Appendix 2.

NATIONAL PEAK AND KEY ADVOCACY ORGANISATION MEETINGS

5.1

Thirty key organisations provided background information on:

- the people served by the organisation;
- what discrimination in education issues the organisation was aware of;
- the appropriate methods needed to reach the group concerned; and
- the level of assistance the organisation could provide to publicise the project and distribute questionnaires.

A list of contributing organisations appears at Appendix 3.

FOCUS GROUPS

5.2

Seventeen focus groups were held in two capital cities and four country towns. The young people participating included 30 students with a disability and 3 siblings. Different groups targeted different types of disabilities. Some were for students only while others were mixed parent and student groups. Appendix 4 contains details of the location and the target of these groups.

Each focus group followed a similar format to ensure consistency of data collected. The themes discussed were enrolment issues, support needs / resources, belonging and participation, discipline / behaviour issues and complaints processes and outcomes.

5.3 QUESTIONNAIRE

Two thousand (2,000) questionnaires were mailed to approximately 250 organisations and 60 individuals.

Reply paid envelopes were enclosed to encourage responses. It is estimated that some 1,800 questionnaires reached families in which there is a student with a disability.

Three hundred and forty one (341) valid questionnaires were returned, a response rate of approximately 19%.

Responses came from:

• students	94	(28%)
• parents/carers	163	(48%)
• students and parents together	70	(20%)
• others	14	(4%)

Appendix 5 contains details on questionnaire design, distribution and analysis.

5.4 PHONE-IN

A shortened version of the questionnaire was used for the phone-in, which provided a free call 1800 number for callers from anywhere in Australia.

Seven lines, including a dedicated Teletypewriter (TTY) line, were staffed for 16 hours over two days. Three calls were received on the TTY. 262 valid calls were statistically analysed.

Responses came from:

• students	17	(7%)
• mothers	187	(71%)
• fathers	33	(13%)
• other relatives	11	(4%)
• others	14	(5%)

Appendix 6 contains details.



KEY ISSUES

ENROLMENT

6.1

BLATANT REFUSAL OR SUBTLE DISCOURAGEMENT

Blatant acts of discrimination were reported to have occurred at the time of attempted enrolment of a child with a disability. Parents reported that they often have had to go through a rigorous and intimidating interview, which usually involved the school principal, a counsellor or psychologist and several teachers.

A common concern was that parents of children with a disability are limited in their choice of schools, because many schools say they do not have the resources, are inaccessible or are unwilling to meet their child's needs. Therefore, the parents are often made to feel they "should be grateful for what they get".

I don't know what is worse – the school refusing to take our children or taking them into the school and then not doing anything to assist them.

MOTHER OF NINE YEAR OLD CHILD WITH AUTISM

Some parents find it difficult to get information about schools that take children with a disability and they have to seek the schools out themselves.

I went to 15 schools before finding one that would take my child, and still then I was only offered partial enrolment. I could not be fussy because I had limited choices.

MOTHER OF SIX YEAR OLD CHILD WITH INTELLECTUAL DISABILITY

In the last 12 months I have rung and visited 18 schools, both public and private, and received negative responses from them all. Most said they could not cater for children in wheelchairs, or all the classes were full, or questioned why they should take these children as there is no assistance for them and they only add extra work for the staff – at least he was honest.

MOTHER OF 11 YEAR OLD CHILD WITH PHYSICAL DISABILITY

PARTIAL ENROLMENT & OTHER ENROLMENT CONDITIONS

Sometimes a student was enrolled only if certain conditions were agreed to by parents. Such conditions reported by parents included:

- the student was enrolled on a trial basis;
- a parent had to be available to visit the school during recess and lunch or the student was to go home during these times;
- the student was only allowed to attend for a limited number of hours or days per week.

Partial enrolment and special conditions can mean that parents are expected to attend regular reviews at the school. Some parents reported review processes were time consuming, could be intimidating and were held more often than for other students.

Many parents reported that partial enrolment had a negative impact on the children. It is disruptive to both the student's academic and social development. The student may be attending two or three different schools, without any enrolment being formally accepted. This can lead to uncertainty, and reduces the opportunity for the student to keep up with peers, to make friends or be included in school or class activities.



My son hated partial enrolment. He said no-one would talk to him and that everybody hated him. He became very depressed and would often cry uncontrollably. The school blamed his depression on me and refused to see their role, especially his teacher's role, in causing my son's depression.

MOTHER OF EIGHT YEAR OLD BOY

The public school would only offer two hours per week with aide time. We kept asking them to increase our son's hours but year after year this would not happen. We later found out he was never technically enrolled. We have now pulled him out and he is in a special school. This is the first year he is enrolled full-time.

PARENTS OF 10 YEAR OLD BOY WITH DOWNS SYNDROME

I can only go half days as they don't like me. When there are other teachers in the class, apart from my teacher, they pick on me. They can't wait for me to leave the school.

12 YEAR OLD BOY WITH MULTIPLE DISABILITIES

LIMITED CHOICES AND TRAVEL BARRIERS

Due to limited options, students may have to attend school many kilometres away from home. This is an even greater issue in rural areas. Issues of safety, time and money are involved. Parents often have to spend most of their time travelling to and from school, either because the public transport system does not cater for their child's disability, the school or government does not provide transport or, when it does offer a service, parents may be required to attend on the journey to ensure their child's behaviour is kept under control.

We elected to send our son to a special school as he became so unhappy in an integrated secondary setting. The closest school was 45 miles away. It refused enrolment because our son did not have an intellectual disability. The school where he was forced to move to is 135 miles away. There was no special school near home. My child can now not live at home during the week.

MOTHER OF 10 YEAR OLD BOY WITH PHYSICAL DISABILITY

My son, whose behaviour is hard to manage, has to travel a long distance by bus to and from a special school. As there is no funding for an aide and I work and so can't pick him up, he is tied to his seat in the bus for the whole journey.

MOTHER OF 14 YEAR OLD BOY WITH BEHAVIOURAL DISABILITY

6.2 AFTER ENROLMENT

PARENTS AS SUPPORT STAFF AND ADVOCATES

Once students with a disability are enrolled in a regular school, the needs of the child are not always fully recognised or are sometimes dismissed, and parents, in most cases the mothers, report they often have to fulfil support roles.

Parents frequently said that they were tired of being relied upon to meet their child's needs at school during school hours.

The thing is, my child no longer sees me as his mother but as his voice, therapist, nurse and advocate. I know I will not be able to rest until the day I die because no one else is willing to meet my child's needs.

MOTHER OF 12 YEAR OLD STUDENT WITH A PHYSICAL DISABILITY



Another significant role played by parents is that of advocates for their children, which can be stressful.

It is a parent's never ending battle to advocate for their child - sometimes affecting personal relationships with teachers, aides, friends and family.

PARENT OF 10 YEAR OLD CHILD WITH PHYSICAL DISABILITY

ASSESSMENT AND DIAGNOSIS

In some instances it is not easy for health professionals to accurately assess or diagnose a young child's disability in the pre-school years. Consequently, many children with a disability are enrolled without the necessary arrangements. Over time, the disability becomes apparent as disruptions to learning and school life occur.

Parents know their children best and are usually among the first to suspect something is wrong, yet they can have a difficult time communicating to school authorities that the student is in need of formal assessment and may have a disability.

Some parents reported having to pay privately for formal assessments. In some cases, when reports of a health professional were presented to schools, they were disputed. Some schools preferred to believe their own uninformed assessment of the situation, often invoking the "bad parenting" theory.

We get blame, criticism. We are told we are useless, not good parents – it is all our fault. Parents are always to blame, even with a medical and psychological diagnosis.

These kids, we are told, should be institutionalised. Psychologist's and psychiatrist's reports are very expensive. It cost us over \$600 and Medicare would not pay. This is discrimination. If reports are not provided, then aide time is not forthcoming.

PARENT OF 12 YEAR OLD BOY, WITH MULTIPLE DISABILITIES

LABELLING

For some students and parents involved in this project, the use of disability diagnostic labels was detrimental. Labels can result in either negative or positive responses, depending on the disability.

When my child was enrolled, he was labelled as an ADD student, a trouble maker. I was then also labelled a bad parent. Further on into his schooling his behaviour was assessed by a therapist, who then labelled him as autistic. I was then labelled a remarkable parent for my parenting skills with my child and was given greater assistance for his needs.

MOTHER OF NINE YEAR OLD BOY WITH AUTISM

Other respondents felt relief at having a problem identified with a diagnosis. Often diagnosis and assessment are necessary aspects of gaining access to any available services.

THERAPY

Some disabilities require regular therapy which may be provided at school or in other settings. Complaints were received of insufficient funding for therapy, and difficulty in making arrangements for students to attend therapy. Frequently, there were no catch-up arrangements for school work missed when therapy had to be attended.

Morning is the best time for my child's therapy but it is also Maths and English time, so {L} misses out. We have hired a tutor.

PARENT OF NINE YEAR OLD CHILD WITH PHYSICAL DISABILITY
ATTENDING A SPECIAL SCHOOL

6.3 PERSONAL SUPPORT NEEDS

MEDICATION

Many parents complained of medication-related problems and the need for the student to be assisted in administering the medication or injections. Others complained of too much interference when students were old enough to look after their own medication.

We were told that teachers often refuse to administer medication. Generally, the only available solution is for the parents to attend the school to do so for various reasons including potential legal problems. This may involve long distances and much time, and is a task often delegated to mothers. There is a consequent negative impact on work opportunities, family income and stress levels for the parent involved.

There is a widening gap in health services available at schools, with visits by community nurses declining in recent years. Teachers are concerned about their duty of care, their lack of medical qualifications and their potential legal liability if something goes wrong. They are also concerned that medication should not be taken away from a student or be misused. Policies appear to rely on teachers or other school staff voluntarily agreeing to assist with medication. Students in some states have asked parents to sign an indemnity freeing the school from liability if anything goes wrong.

The storage of medication in the school office and the need for the student to visit the office to get it proves difficult for some children to remember, or embarrassing for others.

My daughter needs medication before eating or drinking, but hates going to the school office. So she doesn't eat or drink during the school day, no matter how hungry or thirsty she feels. She is not allowed to carry and take her own medication.

MOTHER OF A 17 YEAR OLD GIRL WITH CYSTIC FIBROSIS

My daughter experiences great pain but was refused assistance with pain relief medication, even though she had taken medication for seven years. I had to attend the school to give it. We resorted to hiding pain killers in her pocket so she could take them secretly when necessary.

MOTHER OF A NINE YEAR OLD GIRL WITH A PHYSICAL DISABILITY

PERSONAL HYGIENE, EATING AND DRINKING

Some students with a disability need assistance with personal hygiene and with eating. Parents reported that teachers feel that it is not up to them to provide such services as to do so takes time and attention away from other students. Some teachers do take on these tasks, some students have personal assistants or aides assigned to help them and in other instances, parents are called to the school on a regular basis. Sometimes aides are only available for part of the school day, even though personal assistance may be needed at any time.



A school assistant was allocated to assist my daughter in the event of any incontinence accidents but only until 1pm. School went until 3.15pm. On numerous occasions by that time she would be soiled. When I asked the teacher why my child was sitting in soiled clothes, the answer was "Everyone has grown up with her and we are used to her soiling so we leave her in the soiled clothes". It got to the stage that if she was soiled or wet after 1pm no-one was available to help her, so we would pick her up from school at 1pm.

MOTHER OF NINE YEAR OLD GIRL WITH PHYSICAL DISABILITY

There were several reports of insensitivity in the management of personal hygiene issues. One example comes from the same mother:

The room was broken into where my daughter's catheters and pads were kept and gear was tampered with. A school assembly was held and the principal showed everyone the catheters and pads and said who and what they were for, resulting in a lot of teasing, "You wear a pad because you shit your pants". The assembly was held without our knowledge or consent.

Some students need accommodation of their special dietary requirements, but that was cause for complaint by some respondents.

Once on a camp, the supervisor would not let me go into the kitchen for a snack even though I explained I needed small frequent snacks to keep my blood sugar levels up.

14 YEAR OLD STUDENT WITH DIABETES

We requested our child have a jug of water on her desk to encourage her to drink. She was six years old and had trouble with her kidneys. We were told it was not fair on the other children. We had to devise a plot to have her take vitamin tablets three times a day with water, so we could ensure she got enough fluids. The school insisted it was not their responsibility.

PARENT OF SIX YEAR OLD CHILD WITH PHYSICAL DISABILITY

ACCESS

6.4

Physical access to school buildings is a major problem in Australian schools and one which cannot be resolved overnight. During this research, it became apparent that poor physical access impacts adversely not only on students who use wheelchairs, but also on students who cannot easily climb stairs, those who are visually impaired or blind and those whose conditions are variable or deteriorating. Students are often refused enrolment and forced to go elsewhere because of a lack of access.

My daughter had partial enrolment at a regular public school, and attended a class with her peers on the ground floor of the school. For some reason, the class was moved upstairs. I was told she could come back next year. After complaining to the principal I was told "the school should not have to take children like this". As result of a complaint higher up, the class was moved back downstairs, but only for half of one afternoon to do singing or simple work, which did not benefit her academically.

MOTHER OF A SEVEN YEAR OLD CHILD
WITH MOBILITY PROBLEMS DUE TO PHYSICAL DISABILITY



In some cases although a student has a wheelchair, he or she is not allowed to use it, although access is not the problem.

My child has a wheelchair for long distances and on many occasions she was not allowed to use her chair when she needed it. The wheelchair was not allowed in the classroom, as the teacher said there was no room for it. My child's legs were in plaster at the time.

MOTHER OF NINE YEAR OLD GIRL WITH PHYSICAL DISABILITY

Another parent reported problems about her son's participation in sport, when use of the wheelchair was encouraged by staff.

My son is not wheelchair bound but walks slowly in a kaye walker. The aides and teachers would like him to use the wheelchair for sport etc as it is quicker for them and he can keep up with the others, but he would then seize up, as his surgeon and physios have verified. Staff reluctantly and grudgingly agreed to let him use the walker.

PARENT OF 10 YEAR OLD BOY WITH PHYSICAL DISABILITY

Requirements for all new public buildings to be accessible will gradually improve the situation but this will take many years. In the meantime, careful planning regarding the location of classes which include students with a disability can help reduce access problems.

6.5 AIDES, RESOURCES AND EQUIPMENT

Many complaints were made during the research about the inadequacy of the funding for aides and equipment. The diminishing pool of resources being spread over an increasing number of students is a major problem, especially in relation to the lack of integration support funding.

There is a move towards "the greatest good for the greatest number". These policies and practices create a rather unsavoury competition amongst disability types to prove themselves more deserving.

AUNT OF SEVEN YEAR OLD BOY WITH MULTIPLE DISABILITIES

The funding submission process which has to be repeated each six months or each year was a concern for many parents. Some parents of students who have a disability which is permanent or long-standing expressed anger and frustration at the need to re-apply for funding.

It takes a long time to get therapy services, such as speech. These are then reviewed once a term and the child is re-assessed. So much time is wasted! Downs Syndrome does not go away - what is the point of reassessing the child so frequently? The time could be better spent in actual therapy sessions.

PARENT OF 10 YEAR OLD CHILD WITH DOWNS SYNDROME

The Victorian questionnaire, which is intended to be more objective, was criticised by several respondents. For example:

The label, Needs Questionnaire, has no relationship to the reality of the questionnaire, where points are awarded on scales which are designed to measure disability. Support needs of an individual can vary according to the setting. The degree of high support needs does not necessarily mean profound disability and people with a mild disability may have high support needs.

AUNT OF SEVEN YEAR OLD BOY WITH MULTIPLE DISABILITIES

Several focus group participants were concerned about the way equipment and support staffing funds are spent by school principals. If applications were made to meet a particular student's need and funds were provided to the school, parents were concerned that the funds could be used for something unrelated to the student. Some people reported computers being placed in staff rooms or in locked storerooms and not being provided for the student who required them. One reported that a new carpet was bought with the funds.

When you enrol a child at school, you should be told what will be provided and then kept up to date with this. You should not have to rely on parents to always fight for children's rights.

MOTHER OF 13 YEAR OLD CHILD WITH MULTIPLE DISABILITIES

The provision of limited support time often means that students can only attend school at those times. They are not provided with any education at the other times.

The aide only worked in the morning. In the afternoon my daughter was often left on her own. She did not have a wheelchair and could not walk to other areas. One afternoon she was locked in the classroom and was unable to get to the toilet. It was very distressing for her. It was not until this event did we realise that our five year old was being isolated in a room without help. Then we found out this was a regular occurrence.

MOTHER OF FIVE YEAR OLD GIRL WITH PHYSICAL DISABILITY

The training of aides was also a concern for many respondents. Non-signing aides may be assigned to work with deaf students, people with training in one disability may be working with students with another disability. It was reported that some aides have no training at all and need more professional development.

I have been told by the Education Department that there is no one in the department with the skills to help me.

14 YEAR OLD BOY WITH MULTIPLE DISABILITIES

At a school meeting on disability, the teacher's aide (not the disability aide who was absent) stated "We don't mind the ones in wheelchairs but the ones with something wrong with their heads use up all of the time and deprive the others of education".

DISABILITY ADVOCACY WORKER

PARTICIPATION AND BELONGING

6.6

The lack of a sense of belonging for some students with a disability may be due to several changes of school, but more often it is brought about by a combination of community ignorance and enforced isolation.

I miss out on fun, and can't do assignments, I'm hopeless.

12 YEAR OLD BOY, WITH MULTIPLE DISABILITIES
ENROLLED PART-TIME DUE TO LACK OF AIDE HOURS

Some students told how they felt embarrassed and different because the special unit they attended was situated in a separate part of the school grounds. One unit was reported as being surrounded by a high metal fence emphasising the isolation from the rest of the school community.



Not being allowed to go on school camps or excursions was mentioned by many respondents as a problem. Sometimes schools requested a parent also attend, which was embarrassing for older students and drew undue attention to their disability. Their response was to not attend. One family was told that they would have to pay extra for an accessible bus to be provided to enable their child, who used a wheelchair, to go on an outing.

I was in the school debating team but was not allowed to represent the school at inter-school competitions because they thought my illness would make me unreliable. My parents and I complained, but the matter was only resolved by me leaving that (private) school. Now I'm completing Year 12 at a government school.

17 YEAR OLD STUDENT WITH DIABETES

A few parents complained that their child was not included in class photos. It is not known whether these omissions were deliberate, but the effect was isolating for those students.

One parent complained that her son's access to art classes is restricted because of concerns he might mess up the paints. One mother reported that her hearing impaired daughter was not allowed to do music at school, even though she is studying music privately and doing well.

6.7 SCHOOL STAFF – ATTITUDE AND TRAINING

The attitude of school principals was seen by many respondents to be critical to achieving successful integration of students with a disability. Decision making powers mainly rest with the principal, who is responsible for meeting the educational needs of the whole school population and for meeting occupational health and safety and professional development obligations to staff.

According to respondents, some principals displayed a positive attitude of "let's look at how we can meet the needs of this student", while others took the "not in my school" position. As enrolment policies often include words such as "whenever practical" or "subject to available resources". Resources are rarely sufficient to meet all needs, and principals have a great influence in the decision of whether to enrol a student with a disability. A principal's personal views concerning integration and segregation will often affect the decision.

With the move to greater local autonomy in decision making there is greater opportunity for people to make up their own rules regarding the provision of education to children with disabilities. Often this is done in ignorance of legislated principles and objectives.

AUNT OF SEVEN YEAR OLD BOY WITH MULTIPLE DISABILITIES

Principals with negative attitudes towards integration, or perhaps towards a particular disability, were reported to have treated parents like second class citizens. Parents reported comments ranging from simple rudeness to outright verbal abuse.

Parents also reported that problems arose during meetings between the school and parents, and especially when issues arise over behaviour and support needs. Some parents reported feeling harassed by school principals who made regular phone calls to them at work or at home, requesting that they attend the school for meetings or that they "remove" their child from the school.

The 93 respondents to the mailed questionnaire who said the student's enrolment was regularly reviewed, advised of the following frequency of review:

- more than once a month 12
- monthly 12
- each term 23
- each year 35
- at other intervals 11

Review processes tended to reaffirm some parents' views that they were not equal partners in the decision-making process.

The one thing I have found in the education system is that there is no one you can trust. Your opinions are not of any value.

MOTHER OF 11 YEAR OLD CHILD WITH PHYSICAL DISABILITY

Meetings, such as Program Support Groups or Negotiated Curriculum Plan, were reported as intimidating for many parents, especially for mothers attending alone. The meetings are intended to negotiate and formalise individual plans for the student. An instance was reported of a plan being posted to the parent for signature without a meeting occurring. At another meeting a parent was expected to agree to a plan already worked out by the professionals.

*At reviews the school staff are overbearing and intimidating.
I have walked out in tears.*

MOTHER OF 11 YEAR OLD CHILD WITH MULTIPLE DISABILITIES

In cases where parents were accompanied by an advocate, the response of principals and teachers was often negative. Parents said they were rarely told they could have an advocate with them. Parents who had advocates present felt they achieved much better outcomes, even if the advocate only acted in a passive support role.

On the positive side, some parents reported having taken part in constructive meetings at the school which focused on students' learning and support needs, rather than on behaviour management. The process seemed to be more satisfactory when parents were articulate and assertive and when they knew the system and knew the level of resources available.

The breakdown of the relationship between parents and school appeared to have serious consequences for the students and sometimes also for their siblings. Some parents who had made complaints had earned a reputation as trouble-makers or harassers. Some parents said they had been banned from school grounds. Sometimes not only the student with a disability but his or her siblings were asked to leave the school.

No matter what is mentioned to the principal about the hurtful teasing and physical abuse, nothing concrete is done. It has come to the point that we are not welcome there any more. The principal says my child does not really "fit in" because it is a sports oriented school. It's been made quite clear that it is in his best interest to go to another school.

MOTHER OF EIGHT YEAR OLD CHILD WITH MULTIPLE PHYSICAL DISABILITIES

Teachers picked on me too, even though I hadn't done anything.

SIBLING OF 11 YEAR OLD STUDENT WITH ADD



Some families had found school principals who were willing to achieve satisfactory education access for the student in the mainstream setting and some successes were reported.

School for my daughter is generally good and a positive experience for her. We are very fortunate in having a caring school principal and teachers. Many of our friends are not so lucky.

PARENT OF 11 YEAR OLD CHILD WITH DOWNS SYNDROME

Teachers' attitudes and skills are important to a student's success at school. Many dedicated and highly skilled teachers are working under enormous pressures and face growing demands. They face challenges, not only of teaching students with a disability, but also of teaching students from non-English speaking backgrounds, students from disrupted families, students who are homeless, those who may have been abused and those living in poverty. Class sizes may be an important component in an overall plan. Teachers' aide time is usually insufficient to meet the requirements of all students with special needs. It is therefore understandable that some teachers are fearful of having to accept a student with a disability, or another student with a disability, into their class.

Fortunately my daughter has had a supportive teacher this year and I suppose that is the only reason she goes. I thought, being hurt by many {students} in her class, that she would have no incentive to learn, but she ignores the children and listens intently to all her teacher says.

MOTHER OF 8 YEAR OLD GIRL WITH MULTIPLE PHYSICAL DISABILITIES

On the other hand, it was reported that there are teachers who do not know about particular disabilities, who hold misconceptions about the effect of certain disabilities, who have ignored information from parents about adjustments to curriculum, to teaching methods or to classroom seating which a student may need, who physically or verbally abuse students with a disability, who allow other students to bully or harass students with a disability, who breach confidentiality, who humiliate students with a disability in front of other students, and teachers who verbally abuse parents or who criticise their parenting skills.

I found school horrible and confusing. I didn't understand what was happening in class and some of the children were mean. I needed understanding that sometimes I can't control my behaviour, and needed help to understand the activities I had to do.

13 YEAR OLD STUDENT WITH ADHD AND INTELLECTUAL DISABILITY

Physical assault by teachers against students with a disability was alleged by a few parents. One parent had personally witnessed what she believed to be an assault, whereby the student was dragged away from a railing and the student was left with bruising on the arms and pain in the shoulders for some days. Another parent was told by the parents of other students about the teacher's "rough handling" of her child who has a disability. The student had no verbal communication so could not explain what had happened to cause her bruises. Whilst not a commonly reported problem, it would appear that the distinctions between guidance, restraint, force and assault can become blurred and may warrant greater attention through in-service and pre-service training.

Three instances were reported where parents were threatened with personal lawsuits for alleged defamation, to the point of receiving letters to that effect from lawyers acting on behalf of individual teachers or the school. The parents in those cases had made written

complaints to the relevant Minister for Education, rather than through an anti-discrimination body. They were, therefore, not legally protected against victimisation and defamation.

Many students told the researchers about how they had to teach their teachers about their disability. This process was on-going, as teachers can change frequently. Parents also have to become educators of teachers and principals, sometimes with the support of community-based disability organisations. Students and parents felt this exchange of information usually, but not always, led to better understanding and awareness.

I give out an information sheet to my teachers at the beginning of each year, but recently I was told off for clowning but I was having a hypo-attack.

14 YEAR OLD STUDENT WITH DIABETES

The most common recommendation from questionnaire and phone-in respondents about how to reduce discrimination in schools was to institute better teacher training to change attitudes and their practical knowledge about disabilities. 62% of respondents made this suggestion and was an idea proposed in all focus groups.

There are now substantial components on disability and education of students with special needs in undergraduate teacher training, but newly trained teachers are not yet in schools in any great numbers. Although in-service training modules or short courses exist, it will be many years before all current teachers are able to benefit from such training. A more comprehensive approach is required to deal with the issues raised in this report.

We have found that those people who get to know our son have no difficulty working with or relating to him. The problems have always arisen out of ignorance.

PARENTS OF A 10 YEAR OLD BOY WITH PROFOUND HEARING LOSS

Many respondents suggested that parents, students with a disability, teachers and principals needed to work together to try to resolve the resourcing issues which are the cause of much dispute. Alliances needed to be built to lobby governments and education authorities for additional resources.

STUDENTS' AND PARENTS' ATTITUDES

6.8

STUDENTS

Students with a disability are reportedly often the victims of bullying and abuse by their peers. A common complaint among respondents was that many teachers did not intervene when other students were bullying a student with a disability. There were reports that children would make themselves sick because they hated their school and were fearful of attending.

My child was made to stand out the front of the class while the other class members said why they didn't want my child in their classroom. The teacher then suggested they vote on the matter and he was voted out. He didn't want to go back to school after that and would often make himself sick so he wouldn't have to go.

MOTHER OF EIGHT YEAR OLD BOY WITH ADD



The children make up jokes about her, call her demeaning names and they kick her prosthesis off. She hates school so much and I feel guilty about sending her. She participates as much as possible, she attends gymnastics, plays on the trampoline, runs, skips, plays ball – so she is capable. It's just that her heart is broken as she has very few good days.

MOTHER OF EIGHT YEAR OLD GIRL WITH MULTIPLE PHYSICAL DISABILITIES

I'd rather be teased than beaten up.

12 YEAR OLD STUDENT WITH ADD, FEARFUL OF COMPLAINING ABOUT BULLYING

One parent reported that in response to her complaint that her teenage daughter with intellectual disability had been sexually assaulted by another student, her daughter was confined to a small part of the playground while the other student continued to have free access to the whole school grounds and was not punished. The allegation of sexual assault did not appear to be taken seriously, although there was medical evidence of sexual assault and the parent had reported the matter to the police. This was the only allegation of sexual assault heard during the research, but the issue is a serious one. The need for a prompt and sensitive response to an allegation of this sort should have been obvious.

Students were often alienated in the playground because other students either feared or did not understand their disability. Students with a disability said they wanted and needed friends. One of the reasons their parents push for inclusion is to give their child as many social opportunities as possible. One parent told how she had to plan birthday parties at the school for her child as the other children would never come to her home. However, these opportunities cannot be forced.

People were teasing and picking on me in my other school. They said, "You get lost!"

17 YEAR OLD STUDENT, NOW IN A SPECIAL SCHOOL

During playtime no one would come up and speak to me. They thought I was just so different to them, that I didn't watch Melrose Place or I didn't go out to places they did. One time a teacher sat with me in the playground, pulled students aside and asked them to be my friend. She thought she was helping me, but it was an embarrassing experience for me and the other students.

14 YEAR OLD STUDENT WITH A PHYSICAL DISABILITY

He has no interaction with the other students. He is very lonely.

PARENT OF 14 YEAR OLD BOY WITH MULTIPLE DISABILITIES

PARENTS

According to some respondents, some other children's parents believe disability is catching. They think the slow learning of some students with a disability will negatively impact on their own child's learning. They are also fearful of a negative impact on their child's behaviour.

My child was invited to a birthday party by a classmate. The next day he was un-invited as his parents did not want a disabled child at the party.

PARENT OF SEVEN YEAR OLD BOY WITH INTELLECTUAL DISABILITY

Serious examples of parental intolerance came from respondents who said other parents had threatened to remove their children from school unless the student with a disability was removed. In two cases, the schools agreed to the demands and the parents of the students with a disability were forced to remove the students and the student's siblings from the school.

In one instance, the family was also considering a move to another town or interstate, as they were perceived by others in the community as trouble-makers and life in the town had become intolerable for them. Both examples cited were of primary school aged children, one with attention deficit disorder and the other with an intellectual disability.

It is acknowledged there may be disruption to the learning process for other students, if students with a disability are not appropriately supported and adjustments are not made to assist them to be equal members of the class. The provision of adequate resources and support are therefore critical to acceptance by fellow students and their parents.

21% of respondents to the phone-in and questionnaire recommended students and parents should be made aware of the issues for students with a disability, through education or information sessions. Some suggested disability awareness be included in the formal curriculum.

All we ask is to treat everyone the same. Provide sessions to children about disabled children and how they hurt and have feelings too.

MOTHER OF EIGHT YEAR OLD CHILD WITH MULTIPLE PHYSICAL DISABILITIES

DISCIPLINE, BEHAVIOUR AND SCHOOL EXCLUSION

6.9

The research suggested that a higher standard of behaviour is expected from students with a disability than from other students. Students with a disability may be punished for standing up for themselves against teasing and bullying and are often used as scapegoats for other students' misbehaviour. Examples were reported where the behaviour of students which goaded a response from the student with a disability went unnoticed by teachers. No explanation for an outburst was sought, according to some reports.

Because they know I have behaviour problems, I get into trouble for things that get overlooked for other kids.

11 YEAR OLD STUDENT WITH ACQUIRED BRAIN INJURY

A hearing boy would blame me for things that never happened and I got detention.

14 YEAR OLD STUDENT WHO IS DEAF

They tend to watch and pick up on all her bad things and give her time out all the time.

PARENT OF SEVEN YEAR OLD GIRL WITH DOWNS SYNDROME

When the same discipline code is applied equally to students with and without disabilities, it can have a more harsh effect on the student with a disability. This is particularly true for students with attention deficit hyperactivity disorders and some other disabilities which have a behavioural element.

They made strict rules and regulations on me. I was suspended on the second day for a minor incident which could have been avoided.

11 YEAR OLD STUDENT WITH ACQUIRED BRAIN INJURY

The nature of the punishment can have negative consequences for students with a disability. It was reported that a student with ADD was given detention at lunch-time and was therefore prevented from getting any exercise. This made it more difficult for him to behave well during the afternoon. Some schools have systems of positive or

negative points and the student's score is displayed in the classroom. Parents reported that it was hurtful for the student with a disability to always see their score in the negative. This had a detrimental effect on their self-esteem.

The Education Department have it too easy in washing their hands of such problems, by stating that all students are excluded / suspended for dangerous behaviour. This urgently needs to be changed to accommodate children who at this point in time cannot control their behaviour. As it stands, the student becomes more unsettled (due to time away from school) therefore making the behaviour problem worse.

PARENT OF 14 YEAR OLD BOY WITH MULTIPLE DISABILITIES

6.10 HOME SCHOOLING OR DROPPING OUT

A complete account of what happens to students with a disability needs to include some discussion of what happens to those who leave school early, or who are forced out of school, because the school does not meet their needs.

A number of parents have chosen to educate their children at home. This has usually been a difficult choice after many failed attempts to find a satisfactory school. Parents undertaking home schooling complained of a lack of access to curriculum materials, the inadequacy of visiting teacher support, the lack of equipment or resources and the lack of accommodation by external examination bodies. The responsibility of home schooling is often carried by mothers.

Mum found it hard to get help for me and eventually gave up.

13 YEAR OLD STUDENT WITH ADHD AND INTELLECTUAL DISABILITY
NOW DOING HOME SCHOOLING

I am now educating my daughter at home because of enrolment and on-going bullying problems. The school could not ensure her safety either in the classroom or in the playground.

MOTHER OF 12 YEAR OLD GIRL WITH INTELLECTUAL DISABILITY

Reports were received of some students being suspended from or asked not to return to special units for behaviourally disturbed students in which they had been placed. It appears that staff levels, available skills or programs in some special units have not been able to accommodate these student's needs. Those students then face major obstacles to completing their education. There was some evidence that students with a disability who are suspended from school often drop out of the education system completely.

6.11 SENIOR YEARS AND TRANSITION

The lack of opportunity for older students to participate in work experience programs was identified as a problem by some respondents, especially as students with a disability reach the senior years of schooling. Some students with a disability were reportedly not asked about their work experience preferences, nor were efforts made by the school to find suitable placements for them.

The bodies responsible for senior secondary school examinations and tertiary entrance came in for substantial criticism from parents and older students. Basic problems identified were inflexibility and a lack of willingness to make adjustments.

Certain disabilities require particular adjustments, but if something different is requested the system often appears too inflexible to respond. A common request was for

more time to be allowed for students to complete examinations, because the student has slower reading and comprehension skills or difficulty in writing without rest breaks. The response of examination boards was reported to be that the student could have a reader or writer, but no or limited extra time. Greater dependence on others is fostered by this approach and as it is difficult to dictate answers, grades were said to be detrimentally affected. When appropriate adjustments were made, parents reported that students' grades rose significantly.

I asked for a second chance to sit the examination because I'd been in hospital and missed a lot of work, but they weren't interested. I think they handle sudden bereavement or a student getting influenza on examination day better than they handle the needs of students with a disability.

FORMER STUDENT WITH CHRONIC FATIGUE SYNDROME
NOW DOING TERTIARY STUDY

It may be difficult to make formal complaints about external examinations because of their fixed timing at the end of the academic year and the student's (usually) once only chance to sit for the examinations. Applications for adjustments have to be made by September of the year before the relevant examination, but outcomes of applications may not be known until much closer to examination time. In some states, the decision is made early in the year and there is time to apply for a review of any ruling.

GENDER ISSUES

6.12

Mothers made up 81% of parents who participated in the phone-in and the overwhelming majority of focus group participants¹². Mothers appear to be the parents most likely to deal with the school when problems arise. They are most likely to deal with matters such as personal care for the student with a disability. Some are sole parents, where the presence of a child with a disability in the family may have contributed to family breakdown. Many mothers are not able to maintain paid employment because of child care commitments and families may experience financial hardship as a result.

There is some evidence from the research that women could be being unlawfully discriminated against because they are "associates" of the student with a disability.

As a mother, you're not taken seriously. As a mother you are treated as if you're the one with a disability.

MOTHER OF STUDENT WITH MULTIPLE PHYSICAL DISABILITIES

Of the quantitative research methods, 65% of phone-in callers were talking about male students. The questionnaire responses were more evenly divided with 52% of responses being about boys. Using this self-selected sample method it was not possible to draw conclusions about differences in the experience of discrimination against incidents, based on gender.

TABLE 3: GENDER OF STUDENT

GENDER	PHONE-IN STUDENTS	PHONE-IN ADULTS	Q'NAIRE	TOTAL	PERCENTAGE
Male	9	162	176	347	57.5
Female	8	82	165	255	42.3
Not stated	0	1	0	1	0.2

12. The mailed questionnaire did not differentiate gender of parent/carer.

DIFFERENCES BETWEEN SCHOOL SECTORS & TYPES OF SCHOOL

We received positive and negative comments about all school sectors and types.

PRIVATE SECTOR

Some parents who wanted to choose a Catholic education for their child were unable to do so because the school of their choice refused to accept the enrolment. The refusal was usually, but not always, stated to be because of a lack of resources¹³. They were disappointed, having expected a caring and Christian attitude, and some questioned their own faith as a result.

One report was received of a student being denied enrolment in a Catholic school despite "all reasonable integration expenses" being guaranteed in writing from an accident compensation fund. The student had had a serious accident which left him severely physically disabled, dependent on a ventilator and using a wheelchair. His parents wanted him to return to the parish school he had attended before the accident. The school refused despite meetings and several requests. Meanwhile the student was attending regular schooling in a public school.

It was reported that some independent schools which set a high standard of academic achievement and behaviour do not want to accept any student who might lower the standard. One example was mentioned of a student who won a scholarship to attend an independent school, but who was refused entry once the disability and support needs were known. Another school, which emphasised its sporting prowess, made life so uncomfortable for a physically disabled student that he changed schools. In another example, enrolment was refused because of the child's perceived inability to play sport.

At first we tried the Catholic system because that's where I went to school. We gave this up soon, as the principal didn't even hide his discrimination. He said our son could not go to school because "he can't play sport". We wanted to send him to school for an education. The principal has said about children with disabilities "they can't do anything". Our son is now at a private special school.

FATHER OF 10 YEAR OLD BOY WITH DOWNS SYNDROME

Other parents found small Christian schools of various denominations to be their best option after failure in the mainstream system. A loving and accepting environment was welcomed after failure to find a suitable placement elsewhere.

We have transferred to a private Christian school where my son is accepted. The attitude of this principal when we said our child had a disability was "He is a child who needs an education". In the State system, it was closed doors all the way.

MOTHER OF SIX YEAR OLD BOY WITH DOWNS SYNDROME

The cost of private or Catholic education posed financial burdens for some parents, who already face the extra costs of raising a child with a disability. But they said they felt forced to pay for private education because their child could not be accommodated in the government system.

We would like safe schools so we could send our child to a public school. But because other children bullied and harassed him, we need to send him to a private school. It costs more money and involves longer travelling time. Government schools are not safe. It took me seven years to get my son into this private school.

MOTHER OF 12 YEAR OLD BOY
WITH ADD AND MILD INTELLECTUAL DISABILITY

The issue of the lower level of government funding to support students with a disability in non-government schools was raised many times. Some parents moved their children to government schools because the support funding was insufficient in the private school. Parents believed that private schools should contribute more to disability support from their own funds, not only relying on government subsidies. There was also criticism that there is insufficient accountability for the use of Commonwealth funding, with some accusations being made of misuse of funds.

My son was at the local Catholic school from grades prep. to six, but he went to a State secondary college in 1995. In 1994 he had \$1,500 allocated through the Catholic Education Commission and \$1,000 through the parish school itself. The state school received \$19,000 for his integration in Year 7.

PARENT OF BOY WITH MULTIPLE DISABILITIES

SPECIAL AND REGULAR SETTINGS

Widely varied comments were made about special schools, some of these coming from parents and some from teachers or other health professionals. Some parents said all special schools should be closed, while other parents were adamant that the special school option should remain. This was especially true for parents whose children had negative experiences in the regular classroom or special unit settings.

Teachers in a special school reported experiencing resource problems. They confirmed there are not enough funds for a wheelchair accessible bus although several students use electric wheelchairs, and that therapy services are diminishing because they are now being provided only on a consultancy rather than direct basis. Also more resources are needed for appropriate technology.

Some students currently or previously attending special schools participated in focus groups and their comments are of particular interest.

I miss having any friends of my own age.

17 YEAR OLD STUDENT AT SPECIAL SCHOOL WHERE
ALL OTHER STUDENTS ARE YOUNGER THAN HIM

I liked [the special school] but it got to a point where I wanted reality. I wanted to meet people and be part of society. The teachers disagreed. They thought regular school would be too fast for me. I went to an integration program. It was hard, but it was reality.

21 YEAR OLD FORMER SCHOOL STUDENT WITH A DISABILITY
NOW STUDYING AT TAFE



The limited curriculum and sometimes low academic expectations set for students in special schools was a widespread concern, especially when students did not have an intellectual disability.

I like school but I wish it was more challenging. I have a tutor on Saturdays who teaches me spelling and maths and encourages me to write, so now I want to be a writer.

11 YEAR OLD STUDENT WITH A PHYSICAL DISABILITY
ATTENDING SPECIAL SCHOOL

A letter from a health professional painted a disturbing picture of one special school. A student was left asleep on the toilet for more than half an hour and was later verbally abused by a teacher's aide for "deliberately" vomiting a piece of toast she was choking on. Also a 24 year old male student had an incontinence pad changed in full view of other students in the classroom. At the same school no communication equipment was in evidence despite five students being unable to speak. The teacher spent the afternoon doing paperwork in a classroom decorated like a kindergarten. She concluded:

Whatever the problems of integration, at least I have never seen staff remove a student's knickers in the regular classroom. If the Education Department is unable to ensure it employs caring, well-trained educators, the presence of students who can speak may be the only protection for students who can't.

VISITING HEALTH PROFESSIONAL

DIFFERENT DISABILITIES

DIFFERENT BARRIERS

8

There are many different disabilities and every child is different. Sixty five different disabilities were named by phone-in and questionnaire respondents, with 178 respondents naming multiple disabilities.

TABLE 4: CATEGORY OF STUDENT'S DISABILITY

CATEGORY OF DISAB.	PHONE-IN STUDENTS	PHONE-IN ADULTS	Q'NAIRE	TOTAL	PERCENTAGE %
intellectual	0	17	28	45	7.5
physical	6	55	58	119	19.7
cognitive	1	22	7	30	5.0
mental	1	45	73	119	19.7
sensory	7	17	63	87	14.4
multiple	2	81	95	178	29.5
other/not stated		8	17	25	4.1

The section below deals with some disabilities which seem to be more challenging for education providers than others.

ATTENTION DEFICIT DISORDER & RELATED DISABILITIES

102 respondents to the questionnaire and the phone-in identified the student's disability as attention deficit disorder or a closely related disorder. Two focus groups were held specifically for these types of disabilities.

Parents reported that it was an assumption made by many teachers that every child with ADD or ADHD has behaviour problems, that poor parenting is to blame, that doctors are falsely diagnosing the disorders, that parents are over-medicating their children and that such children can only be "managed" in a special school setting. These assumptions, they said, are wrong.

The medical and psychological professions are still debating these disabilities and their degree and the variations in diagnosis and treatment. Some students respond to medication. Support and adjustments to teaching methods are required to enable these students to succeed at school. In many cases, the skill, experience, and confidence of the teacher, together with simple modifications such as providing clear instructions and cues, employing active learning techniques and re-organising seating can help to keep students focused on their work.

AUTISM AND ASPERGER'S SYNDROME

43 respondents to the phone-in or the questionnaire identified Asperger's Syndrome, or autism or both as the student's disability.

Autism and Asperger's Syndrome, which is a higher functioning form of autism, is a disability which is more common in boys. It is characterised by withdrawal and inability to communicate with others, and can be associated with behaviour problems, sometimes repetitious or obsessive behaviours. There is no doubt students with these disabilities are difficult to teach in any setting, and teaching in a regular classroom poses challenges.



One parent was told that her child would have to be removed from the school if she did not stop the child's obsessive behaviour. Although the behaviour (zipping up school bags) was annoying, it did no-one any harm.

Parents of students with Autism and Asperger's Syndrome reported that their children communicate with smiles, simple phrases and are able to learn, with patience and understanding. Being with other children is a powerful form of learning for them.

DEAFNESS

Deafness of the student was identified by 53 respondents and hearing impairment by 16 respondents to the phone-in or questionnaire. Two focus groups involved parents and students who were deaf or hearing impaired.

Deaf and hearing impaired people have a wide variation in the level of hearing or hearing loss and have differing abilities in verbal communication and comprehension. Deaf students may be part of deaf families or mixed hearing and deaf families. Some communicate through the use of Auslan, some through signed English and some through speech. Many deaf people do not regard deafness as a disability and are proud to be part of the deaf community. Their first language is Auslan and some identify themselves to be of non-English speaking background.

The critical issue concerning deaf students and their parents is the lack of trained teachers who can communicate in Auslan. There are very few deaf teachers of deaf students. Many deaf students are in integrated classes where their teachers do not have sign interpreting skills. They are supported by visiting teachers of the deaf or by teachers' aides, who mainly use signed English.

My child was changed to a ten unit at school this year. The first teacher could sign, but he only stayed six months. Now no-one can communicate with my daughter as neither the teacher nor the aides can sign. There have been three teacher changes in six months. The teacher has no special education training.

MOTHER OF 9 YEAR OLD STUDENT WHO IS DEAF

I was watching a video for English without sub-titles. The interpreter went out of the room. I failed the task because the interpreter wasn't there.

13 YEAR OLD STUDENT WHO IS PROFOUNDLY DEAF

Another issue, raised by deaf students, was that of the confidentiality of what they say to or through the interpreter. They appear not to be able to have any private conversations as everything gets interpreted to the teacher. Sometimes the interpreter takes a moral stance or adds their own words or interpretation.

The interpreter answers for me in his own words. They should be our voice and nothing more!

15 YEAR OLD STUDENT WHO IS DEAF

Students are sometimes embarrassed by the interpreter sitting near them at large gatherings, rather than up the front with other speakers. It draws attention to the student.

There is disagreement about what is the most appropriate language, but the trend appears to be away from signed English and towards Auslan. This poses problems for the students and families who rely on signed English.



A method has to be found to impart the curriculum. If someone doesn't go through school reasonably successfully, then they are being denied access to education.

FATHER OF 16 YEAR OLD PROFOUNDLY DEAF STUDENT

The desire for separate education in a deaf-only school was a common request by both deaf students and their parents. Alternatively, they believed that education in a regular school had to ensure that Auslan teachers or aides were available full-time and that a bilingual approach was taken using both signed Auslan and written English.

LEARNING DISABILITIES

Students with learning disabilities are not a homogeneous group as there are many forms of learning disabilities. Nineteen phone-in or questionnaire respondents identified learning disability as the name of the student's disability.

A major issue among parents of students with a learning disability is their desire for the disability to be accepted as such and not be regarded as a "learning difficulty" which might be time limited and ameliorated by remedial teaching. A particular disability called scotopic sensitivity was mentioned often. It affects the optic nerve and requires adjustments in the form of classroom seating, non-glare lighting, different coloured paper or chalk, and sometimes the wearing of tinted glasses or hats in class. These adjustments do not cost much money or take much time, but there were many reports of refusal by teachers to make the adjustments, because they believed the disability did not exist.

One report was received of a student who needed her exam papers to be on coloured paper not white paper. When arriving at the examination room and finding only white papers, she was told to go to the school office and copy them herself onto coloured paper, losing valuable examination time as a result.

It was reported that removal from class for remedial lessons leads in many cases to lower self-esteem because through the learning the disabled student cannot overcome the disability through such lessons. The student misses out on other work and catch-up teaching is not always provided.

One school was mentioned which has made great efforts to assist students with scotopic sensitivity and in which the students were doing exceedingly well as a result.

CHRONIC FATIGUE SYNDROME

Chronic Fatigue Syndrome (CFS) is a relatively newly identified illness which is not well understood in school systems. Five respondents to the phone-in or questionnaire said the student had CFS. As with some other disabilities, it was reported that there is a denial that it exists, with students often being accused of laziness and lack of will to apply themselves or make an effort.

Parents and students reject those accusations and seek suitable adjustments. When those adjustments have not been made, students with CFS have had to leave school and try to continue their education at home.

CHEMICAL SENSITIVITIES

An increasing number of students are affected by extreme forms of allergies due to sensitivity to chemicals which are commonly used in schools. Five respondents to the questionnaire or the phone-in reported chemical sensitivities as the student's disability.

Students with chemical sensitivities often have limited subject choices. They cannot tolerate the fumes in art rooms or science laboratories in particular, but all classrooms can cause problems for them.

One adjustment requested by these students is that the school staff not use whiteboard pens, whiteboard cleaning fluids or other strong smelling cleaning products in the classroom. According to parents, schools have found it very difficult to accommodate these requests, forcing some students out of school as a result.

Our son has missed a lot of school because of the chemicals in the school. He was made to feel uncomfortable because he has to sit on a chair when other students are sitting on the carpet in group situations. No-one wanted to listen or understand his difficulties. They became very defensive.

PARENT OF EIGHT YEAR OLD BOY WITH SEVERE CHEMICAL SENSITIVITIES

MENTAL ILLNESS AND MENTAL HEALTH PROBLEMS

Reports were received that schools have difficulty in dealing with students who have mental health problems which are episodic or variable in their effect. The student usually appears to be "normal" and the illness may appear to be a behaviour problem and be treated as such. Only three respondents identified mental illnesses in the phone-in or questionnaire, however a focus group was held for students with serious mental health problems.

Complaints were received about the secrecy and shame which surrounds a mental illness compared to say, a physical disability. One student reported that her written enrolment contract with the school was conditional on her not becoming too emotional at school and on her not talking to any students or teachers, apart from two designated staff, about her problems. The school was fearful that her suicidal tendencies would affect other students and presumably teachers as well.

There's a big taboo around suicide. They try to hide the problem.

15 YEAR OLD STUDENT WITH DEPRESSION

Another concern of students with mental health problems was the fact that they missed a lot of school work when hospitalised and some teachers expected them to catch up, even if they had been away for extended periods. It appeared from those students that little assistance was given for remedial lessons or catch up.

I can't learn as quickly as others, but the teachers expect me to keep up, even if I've been away for two or three months.

13 YEAR OLD STUDENT WITH A SERIOUS MENTAL ILLNESS AND DYSLLEXIA

The stigma associated with mental illness was a problem for the students. They reported the only really poor treatment they experienced was from other students while the teachers were mostly supportive.

The students suggested awareness-raising sessions for teachers and students about mental illness would be valuable. They also realised there was a need to protect the student's confidentiality, so the sessions needed to be in general terms, not specific to any one student's situation.

DOUBLE DISADVANTAGE

9

INDIGENOUS STUDENTS AND PARENTS

9.1

Few indigenous people participated in the research: four people identified as an Aboriginal or Torres Strait Islander in the phone-in and eight in the mailed questionnaire (2% of respondents). None of the focus group participants identified themselves as Aboriginal or Torres Strait Islander. An Aboriginal consultant was engaged to canvass issues among members of indigenous communities in Sydney and a number of telephone inquiries were made to organisations working with indigenous people in other areas. Through these methods, the research was only able to touch the surface of issues faced by indigenous students with a disability.

Some reports by members of the Aboriginal community showed they had suffered not only discrimination on the basis of the student's disability, but also discrimination on the basis of race. Aboriginal students and families are dealing with a community that has limited understanding and tolerance for their child's disability and are also dealing with the non-Aboriginal community's ignorance and intolerance of Aboriginal culture.

Lack of tolerance and understanding of cultural values is one of the reasons that discrimination exists. This is one of the many instances that Aboriginal people complain about, we are not fully understood because the person hearing the complaint doesn't entertain those same values.

FATHER OF STUDENT WITH AN INTELLECTUAL DISABILITY

For Aboriginal people living in rural areas, a lack of access to special education offers even greater barriers. In most rural areas there is usually only one school to choose from and it may not offer special education or teachers with adequate experience in dealing with the requirements of students with a disability.

We wanted to send our child to an Aboriginal community school but after two days he was rejected by the non-Aboriginal teacher, because "he did not have an accredited disability worker". As a result my son was denied access to a culturally appropriate environment. We were not informed of the availability of resources to fund a position that would cater for my son at pre-school.

FATHER OF BOY WITH MULTIPLE DISABILITIES

Aboriginal students and parents reported that they were expected to have a higher standard of behaviour than non-indigenous students or parents, and suffer greater consequences if they do not conform to school regulations.

I brought my child late to school because my pension had not come through and I had to make arrangements for a counter cheque so I could buy food for my family. I phoned the school to inform the teacher I was going to be late dropping off my child. However, when I turned up at the school, the principal informed me that he would ring the police if I was late again.

SOLE PARENT FATHER OF STUDENT WITH A DISABILITY



9.2 NON-ENGLISH SPEAKING BACKGROUND STUDENTS AND PARENTS

Thirty nine respondents to the phone-in (10) and questionnaire (29) identified as being from a non-English speaking background (NESB), representing 6.5% of respondents.

Among general focus groups, a few participants were of NESB, but none required interpreters. Two focus groups were planned specifically for people of NESB, but only one was held. The organiser of the second group revealed that most parents contacted, who had experienced difficulties in the school system, were reluctant to complain and did not necessarily identify what they experienced as discrimination.

A questionnaire respondent explained the reasons for not complaining about discrimination as follows:

*They thought the child would be taken away from the family.
Also, because of their NESB, the family were unsure, and unconfident of the
processes in Australia.*

ADVOCATE FOR 15 YEAR OLD STUDENT WITH MULTIPLE DISABILITIES

There are wide variations in responses to disability within NESB communities, but it was reported that some people respond with shame and try to keep problems hidden. Some have a deep distrust of bureaucracies and governments and are reluctant to seek services or believe they are lucky to receive any services. Some have been persecuted in their countries of origin for freely expressing their views. These factors may have influenced their unwillingness to participate in this research.

The focus group participants highlighted how isolated and frustrated many families feel. Some NESB families had experienced racism as well as discrimination because of their child's disability.

A major and obvious issue mentioned by advocacy groups working with people with a disability of NESB is the language barrier. Students are sometimes used as interpreters when parents attend meetings at school. School policies and notices are usually only provided in English, so parents may miss out on vital information. Parents may not have the ability to articulate their concerns to the school.

When trouble occurs and the student faces suspension or exclusion, the meetings can be even more intimidating for NESB parents. Experiences of enrolment barriers, failure to meet support needs, negative attitudes and possibly unfair application of discipline policy appear to be similar to those experienced by other parents of children with a disability.

My child has been in the same class for three years and we have now been told he cannot stay in the school due to behaviour problems. He has been suspended frequently. When I wrote a letter to the teacher complaining about his treatment, the teacher ripped it up and placed it in the waste basket. I complained to the principal who didn't help at all, just dismissed the problem. My son's hours were reduced to one period a day.

With the help of the family solicitor, we got my child back in school full-time. We now want him to go to a different school but the principal has contacted that school and given the principal a bad report on my child.

PARENT OF 12 YEAR OLD BOY WITH INTELLECTUAL DISABILITY
SPEAKING THROUGH AN INTERPRETER

GEOGRAPHICAL DISADVANTAGE

9.3

Five focus groups were held in country towns. Respondents to the phone-in and questionnaire came from widely dispersed postcodes, which included many country locations.

Generally the problems and concerns of rural people were similar to those of people in metropolitan areas on issues such as attitudes of school staff, difficulties in enrolment and lack of resources. They reported similar types of discrimination and similar experiences of using complaints processes.

Problems mentioned as specific to rural areas were:

- lack of choice in schools;
- distance involved if a special school or special unit was required by the student but not available in close proximity to home;
- difficulty in attracting and keeping skilled teaching staff and aides in country areas;
- difficulty for or reluctance of staff to access city-based training opportunities;
- shortage or lack of therapists and visiting specialists;
- lack of advocacy services or disability support organisations;
- inequity in funding distribution formulae.

In a country town there is no choice where we go to school and no-one is there to advise us or support us. We have to "take it or leave it".

PARENT OF NINE YEAR OLD GIRL WITH INTELLECTUAL DISABILITY

Principals and teachers don't attend training sessions which are available. I attended one with my child's teacher and two aides. They are always in a capital city and we have to start travelling at 6 am to arrive at the starting time of 9 am. We have to drive 2-4 hours to another town as that is where the services (such as therapy) are located.

MOTHER OF SEVEN YEAR OLD CHILD WITH MULTIPLE PHYSICAL DISABILITIES

Access to services and support is very difficult. The nearest DOCS office staff are untrained in working with people with disabilities. It always goes in the "too hard basket"!

MOTHER OF SEVEN YEAR OLD CHILD WITH MULTIPLE DISABILITIES

COMPLAINTS PROCESSES

10

Many research participants had complained to someone about discrimination against their child. Most often these complaints were made to the teacher or the school principal.

Of the phone-in and mailed questionnaire respondents, 381 or 63.2% had complained. Of those, 224 (58.8%) had complained to teachers and 283 (74.3%) to principals. Only 185 (48.6%) had taken the next step to complain to the education authority, having not satisfactorily resolved the complaint.

196 (32.5%) respondents said they had not complained. Some of these people said they had no reason to complain, while a few were considering whether to complain. Among the most common reasons for not complaining, 60 said they were afraid of the potential consequences, 58 said they thought no-one would act on the complaint and 41 said they did not know who to complain to. Fear was expressed about the impact on the student or sibling if parents wanted the child to stay at the school.

People are nervous about pursuing complaints for fear of failure. Even if you win, you don't want your child somewhere they are not welcome.

PARENT OF FOUR YEAR OLD CHILD WITH MULTIPLE DISABILITIES

A particular concern was expressed about the difficulty of making formal complaints about pre-school education in places where the Education Department is not responsible for that sector. In some states, pre-schools are managed by local parent committees so to make a formal complaint means complaining, possibly, against your own neighbours.

The mailed questionnaire asked an open ended question about making complaints. Of 170 who answered that question, 147 made negative comments, 11 had positive views and 12 had mixed views.

The phone-in asked about complaint outcomes and found that making the complaint had led to no action or change in 101 instances, had a negative outcome for 49 callers and a positive outcome for 48 callers.

My daughter and her sibling were discriminated against because of my complaint.

PARENT OF GIRL WITH EPILEPSY, WHO COMPLAINED TO THE PRINCIPAL

I got a reputation for being over-protective and neurotic. My daughter was forced to leave school because of the hardships she was experiencing. I gave in as my complaints were ignored.

MOTHER OF FORMER STUDENT WITH LANGUAGE DISABILITIES

As mentioned previously, three parents had been threatened with defamation actions as a consequence of their complaints. As one of these instances received media publicity, other parents have expressed concern that the same thing could happen to them if they pursued their complaint.

The only school education discrimination case so far decided in Australia occurred in Queensland under that State's legislation. The decision in the "L" case, was found against the complainant as the discrimination which occurred was found not to be unlawful, due to unjustifiable hardship. During the research, some parents indicated they were aware of this case. Without discussing the merits of the decision, it is noted that the outcome has shaken the faith of some parents in the potential use and benefit of the formal external complaints mechanism.

I followed closely the case in Queensland and was disturbed how the unjustifiable hardship clause was used. How can government departments claim unjustifiable hardship?

The teacher was crying and saying he couldn't teach the child. Why don't they give support and adequate training to the teacher, instead of removing the child?

MOTHER OF FOUR YEAR OLD CHILD WITH MULTIPLE DISABILITIES

Some people reported positive outcomes, such as that the school staff were now more aware of the student's needs or that more resources had been provided.

A small number of parents had made formal complaints under anti-discrimination law (72, or 19% of 341 who had complained) and some had gone through conciliation. A number of comments were made by complainants about complaints bodies or complaint outcomes:

- some parents felt complaints staff didn't seem interested, as they thought the complaint was trivial;
- a few parents reported that complaints staff did not know anything about the disability or its implications for the student;
- a few reports were received of inadequate note-taking of proceedings and hence a difference of views arose about the conciliation agreement which was reached;
- some people reported that they had positive dealings with the conciliation staff, but found the delays in responses by the education authorities to be the most frustrating aspects of making complaints;
- some people questioned whether the training of conciliation staff was sufficient and called for the involvement of disability organisations in training;
- some parents found the process too exhausting, so they withdrew complaints, even though the matter was not resolved;
- some parents were happy with the outcome of conciliation, but were concerned that the terms were confidential and therefore other families were not able to be encouraged by their result.

The time delays in dealing with complaints were a concern for several people.

The process takes too long - you often need to urgently address a problem, but the backlog makes this impossible.

PARENT, WHO COMPLAINED TO EDUCATION DEPARTMENT

It took 14 months for the Commission to provide me with a response to the complaint. Then they wanted a response from me within two weeks and said they would close the file if I did not respond within the time-frame. The Department of Education had taken 11 months to respond to the Commission.

AUNT OF SEVEN YEAR OLD BOY WITH MULTIPLE DISABILITIES

One case went through protracted negotiations for 13 months from complaint lodgement to final conciliated agreement, with the education authority involved seeking a hearing adjournment and finally submitting a workable proposal only a few days before the proposed hearing. The case raised issues for the advocates and the family involved of the need to keep the focus on the best outcome for the child. There was, reportedly, further pressure placed on the parents and some criticism of the complainants for not proceeding to hearing.

A few people complained that the terms of conciliation agreements were not adhered to and that there were no enforcement provisions relating to conciliation agreements. In one example of a complaint under the Victorian Equal Opportunity Act 1984 involving the Catholic education system, it was reportedly agreed that the Catholic church would make a public statement in its Integration Handbook that students with disabilities were, *prima facie*, entitled to enrolment in Catholic schools. It was also agreed that there would be discussion about setting up a Catholic parents consultative group. Neither element of the agreement was kept, according to the complainant involved.

The reduction in the HREOC complaints backlog of 1995/96 is positive, but has yet to influence the perceptions of potential complainants. Although HREOC significantly improved its rate of complaint finalisation in 1995/96, there was still an average 198 days from complaint lodgement to allocation of complaints under the DDA.

It seems that the complaints process can be an unsatisfactory one for parents and students. Although formal complaints are not large in number, they would appear to be costly and time consuming for the family, the school or education authority and complaints handling agencies, with potential benefits to the system but limited benefits to the students themselves.

ADVOCACY SERVICES

181 (45.4%) phone-in and survey respondents who made complaints did so without anyone to support them. For those who had help making complaints, family or friends were the largest category of supporters (80 or 20.1%) followed by 73 (18.3%) who were helped by support groups or non-government organisations.

65 (16.4%) respondents had the help of advocacy or legal services to make complaints. Only a small proportion of respondents reported that they were assisted by the specialist disability discrimination legal services (21 or 5.3%). In meetings with key advocacy organisations, it was found that the numbers of education complaints dealt with was quite small but significant, with employment and accommodation issues predominating the case load.

Usually favourable comments were made about advocacy. This was most obvious in cases where an advocate negotiated with a school by telephone or in person on behalf of a parent. The concerns of the parents or students seemed to be taken more seriously when an advocate was involved.

Sometimes the situation between the parents and the school had deteriorated and the advocate was brought in at the time of crisis. In focus groups, when asked whether principals had told them about their right to an advocate or support person, most respondents replied in the negative.

There needs to be an independent body to oversee children with disability, to monitor formal agreements between teachers and parents.

MOTHER OF 13 YEAR OLD CHILD WITH MULTIPLE DISABILITIES

Advocacy organisations were not without their critics. A few reports were made of legal advocacy services not giving the attention the parent expected to their complaint, or in fact, declining to be involved as they thought the complaint did not have merit. Some parents were told they could not be taken on as clients because the service was already overwhelmed with cases.

PARENTS' AND STUDENTS' RIGHTS

11

Parents of children with disabilities are often under considerable stress. Battles with schools and education authorities are often the last straw. It would be very beneficial if parents knew of their rights in the education system and knew how to go about getting the services they require for their child.

PARENT OF 10 YEAR OLD CHILD WITH DOWNS SYNDROME

Some organisations consulted recommended that HREOC should convene a formal inquiry into the human rights of children and young people with a disability, covering protection, promotion and breaches of those rights in all aspects of their lives. In the light of the present joint inquiry by HREOC and the Australian Law Reform Commission into Children and the Legal Process, which has a mandate to consider discrimination and children with special needs, any further inquiry on these issues would be unlikely.

However, there is clearly a need for improved monitoring of discrimination against students with a disability. There is a need for information for parents and students to increase their knowledge and awareness about their rights to non-discrimination and to participation in decision-making. Education service providers need more information about their obligations under the law and more resources to enable policies to be put into practice more effectively.

Some parents suggested that open information sessions be run by schools on parents' and students' rights and eligibility for support resources. Others believed that more written information should be available, through early intervention services or pre-schools, as well as through schools or education authorities at enrolment.

Schools need to work with parents in providing for children, not in opposition to them. A child with a disability has as much need to attend school as a normal child. It is a basic human right for everyone to receive an education. My child is being denied this.

PARENT OF NINE YEAR OLD GIRL WITH INTELLECTUAL DISABILITY
ONLY ALLOWED TO ATTEND SCHOOL 14 HOURS A WEEK

CONCLUSION

12

There are some parts of the education spectrum where inclusion practices are working well, and there have been many successes for students with a disability and many satisfied parents. Notwithstanding instances of discrimination, inclusive policies are being reviewed and improved upon around Australia. This is a slow process, but the will is there among senior education authorities, some principals and some teachers. The resistance is largely coming from some individual principals who are resistant to change or ignorant of the law and some teachers who are concerned about the implications of inclusion, without sufficient resources, on their own work and on other students.

There is a myth of 'happy' disabled people. In a society such as ours, it has shocked me that it has happened to me. I thought it would be better.

Education has the power to make or break kids.

MOTHER OF 16 YEAR OLD CHILD WITH MULTIPLE DISABILITIES

The voices of students and parents have been used extensively in this report to support an argument for concerted action. Their pleas are for inclusion, acceptance and non-discrimination. They call for parents, students and schools to form constructive partnerships, rather than draw battle lines over educational programs, resources and equal participation of students with a disability in school life.

On a financial level students with a disability need equal access to education and equal opportunity to succeed in schools in order to gain employment and reduce their prospects of long term social welfare dependence. The community faces significant economic costs of maintaining some dependent people with disabilities and those costs will increase with the ageing of the population. Community education campaigns and employment programs emphasise that people with disabilities are entitled to fully take part in community life. Schools are the first and possibly most significant places where such participation must happen.

On the humane level, children with a disability are entitled to the dignity of an education as other Australian children, and the attendant self esteem, confidence and social networks that education promotes.

If you never start to integrate then society acceptance can never be achieved. It is visibility and exposure that helps break down the barriers of difference.

FORMER STUDENT WITH PHYSICAL DISABILITY



RECOMMENDATIONS

SCHOOLS

STAFF TRAINING AND STUDENT AWARENESS

1. Principals should facilitate the training of all their staff in disability, disability discrimination laws and obligations, and how to meet the educational and social development needs of students with a disability.
2. Education authorities should introduce disability modules into the curriculum which emphasise the special needs of children with a disability without portraying them as "victims".

ENROLMENT

3. Enrolment procedures for students with a disability should be handled, as far as possible, in the same time frame as enrolments for students without a disability. The presumption of enrolment procedure should be local school enrolment for all students unless the school can satisfactorily demonstrate to the parent and student why it is unable to enrol the student.
4. Needs assessment and planning should be undertaken as soon as possible after enrolment. If a student cannot be placed in the school of the parent's choice, reasons for refusal should be provided in writing and assistance should be offered to the parent to locate a suitable alternative placement convenient to the student's home. The student should be enrolled on an interim basis at the local school and school work should be provided at home if necessary until a school placement is arranged. Only information necessary for needs assessment should be collected, and it should be kept confidentially and separately from the student's academic record.

ACCEPTANCE AND INCLUSION

5. Schools should encourage supportive relationships between students with a disability and those without a disability.
6. School staff should ensure that all students with a disability are included in the whole school program, including excursions, camps, school dances and concerts, school photos, elective subjects, competitions and sporting activities, to the extent they wish to be and as their disability allows.

PARENT AND SCHOOL STAFF COMMUNICATION AND RELATIONSHIPS

7. Schools should adopt and promote a partnership approach with parents and the students themselves in planning for and implementing the educational and social needs of students with a disability.

8. Principals and school staff should ensure that meetings between staff and parents are conducted in a cooperative way, through the acceptance of the presence of advocates or friends of the parents' choosing, through appropriate facilitation, through the taking of minutes and recording of decisions, through the development and signing of action plans with timelines for review and through the provision of information about appeals or mediation processes to resolve disagreements.
9. Principals should ensure that interpreters are offered, and provided when requested, for all meetings with parents who use Auslan or signed English to communicate. Written information to parents should be provided in a form that parents can understand, if necessary in community languages.
10. Schools should establish, and publicise to all parents and students, an appeals and complaints procedure, if one does not already exist. The right to have an advocate present should be clearly stated.
11. Schools should not threaten or take legal action against parents or students who have complained about their treatment at school and should in all instances attempt to mediate the dispute.

RESOURCE ALLOCATION AND SUPPORT NEEDS

12. Teachers and school authorities should facilitate assessment by appropriate professionals, subject to permission from the parent and/or the student concerned.
13. Principals should ensure that funding allocations for students with a disability are made known to parents and students with a disability and that parents and students are involved in deciding how available resources are to be spent. Parents and students should be informed about all funding to which a student may be entitled and applications should be made, as mutually agreed between parents, students and school staff.
14. School authorities should assist parents to have sufficient resources allocated and should continue to argue for extension of funding to meet the needs of students with disabilities which are not currently or adequately recognised in funding formulae.
15. Schools should adopt a flexible approach to medication. They should assess whether a child has the capacity to look after their own medication, consulting the student's medical practitioner where necessary. If students can demonstrate capacity, and in the case of young students, parents agree, then students should be able to handle their own medication.

If a student is not capable, then nominated teachers should assist when necessary. Parents should not be required to attend, except in a medical emergency. Teachers and aides or assistants should be instructed on all issues in relation to the student's medication use, and written instructions should be kept in a central register in the school office. Assistance with medication should be provided confidentially.

16. Personal assistants should be employed to provide personal care services and teachers should only be required to act in an emergency. Personal assistants and teachers should provide personal assistance sensitively and confidentially, as far as possible. Parents should not be required to attend the school to provide personal assistance.
17. All schools should conduct access audits to assess what improvements can be made to access through funding and capital works programs. Schools which have students with a disability currently enrolled should examine room allocation options and make plans which facilitate the full participation of those students in the school's academic and non-academic programs.

DEPARTMENTAL / EDUCATION AUTHORITIES

INFORMATION

18. State and Territory Education Departments should require that every school have copies of their relevant federal and state/territory discriminations acts, and that Education Departments direct that these be made available to all members of staff of the school.

STAFF TRAINING

19. Education programs about disabilities, disability discrimination laws and obligations and ways of meeting special educational, social development and personal needs of students with a disability should be provided, or expanded, for all teachers and school administrators.
20. There should be mandatory units about access and disability issues in all pre-service courses and all current teachers and principals should be funded and encouraged to attend in-service training modules.
21. Community-based disability and advocacy organisations should be consulted in the planning of teacher training courses and be involved in their delivery on a fee-for-service basis.

RESOURCE ALLOCATION AND SUPPORT NEEDS

22. The education authority should research and collate data of the support resource requirements of all students with a disability and should make resource allocations to fully meet those needs.
23. Resources provided should be sufficient for the student to participate in the school of his or her choice (or his or her parent's choice) on a full-time basis during the compulsory years of schooling, if he or she is able to do so.
24. Funding formulae and distribution mechanisms should be examined and revised to ensure they reflect changes in the nature of placements of students with a disability. Existing arrangements without sufficient resources to meet the needs of current students should be urgently reviewed.

25. The provision of support funding should be made on at least an annual basis and should only require re-application / submission in subsequent years if needs have changed.
26. Educational authorities should change the definition of disability in education policies to ensure that eligibility for assessment of support and resources is consistent with the definition in the Disability Discrimination Act 1992.
27. Catholic Education Offices and independent school authorities should supplement Commonwealth disability funding from their own resources, in order that at least a similar level of resources is available to the student in those schools to the level which would be available in a government school for the same student.
28. Education authorities which receive any government disability funding should provide details in their annual reports, if they do not already do so, of how the funds have been used, how many students are supported, to what degree and in what setting. Summaries of those statistics should be made freely available to parents and disability organisations on request.

EDUCATION AUTHORITY AND PARENT COMMUNICATION AND RELATIONSHIPS

29. Education authorities should make all relevant policies and guidelines, including those covering enrolment, assessment, resource allocation and appeal / complaint mechanisms, widely and freely available to parents and students, in languages and formats they can understand.
30. An appeal and complaints mechanism should be provided at district or regional level about any decision relating to a student with a disability, if one does not already exist. This mechanism should allow for an external representation from disability or other appropriate community organisations. The parent's or student's right to have an advocate present should be clearly stated.
31. Education authorities should adopt an open and responsive attitude towards complaints and aim for best practice and quality improvement. They should seek to resolve parent complaints at an early stage, whenever possible, but should a complaint be made to an external body, the authority should expedite its handling of the complaint and respond within requested time-frames.
32. Education authorities should not threaten or take legal action against parents or students who have complained about their treatment at school.
33. Authorities should advise all their employees that the taking of civil legal action against complainants is not acceptable and is actively discouraged.



STATE GOVERNMENTS

34. Where discrepancies exist, State / Territory governments should amend equal opportunity/ anti-discrimination legislation to reflect the DDA definition of disability.
35. Governments should ensure that any discrimination complaint made by or on behalf of a child, which is deemed to have merit and is not vexatious, should not incur costs irrespective of the outcome of the complaint. Legal aid should be available to all children for their advocates or legal representatives.
36. Governments should, in their next and subsequent budgets, substantially increase funding for disability support resources at **all** levels in the school system, especially the funding for integration support.
37. Governments should provide education authorities with sufficient funds to publicise disability policies and guidelines.
38. Governments should increase the funding for independent, community-based advocacy and disability complaints services, including legal advocacy services, to ensure that such services are comprehensive across all parts of Australia and are culturally appropriate, disability sensitive and accessible.
39. State and Territory Ministerial Advisory Committees on disability and education, where they exist, should include members who are young people with a disability and people who are parents or carers of young people with a disability. Such committees should be created if none exist.

COMMONWEALTH GOVERNMENT

40. The Commonwealth Government in its next and subsequent budgets, should increase its supplementary funding for disability support resources at all levels in the school system, including independent school funding.
41. The Commonwealth Government should make all relevant Commonwealth policies and guidelines covering disability funding and accountability freely available to parents and students.
42. The Commonwealth Government should increase its contribution to funding for independent, community-based advocacy and disability complaints services, including legal advocacy services, to ensure that such services are comprehensive across all parts of Australia and are culturally appropriate, disability sensitive and accessible.
43. A Commonwealth Ministerial Advisory committee on disability and education should be established and include members who are parents or carers and young people with a disability.

44. The Commonwealth Government should provide funds for a community education program targeted to parents, young people and education authorities on the rights of students with a disability to non-discrimination and the responsibilities of education providers to deliver education in non-discriminatory ways.

COMPLAINTS AND ADVOCACY ORGANISATIONS

45. HREOC, having reduced the backlog in complaints handling, should keep the backlog from recurring through the allocation of sufficient staff resources for conciliation, especially for education complaints relating to children.
46. HREOC should encourage deadlines for responses to complaints to be met by education authorities and complainants or their advocates, through efficient follow-up procedures.
47. HREOC should consider conducting research on the outcomes of conciliation agreements six months or 12 months after they have been agreed, to establish the extent of compliance with the terms of agreements and satisfaction with the outcomes in the medium and long term.
48. HREOC should examine its conciliation staff training materials to ensure that information about different disabilities and issues relating to education of students with a disability is included.
49. All anti-discrimination / equal opportunity bodies should accord complaints from school age children, or those acting on their behalf, the highest priority, given the impact that delays may have on the child's equal access to education.
50. Advocacy organisations should make concerted efforts on a regular basis to publicise their services and inform children and their parents or carers of their availability.
51. Advocacy organisations, which currently do not provide advocacy services in the education area, are encouraged to do so or to seek funds to enable an expansion of services into this area.

REFERENCES

Australian Bureau of Statistics *Disability survey*. Canberra: ABS, 1993

de Lemos, M. M. *Schooling for students with a disability*
(for Australian Council for Educational research for DEET).
Canberra: AGPS, 1994

L and Minister for Education for the State of Queensland
Queensland Anti-Discrimination Tribunal No H39 of 1995

United Nations Convention on the Rights of the Child
New York: United Nations, 1989

United Nations Declaration on the Rights of Disabled Persons.
New York: United Nations, 1975

LEGISLATION

Disability Discrimination Act 1992 (Cth)

ACT Discrimination Act 1991

NSW Anti-Discrimination Act 1977

Northern Territory Anti-Discrimination Act 1992

Queensland Anti-Discrimination Act 1991

South Australian Equal Opportunity Act 1984

Victorian Equal Opportunity Act 1995

Western Australian Equal Opportunity Act 1984

EDUCATION POLICIES FOR STUDENTS WITH A DISABILITY

ACT Department of Education
Policy for Services to Students with Special Needs 1992

New South Wales Department of School Education
Special Education Policy 1993

Queensland Department of Education
Educational Provision for Students with Disabilities
Policy Statement and Management Plan 1993

South Australia Department of Education
Students with Disabilities Policy Statement 1991

Victorian Directorate of School Education
Programs for Students with Disabilities and Impairments 1995



APPENDIX 1

ACCESS STRATEGIES

Consultation research may not be the best way to gather the views of people of different disability, cultural, social, racial, geographic or economic backgrounds. The use of multiple research methods aimed to address some of these issues, but not all could be overcome. This appendix outlines strategies used to facilitate participation by particular groups.

YOUNG PEOPLE

Three focus groups were held only for young people, two of them in places attended by young people. One other mixed adult / young person group was held in a special school. Young people were paid to indicate that their time was valued. Triple J Radio was one of the targets for phone-in publicity.

INDIGENOUS PEOPLE

The researchers were aware that many indigenous communities would not feel comfortable with a focus group process. Questionnaires were also thought to be unlikely to attract much response. Community-based disability services for Indigenous people are difficult to find, where they exist at all. However, an Aboriginal person was engaged to consult directly with members of his own community. Individual meetings were held with some people and a report was provided.

DEAF OR HEARING IMPAIRED STUDENTS / PARENTS

The questionnaire draft was circulated to and comments were received from several organisations representing deaf citizens or parents of hearing impaired / deaf children. Language and terms used in the questionnaire were simplified as much as possible in the light of feedback regarding literacy levels of deaf students. An advocacy worker with the Victorian College for the Deaf, Rebecca Adam, distributed 150 questionnaires to deaf students and ran a workshop to assist them to understand and complete the questionnaires.

The phone-in had Telephone Typewriter (TTY) and National Relay Service access.

Auslan interpreters were used in two focus groups and they were offered at other focus groups, if required.

BLIND OR VISUALLY IMPAIRED STUDENTS / PARENTS

The phone-in and focus groups were activities in which blind or visually impaired students or parents could participate as they did not rely on written materials. A reliance on print publicity was a barrier to participation, however Radio for the Print Handicapped stations were included in the phone-in publicity targets.

Focus groups were held in accessible venues.

The questionnaire was printed in 14 point type in a san-serif font, which we were advised would make it easier for some visually impaired people to read.

Unfortunately the cost factors, outweighing the likely increased participation, led to a decision not to produce Braille or spoken word versions of the questionnaire.



PEOPLE WITH PHYSICAL DISABILITIES

Focus groups were held in accessible venues. The phone-in was conducted in an accessible venue, enabling the casual employment of a person with a physical disability.

PEOPLE OF NON-ENGLISH SPEAKING BACKGROUND

Specialist organisations which advocate for ethnic people with a disability were involved in the project.

Two focus groups were planned for people from non-English speaking background communities, but only one was held. An interpreter was used in that group. The other group failed to attract participants. The input from the focus group was valuable, although the information cannot be generalised.

Only English language questionnaires and phone-in publicity were produced due to cost factors. The phone-in was publicised on SBS radio. Phone-in publicity included the Telephone Interpreter Service (TIS) number but it was not used during the phone in, and the number of callers who identified as being of non-English speaking background was low.

LITERACY

The questionnaire tried to use clear language and provide examples to explain concepts where necessary. The phone-in and focus groups were methods which did not rely on high levels of literacy from respondents.

RURAL AREAS

The phone-in provided a 1800 free call number from anywhere in Australia. The questionnaire was posted to many individuals and organisations in non-metropolitan areas. Focus groups were held in four country towns.

ECONOMICALLY DISADVANTAGED PEOPLE

Reply paid envelopes were sent with questionnaires to encourage replies at no cost to respondents. The phone-in provided a 1800 free call number from anywhere in Australia. Focus group participants were paid a small fee for their attendance and to cover any out of pocket expenses. Local organisers and note-takers were also paid.

APPENDIX 2 KEY STATISTICAL RESULTS

These tables only relate to the phone-in and the mailed questionnaire. Focus groups were not statistically analysed. Tables are included only if the information is not already reported elsewhere in the report.

AGE

TABLE 5 AGE OF STUDENT

AGE IN YEARS	PHONE-IN STUDENTS	PHONE-IN ADULTS	Q'NAIRE	TOTAL	PERCENTAGE
under 5		8	1	9	
5		15	2	17	
6		10	9	19	
7		9	14	23	
8		17	17	34	
9		15	14	29	
10	1	27	28	56	
11		27	21	48	
TOTAL # PRE-SCHOOL AND PRIMARY				275	45.6%
12	1	18	21	40	
13	2	20	30	52	
14	5	14	24	43	
15		16	23	39	
16	3	12	30	45	
17		10	28	38	
18	1	11	13	25	
TOTAL # STUDENTS FROM 13 - 18 YEARS				242	40.1%
over 18 or not stated	4	16	66*	86	14.3%
TOTAL				603	100%

→ SOME RESPONDENTS TO THE MAILED QUESTIONNAIRE GAVE THEIR OWN AGE, RATHER THAN THE STUDENT'S AGE.

TABLE 6 WHERE WERE RESPONDENTS FROM ?

STATE OR TERRITORY	PHONE-IN STUDENTS	PHONE-IN ADULTS	Q'NAIRE	TOTAL	PERCENTAGE
NSW/ACT	11	90	93	194	32.2
NT		6	14	20	3.3
QLD		31	31	62	10.2
SA	1	14	64	79	13.1
TAS	1	7	7	15	2.5
VIC	2	54	87	143	23.7
WA		39	41	80	13.3
not stated	2	4	4	10	1.7

➡ TOTAL # WHO RESPONDED TO QUESTION = 603

DETAILS ABOUT SCHOOL ATTENDED

TABLE 7 SCHOOL SECTOR ATTENDED BY STUDENT

SECTOR	PHONE-IN STUDENTS	PHONE-IN ADULTS	Q'NAIRE	TOTAL	PERCENTAGE
public	11	183	190	384	63.7
catholic	2	25	47	74	12.3
private	2	15	39	56	9.3
other	2	21	35	58	9.6
no answer	0	1	30	31	5.1

TABLE 8 SCHOOL TYPE

TYPE	PHONE-IN STUDENTS	PHONE-IN ADULTS	Q'NAIRE	TOTAL	PERCENTAGE
regular school no special classes	10	157	158	325	53.9
regular school with special class	6	67	114	187	31.0
disability only school	1	14	33	48	8.0
other	0	5	10	15	2.5
no answer	0	2	26	28	4.6

➡ TOTAL # WHO RESPONDED TO QUESTION = 603

TABLE 9 BASIS OF LAST OR CURRENT SCHOOL ATTENDANCE

SCHOOL ATTENDANCE	PHONE-IN STUDENTS	PHONE-IN ADULTS	Q'NAIRE	TOTAL	PERCENTAGE
full-time	17	217	296	530	87.9
part-time	0	24	17	41	6.8
not at school	0	0	23	23	3.8
no answer		4	5	9	1.5

➡ In the mailed questionnaire, two questions were asked about activities of students out of school

- 23 were doing school work at home and
- 17 respondents said the student was no longer doing school work.

➡ In the phone-in survey, respondents were asked if they were going to school now:

- 14 students said yes
- three said no

Of the adult respondents, answering about their children

- 215 said the child was at school and
- 30 said the child was not at school. Several of these indicated the student was being educated at home.

SUPPORT NEEDS

TABLE 10 SUPPORT NEEDS AT SCHOOL

SUPPORT NEEDED	PHONE-IN STUDENTS	PHONE-IN ADULTS	Q'NAIRE	TOTAL
staff acceptance	6	105	254	365
student acceptance	3	58	241	302
interpreter	6	3	49	58
support teachers or aides	7	176	254	437
ramps	0	22	44	66
transport	1	25	102	128
scribe in lessons or exams	3	43	91	137
medication assistance	0	49	57	106
assistance with eating	n/a ¹	n/a ¹	35	35
assistance with personal hygiene	0	34	71	105
other [➡]	8	115	139	262

¹ Assistance with eating was not included as an option in the phone-in survey.

➡ The most common "other" types of support requested by respondents were more understanding of the disability, adjustments to teaching methods, special equipment or computers and extra time to do school work.

TABLE 11 DO YOU GET THE SUPPORT YOU NEED ?

GET HELP?	PHONE-IN STUDENTS	PHONE-IN ADULTS	Q'NAIRE	TOTAL	PERCENTAGE
no	3	116	52	171	28.4
partly	0	79	161	240	39.8
[RESPONDENTS WHERE SUPPORT NEEDS WERE NOT MET OR ONLY PARTLY MET]				411	70%
yes	14	45	123	182	30.2
not sure/ no answer	0	5	5	10	1.6

➡ TOTAL # WHO RESPONDED TO QUESTION = 603

DISCRIMINATION

**TABLE 12 HAVE YOU [THE STUDENT] EVER
BEEN DISCRIMINATED AGAINST AT SCHOOL ?**

EVER BEEN DISCRIM?	PHONE-IN STUDENTS	PHONE-IN ADULTS	Q'NAIRE	TOTAL	PERCENTAGE
yes	16	223	216	455	75.5
no	1	21	81	103	17.0
no answer / not sure		1	44	45	7.5

➡ TOTAL # WHO RESPONDED TO QUESTION = 603

➡ The mailed questionnaire asked whether the discrimination was happening now.
Of 341 respondents:

- 146 respondents answered yes
- 100 answered no
- one was not sure
- 94 did not answer or the question was not applicable.

**TABLE 13 SCHOOL SECTOR WHERE
DISCRIMINATION IS HAPPENING NOW**

SECTOR	NUMBER	PERCENTAGE
public	88	60.2
catholic	13	8.9
private	14	9.6
other	16	11.0
no answer	15	10.3

➡ TOTAL # WHO RESPONDED TO QUESTION = 146

➡ THIS TABLE ONLY APPLIES TO MAILED QUESTIONNAIRE RESPONSES.

TABLE 14 WHAT SORT OF DISCRIMINATION HAS OCCURRED ?

TYPE OF DISCRIMINATION	PHONE-IN STUDENTS	PHONE-IN ADULTS	Q'NAIRE	TOTAL
refusal of enrolment	2	30	95	128
partial enrolment	0	14	11	25
battle to get enrolled in school of choice	0	28	49	77
lack of support	7	128	55	190
lack of resources	3	95	n/a ¹	98
limited inclusion or participation	3	78	159	240
negative staff attitudes or harassment by staff	12	169	21	202
lack of staff training	6	96	n/a ¹	102
staff not stopping bullying by students	5	63	24	92
suspension or expulsion	0	38	76	114
other	9	110	45	164

1 GAPS IN THE DATA DUE TO DIFFERENT QUESTION FORMAT FOR MAILED QUESTIONNAIRE.

- ➡ Of the 95 respondents to the mailed questionnaire who had been refused enrolment
 - 25 had been refused by two schools and
 - 22 had been refused by three or more schools.
- ➡ Of 139 mailed questionnaire respondents who said the child had to change schools because of their disability
 - 27 said they had changed school twice and
 - 35 had changed schools three or more times.

TRAVEL AND TRANSPORT

One consequence of enrolment refusal or other forms of discrimination is that the student is enrolled in a school some distance from home.

- ➡ 138 respondents to the mailed questionnaire said the student had to be enrolled a long way from home and for 91 respondents this created problems:
 - long travel time 61 responses
 - need for supervision 12 responses
 - extra costs 8 responses
 - extra support needs 5 responses
 - combination of problems 19 responses



PARTICIPATION

177 of the respondents to the mailed questionnaire said they were able to participate in school activities such as sport, camps and excursions. However, 159 said they did not participate or were only included sometimes.

The table below outlines the reasons given for non-participation or limited participation in the mailed questionnaire.

TABLE 15 LACK OF PARTICIPATION

EXPLANATION FOR LACK OF PARTICIPATION	# OF RESPONSES
disability makes it too hard	33
student not allowed on camps or outings unless parent comes too	24
staff not willing to assist or make adjustments	22
team exclusion as can't compete, doesn't fit in	16
needs support person to enable participation	13
student refused access to work experience	2
playground exclusion as clumsy, lack of skills	2
other	53

COMPLAINTS

TABLE 16 EVER COMPLAINED ABOUT DISCRIMINATION ?

EVER COMPLAIN?	PHONE-IN STUDENTS	PHONE-IN ADULTS	Q'NAIRE	TOTAL	PERCENTAGE
yes	15	175	191	381	63.2
no	2	55	139	196	32.5
not applicable		15	11	26	4.3

➡ TOTAL # WHO RESPONDED TO QUESTION - 603

TABLE 17 IF YOU HAVEN'T COMPLAINED, WHY NOT?

REASON DIDN'T COMPLAIN	PHONE-IN STUDENTS	PHONE-IN ADULTS	Q'NAIRE	TOTAL
fear		23	37	60
thought no-one would act	1	6	51	58
didn't know who to complain to	1	12	28	41
too difficult		7	24	31
takes too long		3	16	19
other	2	23	62	87

➡ The most common 'Other' response was that the person had no need to complain. Some others said they had not defined what happened as discrimination and therefore did not think they could complain about it, while others indicated that they were considering making a complaint. A few respondents indicated they were giving the school the benefit of the doubt and that the school was doing its best to resolve the problems.

TABLE 18 IF HAVE COMPLAINED, WHO DID YOU COMPLAIN TO?

WHO WAS COMPLAINED TO	PHONE-IN STUDENTS	PHONE-IN ADULTS	Q'NAIRE	TOTAL	% OF 381 WHO COMPLAINED ¹
teacher	8	74	142	224	58.8
principal or school counsellor	5	111	167	283	74.3
Department / Education authority	2	77	106	185	48.6
Minister for Education	0	30	n/a ²	30	7.9
Ombudsman	0	7	14	21	5.5
ADB or EOC ³	1	8	29	38	10.0
HREOC	1	11	22	34	8.9

¹ THIS OPTION WAS NOT INCLUDED IN THE MAILED QUESTIONNAIRE.

² EOC EQUAL OPPORTUNITY COMMISSION
ADB ANTI-DISCRIMINATION BOARD

³ RESPONDENTS COULD CHOOSE MORE THAN ONE OPTION
SO PERCENTAGES DO NOT ADD UP 100%.

TABLE 19 WHO HELPED YOU COMPLAIN ?

WHO HELPED?	PHONE-IN STUDENTS	PHONE-IN ADULTS	Q'NAIRE	TOTAL	PERCENTAGE
family or friend	10	12	58	80	20.1
support group / community org.	1	26	46	73	18.3
disability complaints service		3	11	14	3.5
discrimination legal service		7	14	21	5.3
other community legal service		6	9	15	3.7
private lawyer		8	7	15	3.7
no-one	5	100	76	181	45.4

➡ TOTAL # WHO RESPONDED TO QUESTION - 399

➡ A few people said that a teacher or school counsellor or the Human Rights and Equal Opportunity Commission helped them complain, however this response was not quantified.

➡ Almost half of the people who complain have no-one supporting them and one fifth have only friends or family members supporting them. Formal legal advice and support was only used by 13% of respondents.

TABLE 20 GENERAL COMMENTS ABOUT MAKING COMPLAINTS

The mailed questionnaire asked an open ended question about making complaints. Responses were manually content analysed.

COMPLAINTS EXPERIENCE	NUMBER OF RESPONDENTS	PERCENTAGE
positive	11	6.5
negative	147	86.5
mixed views	12	7.0

➡ TOTAL # WHO RESPONDED TO QUESTION - 170
171 RESPONDENTS DID NOT ANSWER.

TABLE 21 COMPLAINT OUTCOMES

In the phone-in survey, the outcomes of the complaints were explored.

COMPLAINT OUTCOME	PHONE-IN STUDENTS	PHONE-IN ADULTS	TOTAL
positive outcome	1	47	48
negative outcome	1	48	49
nothing / no change	10	91	101
left school	0	13	13
changed school	2	21	23
don't know yet, on-going	2	2	4
other	3	37	40

- ➡ Multiple responses were allowed, with some people choosing both positive and negative outcomes. Some remarked that a short term solution was achieved, but no long term change or that with a change of staff, the problem recurred.

TABLE 22 IDEAS TO REDUCE DISCRIMINATION

KEY IDEAS	PHONE-IN STUDENTS	PHONE-IN ADULTS	Q'NAIRE	TOTAL	PERCENTAGE
teacher awareness or attitude change	14	184	174	372	62
student awareness or attitude change	5	53	71	129	21
changes to curriculum, teaching methods, school structure	1	60	81	142	24
other	15	270	157	342	57

- ➡ The categories of "Ideas" were derived from manual content analysis of answers to an open ended question.
- ➡ The most common 'Other' suggestion was additional resources. Other suggestions included the provision of information to students and parents about their rights to support and inclusion and the need for more advocacy services.

PRELIMINARY CONSULTATION MEETINGS

APPENDIX 3

Action for Citizens with a Disability (NSW)
 Action on Disabilities within Ethnic Communities (Vic)
 ACROD (National peak)
 Advocacy Information Network (SA)
 Association for Children with a Disability (Vic)
 Australian Youth Policy & Action Coalition
 Deafness Forum (National peak)
 Defence for Children International (Australia)
 Disability Complaints Service of NSW
 Disability Complaints Service of SA
 Disability Discrimination Legal Centre (NSW)
 Disability Discrimination Legal Advocacy Service (SA)
 Head Injury Council of Australia (National peak)
 Human Rights and Equal Opportunity Commission Disability Discrimination
 Conciliation staff
 Intellectual Disability Rights Service (NSW)
 Kids Belong Together (NSW)
 MALSSA (SA)
 National Epilepsy Association of Australia (National peak)
 National Ethnic Disability Alliance (National peak)
 National Federation of Blind Citizens (National peak)
 National Movement for People with Learning Disabilities
 North Melbourne Community Legal Service
 NSW Anti-Discrimination Board
 Parent Advocacy Inc (Renmark)
 Parents of Hearing Impaired Children – Victorian Federation
 SA Equal Opportunity Commission
 STAR Victorian Action on Intellectual Disability
 Victorian Council for Deaf People
 Victorian Disability Discrimination Law Advocacy Service
 Victorian Parent Advocacy Collective



APPENDIX 4 FOCUS GROUPS IN DETAIL

Focus groups provided a way of directly involving young people with a disability and their parents. Two states were chosen to provide a sample of views and experiences, and to contrast a small population state and a larger one, although the results cannot be generalised.

The researchers relied on other organisations or individuals to organise groups in South Australia and country NSW. One group was run entirely by an external facilitator. Most organisers were paid a small fee for their time.

Participants were paid an attendance fee, which was especially important for rural families and young people. Advocacy workers attended some groups, with the permission of the other participants, but were not paid.

Registrations were required in advance and numbers were intended to be kept to six participants per group. In light of demand and as some participants did not register in advance, the numbers went up to 9 - 10 in some groups.

The groups included students with different disabilities and/ or their parents/carers, some of whom also had a disability:

- students only with mental health problems (1 group)
- students only with any disability (2 groups)
- parents / students with hearing impairment / deafness (1 group)
- parents / students with sensory disabilities (1 group)
- parents / students with physical / multiple disabilities (1 group)
- parents / students with ADD / ADHD or learning disabilities (2 groups)
- parents / students with intellectual disabilities (2 groups)
- parents / students from non-English speaking background (1 group)
- parents / students with any disability (6 groups)

FOCUS GROUPS BY LOCALITY

Berri, SA (one group), Whyalla, SA (one group), Adelaide (seven groups), Wagga Wagga (one group), Lismore, NSW (two groups), Sydney, NSW (five groups)

Auslan interpreters were used in two groups and a community language interpreter was used in the non-English speaking background group.

Groups were evaluated through written feedback. Overall, the feedback was positive, with the main problem being not enough time. Later groups were allocated extra time.

Feedback in the mixed 'sensory' disabilities group indicated it would be better to separate visual impairments / blindness from hearing impairments / deafness, as the issues are distinct and the mix of spoken English and Auslan was unwieldy. Separate groups were scheduled in Sydney.

All venues were accessible, however some rooms were small and conditions were 'cosy' which was not ideal.



A positive spin-off was the sense that people felt less isolated and were able to become part of support groups or advocacy networks which they had not known about before. Some groups arranged follow-up meetings.

Four Sydney groups were cancelled due to the lack of registrations. The geographic spread and the specialised focus of groups meant some people could not attend a group close to home. The choice of written questionnaire or phone-in led to some people deciding against attending a focus group. Three other groups did not attract registrations: one in Renmark, one non-English speaking background group in Adelaide and one for young people in Wagga Wagga.

A workshop held at AYPAC Conference included young people with a disability, siblings of young people with a disability and youth workers. This was not counted formally as a focus group, because the timing and format did not allow the same depth as the other groups.

APPENDIX 5 QUESTIONNAIRE PROCESS IN DETAIL

A draft questionnaire was circulated to 21 organisations. Comments were received from 13 and changes were incorporated. A small trial led to further modifications.

Two thousand (2,000) questionnaires were mailed in early September to organisations and individuals, with reply paid envelopes. Most organisations received five copies, individuals one copy. Some organisations circulated extra copies, but some of those sent may not have been passed on, so it is estimated that some 1,800 questionnaires reached their target, that is families in which there is a student with a disability.

Three hundred and forty one (341) valid questionnaires were returned, approximately 19%. A further eight were not included in statistical analysis because they were completed by adults talking about past experiences (four), or were received after the data was coded (four). Some complaints were received that not enough time was allowed for response (four weeks) but late returns were included until four weeks after the deadline.

The questionnaire design worked well with respondents following prompts, and answers showed that questions were generally understood. Terms used were defined and examples were given to explain some concepts.

The form was long and was no doubt difficult for some people to complete. This problem was specifically mentioned in respect to deaf students whose first language is not English. The consultants did not produce braille or taped versions, nor versions in languages other than English, partly on the advice of the relevant organisations, partly due to the cost and partly on the assumption that many people completing the questionnaires would be non-disabled parents or advocates or that parents and students would fill out the questionnaire together. The consultants acknowledge that these obstacles may have prevented some people from putting their views in writing, but there were other research methods.

It was not possible to ask separate questions about each different school attended in which discrimination had occurred. This would have made the questionnaire even longer. The current school attended by the student may not be the one in which they experienced discrimination.

Many respondents added detailed stories and attached information on incidents of discrimination or complaints. The use of open-ended questions made analysis more difficult, but indicated the level of concern and the degree of discrimination respondents perceive to have had been affected by students with a disability. Many people said they were pleased to have the opportunity to express their views and hoped the results would lead to action.



PHONE-IN PROCESS IN DETAIL

APPENDIX 6

The questionnaire, derived from the mailed version, went through several drafts and a trial, but was modified following staff training.

Publicity began five weeks before the phone-in when the telephone number was confirmed. Notices were circulated to about 250 organisations. About two weeks beforehand, a second notice went to organisations and a first one to about 100 individuals. A media release was sent to 56 media outlets in all capital cities and major regional centres one week prior to the phone-in. Media response was good with pick-up in many newspapers and on radio, particularly on ABC Radio. A flier was included in a major professional journal (1,000 copies) and a regional disability newsletter (approximately 1,000 copies). Radio for the Print Handicapped in each capital city and SBS Radio were among those media sent the release. Even then some people indicated later that they had not heard about the phone-in.

However, phone-in staff had all the calls they could handle. Seven lines, including a Teletypewriter (TTY) line, were staffed for 16 hours over two days. All but the TTY line were constantly busy, with some callers complaining they had trouble getting through. Only three calls (all from deaf students) came via the TTY, but two of them took over two hours to complete. Three other deaf students and at least one deaf parent accessed the phone-in through the National Relay Service. Fliers included the relay service number, which was also a free-call.

The Telephone Interpreter Service number was provided in publicity however no calls requiring an interpreter were received.

Some 262 valid calls were statistically analysed. Four were excluded as they were adults talking about past experiences (two), and teachers talking about groups of students (two). Teachers, adults with past experiences or representatives of organisations were asked to write in as the phone-in aimed to gather information from current parents or students directly. A total of 311 calls were received on the 1800 line.

Staff were rostered in two hours blocks, but some ended up working longer hours. It was estimated that the questionnaire would take between 10 and 15 minutes to complete, but calls often took 20 -30 minutes, especially when parents relayed a long history of harrowing experiences. Phone-in staff required debriefing at the end of the day, as many had heard deeply troubling stories.

There was a lack of clarity in the question on type of school attended: whether a special school, special unit or integrated setting, so that result is not accurate.

Regarding the type of support needed by the student and the type of discrimination experienced, the staff listened and then provided a list of options as needed. It was not possible to get details of experiences in a number of schools over a long period. One question on the outcome of the complaint was not asked in the mailed questionnaire.

The advice of Maree Delaney in planning the phone-in was invaluable and is gratefully acknowledged. The use of the Disability Council of NSW office is also acknowledged with thanks.

APPENDIX 7 ACKNOWLEDGMENTS

We thank the following organisations and individuals for their assistance.

PROJECT STAFF AND VOLUNTEERS

Christine Flynn *Senior Project Officer*
 Melanie Kaplun *Research Assistant*
phone-in coordinator
 Rebecca Lee *Research Assistant*

ADVISORY COMMITTEE

Chris Ronalds *NCYLC Board*
 Helen Hurwitz *HREOC*

PHONE-IN

Disability Council of NSW
 for venue and phones
 Maree Delaney for advice on phone-in

DISABILITY CODING ADVICE

Sutherland Learning Difficulties
 Support Group

PHONE-IN STAFF

Madeleine Bennison	Rachel Connor	Harriet Davidson	Stephanie Dunn
Ben Folino	Andrea Grimes	Connie Kokotas	Carl Lee
Jacqueline Millane	Lisa Murry	Julie Roche	Christine Ronalds
Duncan Smith	Marianne Timbrell		

FOCUS GROUP ORGANISERS

Berri / Renmark	Ros Frazer <i>Disability Action</i>
Adelaide	Lorraine Zenie <i>Independent Advocacy</i> Sandy Newman / Neil Lillicrap <i>DIRC</i> Angela Davis <i>Adolescent Day Service</i> Dalilla Velotti <i>MALSSA</i>
Whyalla	Sandra Walsh <i>Options Coordination</i>
Wagga Wagga	Meaghan Sweeney
Lismore	Coral Wheatley & Trish Luker <i>Disability Information Service</i> Wendy & Doug Ridley
Sydney	Annie Harvey <i>Multicultural Disability Advocacy Association</i> Marie Knox <i>Australian Catholic University</i> Helen Ford <i>Disability Complaints Service</i> Ruth Robinson <i>Action for Citizens with a Disability</i> Joan Hume <i>Loftus TAFE Disability Department</i> Ian Rogers <i>Western Sydney Institute of TAFE</i> Kathy Stait <i>Learning Difficulties Group</i> Liz Binet <i>Disability Services</i>

ABORIGINAL CONSULTATION

Tony Pearce

SPSS ANALYSIS

Susan Byrne

NOTE-TAKERS

Sara Goldman	Vicky Murphy
Deirdre Paillas	Karen Peacock
Duncan Smith	Janet Williams

EDITING

Michael Antrum

QUESTIONNAIRE DISTRIBUTION

Rebecca Adam *Victorian College for the Deaf*
 and too many others to mention

DATA ENTRY

Southside Data Entry

GRAPHICS

Jason Armstrong

PRINT PRODUCTION AND DTP

Madeleine Bennison





NATIONAL CHILDREN'S AND YOUTH LAW CENTRE

The National Children's and Youth Law Centre (NCYLC) is a community legal centre working for and with children and young people.

It promotes the rights and interests of Australian children and young people through advocacy, legal representation, information dissemination and research.

NCYLC is a joint venture of the University of Sydney, the University of New South Wales and the Public Interest Advocacy Centre, primarily funded by the Commonwealth Attorney-General's Department.



ACKNOWLEDGMENTS

The project was funded by the Australian Youth Foundation.

Many people contributed to this research, but our special thanks go to the students and parents who shared their stories and ideas and whose experiences form the basis of this report.

PUBLISHED BY

National Children's and Youth Law Centre
ACN 062 253 874
April 1997
ISBN: 09586463 41
ISSN: 1321-3547
NCYLC Research Report series 01/97

TO ORDER COPIES OF THIS REPORT

NCYLC
c/- UNSW
Sydney NSW 2052
telephone (02) 9398 7488
fax (02) 9398 7416
email: ncylc@unsw.edu.au