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# MORE THAN GETTING THROUGH THE GATE

The involvement of parents with a  
disability in their children's  
school education in NSW

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For the Disability Council of NSW

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# CONTENTS

|  |    |
|--|----|
| PLAIN ENGLISH SUMMARY .....                                      | 4  |
| SUMMARY OF RECOMMENDATIONS .....                                 | 9  |
| INTRODUCTION AND OVERVIEW .....                                  | 12 |
| DESIGNING AND IMPLEMENTING THE PROJECT .....                     | 14 |
| ■ Participants .....   | 14 |
| ■ Participatory research .....                                   | 15 |
| ■ Review of related research .....                               | 16 |
| 1. SETTING THE SCENE .....                                       | 18 |
| <b>Perceptions of parents who have disabilities</b> .....        | 18 |
| <b>Disclosure of disability</b> .....                            | 20 |
| 2. INTERACTIONS WITH SCHOOL PERSONNEL .....                      | 24 |
| <b>Teachers</b> .....  | 24 |
| ■ perceptions of people who have a disability .....              | 24 |
| ■ willingness to accommodate support needs .....                 | 25 |
| ■ communication and day to day interactions .....                | 26 |
| ■ parent teacher interviews .....                                | 30 |
| <b>Principals</b> .....  | 32 |
| ■ perceptions of people who have a disability .....              | 32 |
| ■ interactions with parents .....                                | 34 |
| <b>Liaison and support</b> .....                                 | 35 |
| 3. SCHOOL ADMINISTRATION .....                                   | 38 |
| <b>Access and information</b> .....                              | 38 |
| <b>Responsiveness to suggestions for change</b> .....            | 42 |
| <b>Systemic responses to parents who have a disability</b> ..... | 43 |
| 4. PARTICIPATION IN SCHOOL ACTIVITIES .....                      | 46 |
| <b>Governance</b> .....  | 47 |
| <b>Parent run activities</b> .....                               | 50 |
| <b>Class and group activities</b> .....                          | 50 |
| <b>Whole school activities</b> .....                             | 52 |
| 5. DEVELOPING THE SCHOOL COMMUNITY .....                         | 54 |
| <b>Creating a culture of acceptance</b> .....                    | 55 |
| <b>Education and awareness raising</b> .....                     | 56 |
| CONCLUSION .....   | 58 |
| REFERENCES .....   | 59 |

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## PLAIN ENGLISH SUMMARY

This is a report about parents who have a disability. It is about what happens when their kids go to school – about how they get involved in their kid's schools.

The Disability Council of NSW has asked us to do this project. They wanted to look at this issue because nobody else in Australia has looked at what happens for parents who have a disability at their kid's schools.

We talked to 83 parents who have a disability. These parents told us a lot about what has happened to them when they have been involved in their kids schools.

A lot of parents who were part of the project were not treated very well by their kids schools. They did not get help with things like

- getting into their kid's classrooms,
- reading the notes that come home, or
- being part of the P&C committee.

There were a few parents who have been treated well by their kids schools. They felt that:

- the school liked them being involved, and
- they were given help to do things at the school.

There are five main areas that this report talks about. They are:

### 1. WHAT PEOPLE THINK ABOUT PARENTS WHO HAVE A DISABILITY

When people treat people who have a disability differently, it makes it really hard for parents who have a disability to be involved in their kid's school.

Some parents were treated badly by parents of other kids at the school.

Some parents did not want anyone at the school to know about their disability. This is because they have been discriminated against before.

## 2. DEALING WITH TEACHERS AND SCHOOL PRINCIPALS

### **Teachers**

Some teachers were very helpful, and made sure that parents got information about their children in a way that was easy to understand.

Other teachers didn't do this, and it made it hard for some parents to know what was going on in their kids class.

It was hard for some parents to ask for help – they felt like the teacher didn't really want to help them out.

It was hard for some parents who have a physical disability to get into parent teacher interviews, because rooms weren't accessible.

Some parents felt like the teachers didn't tell them if their kids were not doing well in class.

### **Principals**

Some principals had bad attitudes about people with disabilities, and some principals helped to make sure that parents who have a disability were included in the school.

### **Support**

A few parents talked about how annoying it is to have to explain again and again about their disability to lots of different people at the school.

One idea that parents had was to have a support teacher, like the school counsellor, who could make sure that parents who have a disability got information about their kids, and that they could be involved in the school if they wanted to be.

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### 3. ACCESS AND INFORMATION

It was very hard for some parents who have a physical disability to get into their kids schools and their classrooms.

For some other parents, it was hard because they could not remember their way around the school, and there were no signs.

Getting information in a way that they can understand was really hard for parents who have an intellectual disability, and some parents who have an acquired brain injury.

Almost all the information that comes home from school is written in small print in newsletters and notes. If parents weren't able to read those, they missed out on lots of information that they needed to know.

When parents asked schools to make changes, some schools were happy to help, and other schools were not. It really depended on the school.

There aren't any rules or policies that say that schools have to think about how they include parents who have a disability. There is no information about how to work with parents who have a disability.

### 4. TAKING PART IN SCHOOL ACTIVITIES

#### **The P&C**

Being on the Parents and Citizen's committee (the P&C) was one way that parents got involved, but some parents did not feel very welcome on the P&C, and some parents could not go to meetings because they couldn't get into the room.

#### **Day to day activities**

Parents who have a disability were involved in the school in lots of different ways, like doing reading groups or going on excursions.

Some parents had been involved in the school tuck shop. They said it was hard, because they weren't really included by other parents who were working there too.

However, it was hard for parents to be involved sometimes because there weren't systems to help them.

Lots of parents said that they were worried that the school thought they weren't interested, even though they were keen to be involved.

### **Whole school activities**

Going to speech nights, school concerts and fundraising nights was something that a lot of parents did.

Some parents were not able to really be included in these things. For example, parents who are deaf missed out on a lot of information when the school did not provide an interpreter.

## 5. HOW THE SCHOOL CAN MAKE PEOPLE WHO HAVE A DISABILITY FEEL WELCOME

Schools really need to think about how they make the whole school a better place for everyone, including people who have a disability.

One of the ways that this can happen is through education.

- Teachers, principals and school staff need to learn more about working with people who have a disability.
- Kids at the school also need to find out more about people with disabilities.
- Parents and other volunteers at the school need to know more too.

There could be talks by people who have a disability about what disability is like and how to include people.

Another idea was that schools can have days or weeks where they focus on particular issues about disability.

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They could do projects or talk with people who have a disability, and understand that people with disabilities should be included as ordinary members of the community.

## RECOMMENDATIONS

There are 20 recommendations in the report. You can read them all together on the next page.

The recommendations are ideas about how things can be better for parents who have a disability. They are about things like:

- Making sure that teachers and principals get some training about working with parents who have a disability
- Having a system to support parents who want some help
- Making sure that parents can get into the school and get around it easily
- Making sure that parents can get information in a way that is easy for them to understand

# SUMMARY OF RECOMMENDATIONS

## RECOMMENDATION 1

That the enrolment forms used by schools be modified to include information about parents who have a disability. This section of the form should be voluntary. It needs to be linked into an established liaison role (refer to recommendation 7). The privacy and right to confidentiality of parents who use this section of the enrolment form must be strictly maintained.

## RECOMMENDATION 2

That formal links and communication pathways between the Department of Education and Training, the Association of Independent Schools and the Catholic Education Commission and universities are used to ensure that issues relating to parents who have a disability are included in teacher training curriculum at undergraduate and postgraduate levels.

## RECOMMENDATION 3

That principals ensure teachers and other staff in schools have regular and easy access to support resources concerning parents with a disability.

## RECOMMENDATION 4

That principals ensure that teachers and other school employees are supported to attend regular continuing education and professional development sessions on issues relating to parents who have a disability.

## RECOMMENDATION 5

That principals ensure that mechanisms are in place for teachers to share their professional knowledge regarding parents who have a disability with other teachers and school personnel.

## RECOMMENDATION 6

That principals participate in continuing education on issues relating to parents who have a disability, with an emphasis on their leadership role within the school in developing a culture of acceptance and on the legislative requirements of schools.

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## RECOMMENDATION 7

That a liaison and support role be developed within every school, with the aim of supporting interactions between parents who have a disability and teachers. This role could be linked to the existing position of school counsellor or year advisor. It must be adequately resourced in terms of time allocation and resource support.

The role should be linked to the identification of parents who have a disability through information provided in the enrolment form, but not limited to it.

## RECOMMENDATION 8

That additional training on issues relating to parents who have a disability is provided to staff filling the liaison and support role.

## RECOMMENDATION 9

That schools conduct regular access audits. Access audits consider both barriers to physical access and access to information for parents who have a disability. People who have a disability are involved in the audits, and a budget is allocated for responding to issues identified in audits.

## RECOMMENDATION 10

That principals ensure the school's complaints policy is available and accessible to parents who have a disability.

## RECOMMENDATION 11

That the NSW Department of Education and Training Disability Action Plan be amended to include reference to working with parents who have a disability

## RECOMMENDATION 12

That policy is developed that directly addresses issues relating to parents who have a disability, including non-discrimination, strategies put in place to support involvement, the liaison and support role, and complaints mechanisms.

This policy needs to be developed and implemented at school and regional levels in public, private, independent and catholic schools.

## RECOMMENDATION 13

That funding is allocated for the development and distribution of a State wide resource kit for schools which addresses issues relating to the participation of parents who have a disability in their children's schools.

#### RECOMMENDATION 14

That professional development and continuing education concerning issues relating to parents who have a disability is developed and implemented for teachers, principals and other school staff at a regional level.

#### RECOMMENDATION 15

That principals ensure the resource kit and other relevant information concerning parents who have a disability is available to the P&C and other school committees.

#### RECOMMENDATION 16

That the NSW Federation of P&Cs provide training on issues relating to parents who have a disability for office bearers of P&C committees.

#### RECOMMENDATION 17

Information that schools regularly provide to families, such as policies and school orientation materials, include information on issues relating to parents who have a disability, where appropriate.

#### RECOMMENDATION 18

That in the planning and implementation of school activities, both physical and information access issues related to parents who have a disability are considered.

#### RECOMMENDATION 19

That a range of awareness raising educational activities related to people with a disability are structured into the school calendar at the commencement of the school year. These are to be implemented by people who have a disability.

#### RECOMMENDATION 20

That issues relating to people who have a disability are integrated into the school curriculum across all years K – 12, at both regional and school based level.

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# INTRODUCTION AND OVERVIEW

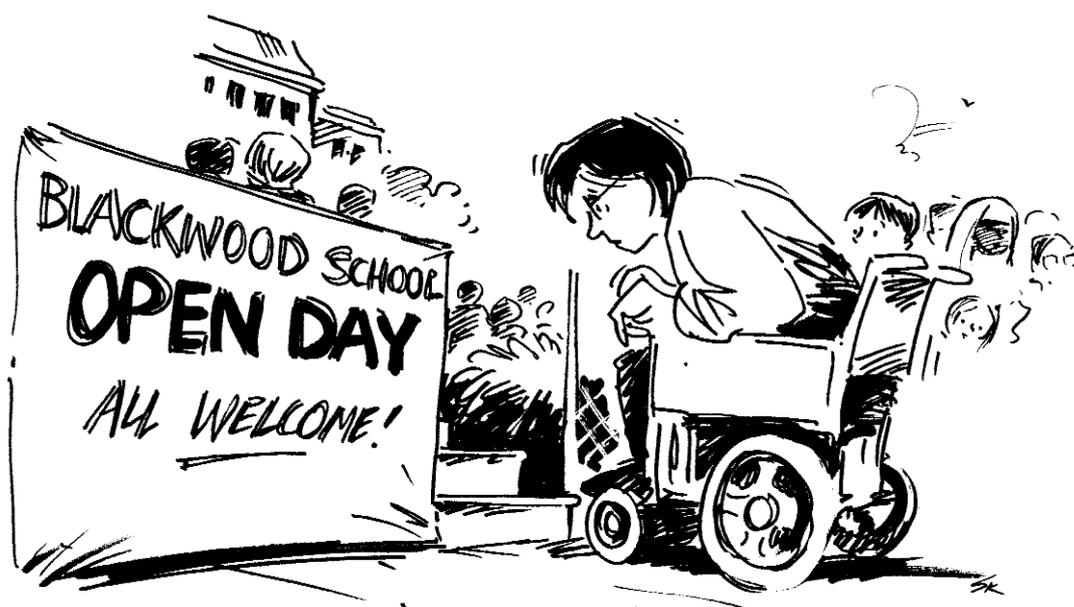
There's no reason why the human rights of people with disabilities should stop outside their children's school gate.

– India, mother who is blind

The involvement of parents who have a disability in their children's schools is an issue which has been largely overlooked by both the education and the disability sectors.

In the course of conducting this project, eighty three parents who have a disability shared with us a range of experiences, thoughts and ideas about their participation in their children's schools. The report is constructed upon their views and perceptions and the recommendations are drawn from their experiences.

We do not intend for this report to be seen as a document which provides all the solutions. One of the issues that has arisen clearly from this project is the need for further research. Our aim was to map the experiences of parents who have a range of disabilities and who have children attending different types of schools. We have drawn people's experiences and perceptions together into a number of themes, which describe the interactions that parents have had with their children's school communities in several contexts, which are outlined below. We have included recommendations for changes that will support parents who have a disability to be actively included and involved in their children's schools on a range of levels.



The impact of attitudes on the participation of parents who have a disability is a theme which has consistently appeared throughout the project. The first section of the report addresses the ways in which parents who have a disability reported being treated differently from other parents. This significantly affected the ease with which they were able to become involved in their children's schooling.

Interactions between parents and their children's teachers is an area which many parents felt was vitally important. Similarly, the role of the school principal is one which has a considerable impact on the degree to which parents are able to actively participate in the life of the school. These issues and interactions are considered in the second section of the report.

The third section of the report outlines issues arising in the administration of the school. These include physical access into the school and access to information in accessible formats. The manner in which schools respond to suggestions for change and the ways in which schools act proactively to encourage and support the participation of parents who have a disability are also considered here.

Participation in a variety of school activities ranging from the Parents and Citizen's committee to the tuck shop are discussed at length in the fourth section of the report.

Finally, attention is paid to the development of the school community in the fifth section of the report. Education and awareness raising initiatives are a key strategy in developing a positive school community which actively includes and encourages parents who have a disability. Ways in which schools can foster, or prevent, the development of a culture of acceptance are discussed, and there is an emphasis on strategies for improving the experience of parents who have a disability.

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# DESIGNING AND IMPLEMENTING THE PROJECT

## PARTICIPANTS

In total, 83 parents who have a disability took part in the research. Each of these people were willing to speak with us in some depth about their experiences in their children's schools and gave us a wealth of information from which to draw.

We spoke with parents who have physical disabilities, who are deaf, who are blind or have a vision impairment, parents with an acquired brain injury, parents with a mental illness or mental health issues and parents who have an intellectual disability. Some of the people who participated in the project had more than one disability.

Parents who participated in the project were involved in a range of different schools. Their children were in classes in both primary and high school, from kindergarten to year twelve, and all school types were included – public, private, independent and catholic.

In structuring and conducting our consultations, we endeavoured to ensure that we spoke with similar numbers of parents who share the same disability. We also sought out a balance of men and women as participants. The large number of female participants could perhaps be seen as a reflection of the broader division in the community, where women are more commonly involved in the schooling of children.

| TYPE OF DISABILITY PARENTS HAVE                        | NUMBER OF PARTICIPANTS |
|--|------------------------|
| Physical disability                                    | 15                     |
| Blind or vision impaired                               | 9                      |
| Deaf or hearing impaired                               | 17                     |
| Intellectual disability                                | 12                     |
| Mental illness   | 14                     |
| Acquired brain injury                                  | 16                     |
| <hr/>  |                        |
| TOTAL PARTICIPANTS                                     | 83                     |
| From culturally and linguistically diverse backgrounds | 18                     |
| Rural/regional   | 20                     |
| Women  | 64                     |
| Men  | 19                     |

There were a number of ways in which people could choose to participate in the project. Fourteen individual interviews were held, both face to face and by telephone. A series of ten focus groups in Sydney and in two regional areas were held with groups of parents. A three day phone-in was held as part of the consultation process, which was widely publicised in both the disability and mainstream media. An internet discussion group was started and a number of parents also completed questionnaires over the internet.

We actively sought participation by parents who are from culturally and linguistically diverse backgrounds and parents from Aboriginal and Torres Strait islander backgrounds. While a significant number of participants came from culturally and linguistically diverse backgrounds, we were not aware of the participation of any parents from Aboriginal and Torres Strait Islander background.

In a number of instances, the type of disability that the person had was seen to have impacted on their participation in their children's schools in a specific manner and this is reflected in the report. It was, however, clear that problems faced by parents who are from culturally and linguistically diverse backgrounds were compounded by cultural and language barriers in addition to the barriers created around their disability.

We did not find any clear indications that having a particular sort of disability led to a particularly positive or negative experience in more general terms with schools. Neither did we find any significant differences between school types. However, it should be noted that our sample size is not large enough to draw any firm conclusions in these areas.

As this is a qualitative research project, we have not sought to give any figures when discussing issues that were faced by more than one parent. We felt that it would not add any clarity to the research to speak in figures or percentages. We have included many quotes in the report, as it is clear that the voices of the participants are the ones which carry weight in describing and analysing their experiences in their children's schools. Names of those who are quoted have been changed, in order to protect people's privacy.

## PARTICIPATORY RESEARCH

Under the direction of the reference group, we have used a participatory research model in developing, conducting and writing up this project. In this approach, it was seen as particularly important that parents who have a disability were themselves in control of the research agenda, that the expertise, time and travel expenses of participants in the project were recognised, and that the final product of the project, the report, is a tool which can be used by parents with a disability and other allies to lobby and argue for change.

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Historically, research in the disability area has taken a positivist or empirical approach, where people with a disability become the passive 'subjects' of study rather than equal participants in the research process. In this sense they are merely the conduits for supplying information required by the researcher (Barnes, Mercer & Shakespeare, 1999). Such approaches have been increasingly questioned, leading to the emergence of a new research agenda that favours participatory and emancipatory research models (Oliver, 1992, 1997; Zarb, 1992, 1997; Rioux, 1994).

Participatory research is distinct in that it does not seek to direct or pre-design a research agenda but is guided and shaped by the voices of the research participants themselves.

Ward (1997) stresses that true participatory research requires researchers to make a range of accommodations to their research practices. These include the preparation of accessible materials, paying attention to issues of meaningful consent, arrangements for appropriate payment of fees to participants, the organisation of accessible venues for participants and strategies for feeding back information to both the participants and any wider group they might represent. All of these accommodations were addressed in the development and implementation of this project.

Proponents of participatory research (eg Zarb, 1992, 1997) strongly contend that people with disabilities must be actively involved in determining the aims, methods and uses of the research before it can have any potential for change. Oliver (1992, 1997) criticises participatory research that does not address clear mechanisms for influencing policy. This report includes clear recommendations which, if implemented, will influence educational policy and practice.

## REVIEW OF RELATED RESEARCH

Although the literature on parents with a disability is extensive, there is little international research, and no research in an Australian context that we are aware of, which addresses the issues which arise for parents in supporting their children's school education.

An extensive search of literature related to parents with a disability established that the major focus of the studies reported was on issues of service provision. Studies by Llewellyn (1995) and McConnell, Llewellyn & Bye (1998) investigated the nature of provision of services to parents with an intellectual disability and a study by Cowling (1998) looked at service issues related to parents with a mental illness.

General parenting issues have also been extensively studied, such as the necessity for parenting support in regard to parents with an intellectual disability (Llewellyn, 1995; Jewell, 1998).

The needs and experiences of children of parents with a mental illness (Lunzt, 1995; Rimington, Olsson, Walsh & Sawyer, 1998; Cowling, 1998) and those with parents who have an intellectual disability (Chapman, 1994) are also discussed in the literature. Issues related to child protection, in particular the threat of child removal have also been the focus of research in relation to both parents with an intellectual disability (McConnell & Llewellyn, 1999) and parents with a mental illness (O'Donovan, 1993).

There are a number of web sites which address issues that are relevant to parents who have a disability. Through the Looking Glass, a national resource centre for parents who have a disability in the USA, maintain a comprehensive site, with information covering a broad range of issues. Two other parent run groups, the Disabled Parents Network in the UK and Parents With Disabilities Online in the USA, also have web sites that address issues such as technical aids, pregnancy and birth, and caring for kids. None of the sites, however, have information that specifically refers to parent's interactions and experiences with their children's schools.

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# 1. SETTING THE SCENE

One teacher said to me once 'well, how am I supposed to treat you?'

– I'm a parent! I don't need to be treated any different than any other parent. I want to be treated just the same. And I think that's what everybody here is trying to say, that we just want to be treated the same as any other normal parent, we want to be able to get in and out to see our kids, we want to be able to participate in the children's activities, like any other parent does.

– **Costas, father who has a physical disability**

## PERCEPTIONS OF PARENTS WHO HAVE DISABILITIES

The perceptions of people who have a disability that are held by people who are involved in the school have a powerful impact on the degree to which parents who have a disability feel welcome, involved and a part of the school environment. Many parents who participated in the project expressed the view that they were seen by other people to be different and that this perceived difference somehow set them apart from other parents.

There were a small number of parents who found their relationship with other people at the school quite straightforward and unremarkable. However, it was a more common experience that parents received comments from others that reflected attitudes and behaviour that were intolerant, discriminatory and unjust.

Other parents make life difficult. When I attended a parent meeting after hospitalisation the stigma was palpable from other parents. It probably stems from fear of the unknown, but I won't go to large parent functions any more.

– **Andrea, mother who has a mental illness**

We don't know the mothers, cause a lot of them, I don't know, I don't feel like I fit in. Cause they're a bit snobbish, some of them... they treat you like, I don't know, because you've got a disability and they haven't.

– **Megan, mother who has an intellectual disability**

Another experience shared by many of the parents involved in the project was that other parents avoided contact and conversation with parents who have a disability, or expressed sympathy which was not wanted or needed.

I was always seen as an extra, as a problem – poor Mrs Davis.

– **Gwen, mother who has a physical disability**

Some of the parents, as soon as they see you coming in, some parents don't do it, but a lot of the parents, they think 'oh, there's something wrong with them, we'll go over there' and you're left in the corner here and everyone else is over the other side.

– **Costas, father who has a physical disability**

The dominance of these sorts of attitudes leaves parents who have a disability isolated and unable to draw on the informal parent networks that develop as part of the school community.

If parents don't feel comfortable with fronting the teacher directly, they use their parent network. If parents with disabilities don't have access to that network, they haven't got that to fall back on.

– **Julia, support worker to mothers who have an intellectual disability**

I miss out on making friends – don't get the chance to get camaraderie with other parents.

– **Victoria, mother who is blind**

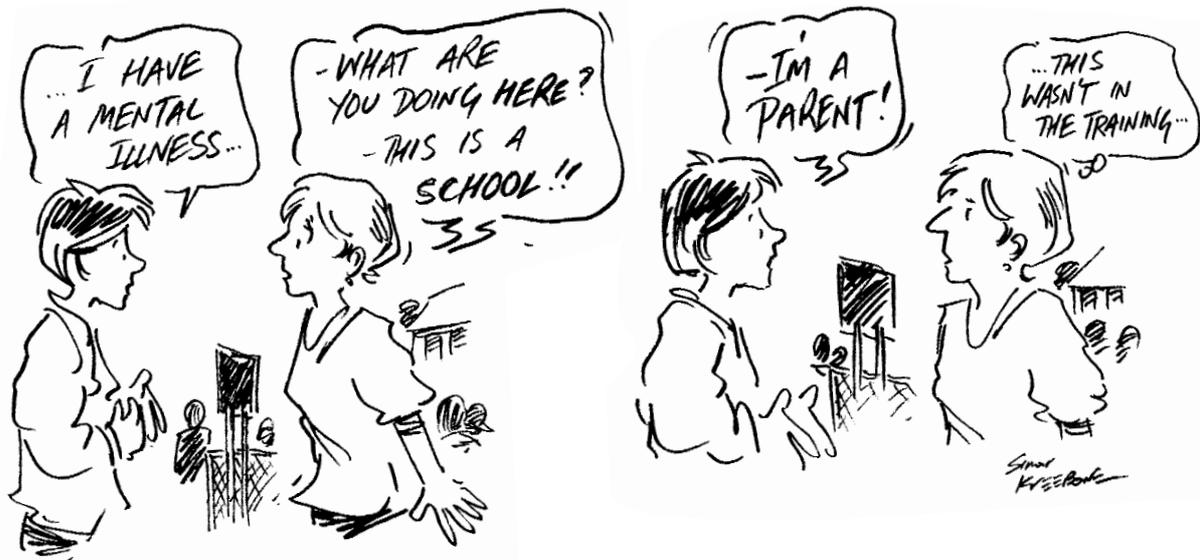
A lack of accommodations by schools adds to parents isolation, and impacts on their children too. If parents are unable to get into the school or classroom, or unable to communicate with teachers effectively, then they have fewer choices about how to be involved with the school.

When stereotyped views or myths about disability are applied to parents, people relate to them differently. One mother describes the way that the school found out about her disability, and the subsequent reaction from parents and teachers.

I hadn't told them I had MS and my daughter went in the MS readathon [and did really well]. The paper rang up the school and asked if they could come and do a story on it. [My daughter got a prize and said that] she did the readathon because her mum's got MS, and that went in the local paper. And all of a sudden, I got all these people that I had met from around the school doing various things, coming up to me and saying 'Sarah, we didn't know, did you know so and so's got MS?'. And it threw me, totally. I felt that teachers started to patronise me and have low expectations.

– **Sarah, mother who has multiple sclerosis**

Some parents talked about more positive responses to their disability from their children's schools. However, of the eighty three parents who participated in the project, only two parents reported continuously supportive and positive interactions with their children's schools.



A number of parents mentioned their relief when teachers or other parents asked them directly how they would like to be accommodated, for example, if they needed a hand to find a classroom or required information in large print. Among these responses, requests from teachers and principals for awareness raising strategies and education sessions was generally perceived by parents as a positive reaction to difficult situations.

They came to me and wanted to have disability awareness lessons and they asked me how do we get those. So the kids would get to understand that just because someone looks, sounds or behaves differently that they're not actually that different. So they asked me for the contact and I presume they actually had the meetings. But the teachers actually changed the last terms Social Studies unit about 'people around us'. You know how they have these themes, well they did a 'people around us' theme. It was basically acceptance of differences.

– Margaret, mother who has a mental illness

## DISCLOSURE OF DISABILITY

For the school to help or understand, the person would have to disclose their disability. While there is still such a lack of understanding and ignorance, there's no benefit in disclosing. Perceptions of people with mental illness as violent are very hard to get over.

– Jeff, father who has a mental illness

It is not surprising that a number of parents who were involved in the project indicated that they did not speak to the school about their disability – particularly

parents who have an ‘invisible’ disability. These parents openly acknowledged that schools could not provide them with support or assistance if they were not told that it was needed. However, the stigma that is still commonly applied to people who have a disability was felt keenly enough by some parents that they felt it would be counter productive to tell the school about their disability. This was particularly strongly expressed by parents who have a mental illness. As one mother put it,

People patronise people in wheelchairs and fear people who are mentally ill.

– **Jill, mother who has a mental illness**

A number of parents expressed the view that talking to the school about their disability helped them to overcome attitudinal barriers and allowed people to support their participation.

I think what helps is when you communicate with the parents and teachers about what is your disability, makes them understand and they can help. But when you close up, you’re too scared to tell people what your disabilities are, then more people can’t help you if they don’t know.

– **Renata, mother who has an acquired brain injury**

Yet another group of parents found that talking to the school about their disability has had little impact on their opportunities to participate.

I have been very open and upfront about my disability all the way through the kid’s schooling. Schools and teachers have not been very accommodating or interested.

– **Victoria, mother who is blind**

The lack of an opportunity to talk with the school about issues concerning their disability was raised by several parents. These people felt that it would have been helpful to them, their children and the school to have had the chance to talk about their disability and any issues arising from it that teachers needed to know.

One thing that I think would have been very helpful when I enrolled my children in the school, if there had been an opportunity then for me to discuss my situation.

– **Jill, mother who has a mental illness**

Parents were divided about whether it would be helpful to include a section on the enrolment form to indicate when a parent has a disability and if they require assistance in any way in order to be involved in the school. Some parents felt that it would be useful for schools to know how many parents who have a disability are a part of their community.

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I think schools need to develop some ways of actually finding out how many parents have you got at the school who've got disabilities. And that wouldn't be terribly difficult, you get so many other bits of stuff that come home, what's one more?

**– Angus, father who is blind**

Other parents felt that this would inappropriately label them, when they had spent years working towards being included in an ordinary manner.

I think that's labelling...if I choose to inform them that I have difficulties from time to time, or if they want to ask me, fine, but not on a piece of paper. It's not going to make the slightest difference.

**– Margaret, mother who has a mental illness**

If schools provide meaningful opportunities for parents who have a disability to discuss any issues that the school needs to be aware of, the range of opportunities for participation could broaden significantly. The key to this strategy working effectively, however, lies in the response of school personnel to the information. If the negative perceptions and attitudes to disability that parents reported above come into play, then there is little benefit to parents disclosing their disability, and some risk that they and their children will be marginalised or discriminated against.

You're not necessarily going to get people with disabilities self identifying and making an issue of it, but if they're invited, you know 'if you're a parent with a disability, you're welcome to come and talk to us', rather than having to say 'look, I'm a person with a disability, I've got a right to be included'. You know, I think it would be nice if it were up to the school to actually extend the invitation first and I've never seen that.

**– Angus, father who is blind**

Obviously, inclusion of any information on enrolment or other school forms needs to be completed voluntarily. Parents must not be pushed into disclosing their disability where they are not comfortable in doing so. For those parents who would like the school to know about their disability, it would be useful for schools to develop mechanisms for finding out and responding effectively and sensitively to the expressed needs or wishes of parents. Including information about parents' disability in the school enrolment documentation is one way for schools to be active in supporting parents who have a disability. There do, however, need to be a range of ways, both formal and informal, in which parents can speak with schools about their disability if they so desire.

A sound response to the disclosure of disability could lay the ground for parents to participate effectively in the activities of the school and communicate more easily with teachers. A response which belittles or denigrates parents who have a disability will do nothing to support their participation and involvement in the school community.

### RECOMMENDATION 1

That the forms and documents used by schools be modified to allow the inclusion of relevant information about support required by parents in order to participate.

The information gathered needs to be used proactively by schools to support parents to participate in a range of school activities.

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## 2. INTERACTIONS WITH SCHOOL PERSONNEL TEACHERS

My son had a detention and the teacher called me to say that he had to stay after school. I have to take my medication at three o'clock and I knew I wouldn't be able to drive to collect him. I explained this to the teacher, who said he would be happy to drop him home afterwards. I was pleased that my son was given equal treatment and that a big fuss wasn't made about my disability, but my son wasn't too thrilled!

– Sarah, mother who has a physical disability

Many parents felt that their relationship with their child's teacher was a cornerstone of their participation in the school environment. It was very evident that effective relationships between parents and teachers resulted in parents feeling more able to participate in the activities of the school and also resulted in them feeling more confident in supporting the learning of their child and often other children in the class too through their involvement in class activities such as reading groups. On the reverse side, negative attitudes and interactions and a failure to accommodate the support needs of parents invariably resulted in parents feeling disenfranchised and isolated from their children's learning and the school community at large.

An experience that was commonly related by parents was that they were reliant on the goodwill of particular individuals in order to participate in the school on a range of levels. The interactions with teachers described below certainly give a very clear indication that the attitudes and skills of teachers have a central part to play in the participation of parents with a disability in their children's schooling on both a formal and informal level.

### Perceptions of people who have a disability

Teachers' experience of people who have a disability and, in a broader sense, their attitudes to disability impacted strongly on the interactions that parents described. Many parents felt that teachers made assumptions about them, based on their disability, which were not true.

Especially being in a wheelchair, they think that because your legs don't work, your brain doesn't work, so then they palm you off by thinking that 'well, he won't understand any of it anyway'.

– Costas, father who has a physical disability)

Isn't it wonderful that even though he's got funny parents he's such a clever child?' and they'd never think that we had any intelligence, we were pretty well miracles walking.

– **Margaret, mother who has a mental illness**

A number of parents expressed the view that teacher's perceptions of their disability had influenced the way in which their children's educational needs were perceived. This was particularly evident among parents who have a mental illness, where several parents expressed the concern that assumptions about disability impacted negatively on their children.

I think there are real difficulties in those kids [with learning difficulties] getting help, because so much is put down to the disability of the parent, not the specific problem that the child is having.

– **Jill, mother who has a mental illness**

Other parents felt that there had been a shift in attitudes and that teachers were responding more effectively to the educational needs of their children.

Schools now see the resilience in kids rather than blaming the behaviour on the mother's mental illness, due to a higher media profile of mental illness.

– **Andrea, mother who has a mental illness**

## **Willingness to accommodate support needs**

A number of parents described relationships with their children's teachers where understanding and a willingness to do things a little differently was openly offered by teachers.

I had a lot of support from teachers, they'd give him a chart of how to explain it to me and then once my son explained it to me, I could explain it to him. And I told the school, 'look, he tells me, he gives me the notes, but I lose them, or I forget to write it up' so then they decided that they'd give me reminders - instead of giving it to my son, they'd mail it to me.

– **Renata, mother who has an acquired brain injury**

A number of parents who had acquired their disability after their children had started school felt that they received strong support from the school. They put this down to the fact that they had been involved at the school in a range of ways before they acquired their injury or disability. While these parents enjoyed a more understanding relationship with their schools, they did question whether parents who had their disability before their children started school had the same quality of interaction with their children's teachers and the school community at large.

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It's how much you put in at the school before you have an injury or an accident or whatever, as to what you get back out of it along the way.

– Cheryl, mother who has an acquired brain injury

Many of the accommodations that were made by teachers cost very little in terms of time or money and were based on a willingness on the part of the teacher to approach their interactions with the parent a little more flexibly. Strategies such as giving parents a phone call to notify them of upcoming excursions or parent teacher nights, being able to have a quick conversation to explain homework verbally and coming down the stairs and into the playground at the end of the day's classes were all reported by parents as being very effective in helping them to support their children's learning.

One example given by a mother illustrates the importance of teachers and parents maintaining an open and mutually supportive relationship and the impact on both parent and child when that relationship is not present.

When my daughter was in third class, I used to be in and out of the classroom all the time, with doing the reading groups and things. I used to take the book home a week early and practice it, so I would be able to read it right for the kids. When my daughter brings her homework home, I always help her with it. Sometimes, we don't get it and then we used to go and talk to the teacher just before class and she would set us straight about it. Then, we could do it the next night. My daughter did really well in school that year.

When she went up to fourth class, she got a different teacher. I can still remember what happened the first time we went to find out about the homework.

The teacher wouldn't talk to us and she said to me 'it's not my job to teach you to read!'. I was really upset. I didn't do anything in my daughter's class that year. She didn't do so well in fourth class.

– Jessica, mother who has an intellectual disability

When teachers either do not understand the need for accommodations, or are unwilling to interact with parents who have a disability a little more flexibly, many parents stated that they were excluded from being involved in important parts of their children's education. Unfortunately, this was a far more common experience than those positive interactions outlined above.

## **Communication and Day to Day Interactions**

I have to write notes to the teacher, because I can't get up to the school very often [due to physical disability]. The teacher asked my son 'what can we do to stop your mother from writing to us?'

– Petra, mother who has a physical disability



It is readily acknowledged that teachers generally have heavy workloads and minimal time in which to talk with parents. However, there is great value in them making accommodations such as those described in this section of the report.

A willingness by teachers to be informal in communicating with parents on day to day issues was raised by many parents as something which gave them practical assistance in supporting their children's learning and in being an active part of the school. Again, small and basic accommodations were repeatedly reported as making a big difference in the degree to which parents with a disability could become or remain involved.

One teacher would ring me instead of sending notes home. I have asked others to do this – they say they will, but don't do it.

– **Bernice, mother who has an acquired brain injury**

When this flexibility is not offered, or worse, when teachers refuse to make basic accommodations which would allow parents with a disability better access to teachers to discuss the day to day issues that arise in their children's education, the outcomes are quite clearly detrimental and negative. As one mother related,



At one stage, I needed to see my son's teacher. At that time, I was in a great deal of pain and I spent most of my time at home. But I wanted to go and talk to the teacher. And I sent a written note, because she wasn't listening to my son and she was like 'well, tell your mother when she's better, then I'll see her'.

But I didn't want to see her when I was better, because it could take me a year – I wanted to see her now. And I believe she could have come down the hall, or even to the playground and sat with me for five seconds, because I couldn't climb stairs, it was as simple as that.

– **Maria, mother with a physical disability**

When teachers were receptive to parents speaking with them on an informal basis, such as before or after school, parents said they found it much easier to ask for information, clarify their understanding, or communicate information that the teacher needed to know about their child. For some parents who have an intellectual disability or acquired brain injury, having to make an appointment to speak with the teacher was a significant barrier. Problems with time keeping and memory made it difficult for some parents to remember and keep appointments. Making an appointment also puts the relationship with the teacher on a more formal footing, which a number of parents felt made it harder to ask questions or to seek information without feeling embarrassed.

Physical access was reported as a problem by most parents who have a physical disability – a number of parents who participated in the project had their children placed in classrooms which were completely physically inaccessible to them.

Lack of access means that you are waiting in the playground and waving at the teacher, because I wanted a ten minute interview because I was concerned over some things that were happening. I wasn't able to approach a teacher in an appropriate manner.

– Penny, mother who has a physical disability

### **Involving children in interactions with parents**

On a number of occasions, parents described their children's involvement in interactions with teachers. Several parents felt that teachers used their children as a 'mouthpiece' and at times expected children to relate information back to parents in a way that they generally would not for parents who did not have a disability. This included interpreting for deaf parents, or reading information to parents who are blind. Two fathers who are blind separately told of their children coming home with their school reports, with instructions from the teacher to read them to their parents – a clear case where children could be unreliable readers! Other parents said,

She seems to be a bit scared to talk to me. She often says to my son 'tell your mum, blah, blah, blah' and I say 'if you talk directly to me'...I had little interaction with the teachers. They refer things through my son.

– Angie, mother who is deaf

### **Asking for assistance**

Asking for assistance from teachers is an area where many parents with a disability felt uncomfortable. There were several responses that indicated that parents felt they were discouraged from asking for assistance with reading notes and homework, filling out forms and so on.

Asking teachers to read information to you helps, but it's hard, because they make you feel like you're taking up their time.

– Kelly, mother who has an intellectual disability

You make every effort not to ask for help when you get bad responses from teachers and principals. The responses people give you are very belittling.

– Zoe, mother who has an acquired brain injury and a vision impairment

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## Parent Teacher Interviews

Last year at parent teacher interviews, we were first cab off the rank and we were sitting there outside under cover and the teacher got there and said 'oh hello, blah, blah, blah, I'll just go and put my bag down' and she went to put her bag down and she didn't come back, but there's three steps into the classroom. And she came out laughing and she was waiting for us to come into the classroom. And when things like that happen, you think 'what hope have we got?'

– Penny, mother who has a physical disability

Parent teacher interviews were the main form of formal communication that parents reported having with teachers. Experiences of parent teacher interviews were varied and the problems parents reported about this area centred around two issues – access to the interview and the attitude of teachers to them as people with a disability.

### Access to the interview

Physical access to parent teacher interviews was not made possible for several parents who have a physical disability. Teachers dealt with this differently, ranging from sitting outside with parents to discuss their children's progress to coming to the home of one parent to conduct the interview. This could certainly be seen as a useful and flexible strategy for supporting some parents. However, if they are not asked for their preferences and able to make a choice about how (and whether) they would like to participate, the decision to structure a parent's participation in the parent teacher interview process is tokenistic. The parent who experienced this states,

Teachers seem to think that coming to your home is the same as being able to go along to the school like everyone else. School business needs to be dealt with at school! The school came up with the idea of coming to my home to conduct the parent teacher interview and inflicted it on me. I was not offered any choice for how to be involved. It was condescending.

– Gwen, mother who has a physical disability

Access to the interviews was also impossible for a number of deaf parents, when their schools did not provide interpreters to enable them to communicate with their children's teachers. Some parents were not able to participate in parent teacher interviews due to a lack of information in accessible formats – for parents who are unable to read, information about the date and time of the interview is not accessible if the invitation comes home in a newsletter or printed material.

Letters come home for parent teacher interviews, but because I can't read, I've missed out on every one. I have never had a teacher ring or follow up to see why I haven't come.

**– Zoe, mother who has an acquired brain injury and a vision impairment**

On a more positive note, one parent describes the way in which her daughter's school responded to her complaint about access.

With their parent teacher night, it's in the library [because it is accessible to people in wheelchairs]... and all the teachers are sitting around in the library and you go around to each one. Yeah, advantaging everyone, but not pointing me out as someone with a disability, in a way that I can't get to them. Actually being given a choice to have participation...

**– Anna, mother who has a physical disability**

## **Attitudes and responses to disability**

Once in the parent teacher interview, two parents described the way that teachers were uncomfortable in giving them frank information about their child. One mother explains,

There were times when Dennis wouldn't do homework and we would go down there and say 'you must put the screws on him, you know, please, you've got to really tighten up on him'. They'd say, 'but he's such a lovely boy, such a lovely boy, you don't need to worry about him' ... they didn't want to rock our boat. We couldn't possibly have that stress. They didn't see that it was a bigger stress not to have the kid pulling his socks up.

**– Margaret, mother who has a mental illness**

Another mother stated,

It was more or less up to me to see the teachers. I think they were initially as scared as I was about it... I don't think they wanted to say anything bad.

**– Elaine, mother who has a physical disability**

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## RECOMMENDATION 2

That formal links and communication pathways between the Department of Education and Training, the Association of Independent Schools and the Catholic Education Commission and universities are used to ensure that issues relating to parents who have a disability are included in teacher training curriculum at undergraduate and postgraduate levels.

## RECOMMENDATION 3

That principals ensure teachers and other staff in schools have regular and easy access to support resources concerning parents with a disability.

## PRINCIPALS

### **Perceptions of people who have a disability**

On an individual level, the attitudes of principals towards people with a disability considerably affected the way in which parents were encouraged or discouraged from participating in the life of the school community. Principals have the capacity to make changes, encourage and guide the development of a school community that accepts and embraces difference. Their role in leading and guiding students, staff and other parents means that they are well placed to initiate strategies that support parents who have a disability and to make them feel welcome and valued by the school community.

One mother described how her son had been placed in an inaccessible classroom three years running, despite her repeated requests that his class be placed in one of a number of accessible classrooms at the start of each school year. When she made a formal complaint about this situation, she felt that the principal's response indicated that the school accepted her presence at the school, but were not going to make any real effort to encourage her involvement.

The school responded that they want to make the whole school accessible, but the Department of Education wouldn't give them the funds and that technically I shouldn't be on the parts that aren't accessible because of their Occupational Health and Safety if anything went wrong.

– Penny, mother who has a physical disability

The involvement of parents in the running of the school through the Parents and Citizens committee was also an area in which the attitudes of principals were seen to be less than supportive. One mother described the change in the responses of the school to her after her disability required that she use a wheelchair. This person was the President of the P&C committee and had been in that role for a couple of years. She said,

Responses from the school changed overnight. The Principal approached other members of P&C committee and said 'how would you like to have a cripple for a P&C president? It's ridiculous!'

**– Dianne, mother who has a physical disability**

In that instance, the other parents involved in the committee stood behind her, rejecting the principal's view. However, there were other instances where parents received treatment from principals which they found very distressing, stigmatising and discriminatory and where they received no support from the school community to either resolve the issues or work around the situation. One mother has had a long running battle to simply be on the school grounds. Her understanding is that she has been barred from the school, because

The Principal says I am an embarrassment to the school, because I fall over [due to vision impairment].

**– Debbie, mother who has an vision impairment and an acquired brain injury**

Attitudes such as these represent the extreme end of the range of experiences parents spoke of in the consultation process. However, parents who have a disability feel that they are in a powerless position when faced with this sort of discrimination. They do not have anyone within the school to complain to about unfair treatment and must make a formal complaint to the District Office of the Department of Education and Training or to the Human Rights and Equal Opportunity Commission (HREOC) in order for issues such as these to be addressed. As one father stated,

The reality is, even if the school said, 'go away, we're not going to do anything', I'd be very unlikely, I think, to take a matter of disability discrimination, or whatever, just because I wouldn't be certain that the kids wouldn't get in some way victimised... I can't see myself in that situation, you know, pushing the issue too much. I'd probably ring up the Education Department, but the bottom line is, if the school wants to be difficult, there's not a lot you can do about it, at an individual level. If the principal isn't going to be cooperative, then what can you do, other than get another principal? Or take them out and go to another school?

**– Angus, father who is blind**

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## Interactions with parents

Parents generally reported that the nature of the contact they had with principals made a considerable impact on the degree to which they felt comfortable in being actively involved in their children's schools.

There were a number of responses where parents indicated that the support of the principal made a real difference to their feelings about the school and their level of comfort in being involved in a range of ways.

The principal gave me a bit of confidence. She responded well to my disability and asked how she could help [eg with large print].

– **Brenda, mother who has a vision impairment**

Another mother was approached by the principal of her children's school to conduct an awareness raising session about acquired brain injury. She says

They... asked me if I could talk to the students and explain a little bit about it, which I did...and that made a big difference, or the principal said that it made a big difference, once the students understood what was wrong.

– **Renata, mother who has an acquired brain injury**

There were also many examples of instances where sharp responses and insensitive comments from principals left parents feeling they were not welcome at the school and that they were unable to get support to be involved in their children's schooling.

I have avoided the school after consulting with the principal once. I left the school in tears, because when I asked for an explanation of written material and explained my situation, the principal reacted very sharply and treated me badly.

– **Yvonne, mother who has an acquired brain injury and a vision impairment**

The following example demonstrates very clearly that there are still principals who have the attitude that providing the supports necessary for parents to participate is an optional extra – it is not something that happens as a matter of course and those supports can be provided or refused at whim.

When my son graduated with his HSC I wrote to the school several weeks before and said please arrange for an interpreter. My husband called and asked... the following week I asked my son to speak to the Principal about it and also the importance of actually having an interpreter there. My son went to the Principal. The Principal's response was – 'when we see what this family has done for the school we'll see about an interpreter. The family hasn't contributed much'. A friend

who could interpret was available. I gave the number to the Principal and offered to pay half the fee. I never got contacted . Eventually they phoned my husband and said ‘no, you can’t arrange for an interpreter’. Even though a friend of mine who is an interpreter was available and she came with us anyway. The Principal actually avoided us... I was really upset at this discriminatory behaviour.

I approached HREOC, told them about the issues and lodged a complaint. They were very good and gave us a lot of support but eventually what happened was the law changed and we have to go to the Supreme Court to resolve this issue.

Another case had failed. They asked us to hold on. Basically we are still on hold. We paid thousands of dollars for my son to attend that school and we don’t have the right?

**– Leanne, mother who is deaf**

#### RECOMMENDATION 4

That principals ensure that teachers and other school employees are supported to attend regular continuing education and professional development sessions that include issues relating to parents who have a disability.

#### RECOMMENDATION 5

That principals ensure that mechanisms are in place for teachers to share their professional knowledge regarding parents who have a disability with other teachers and school personnel.

#### RECOMMENDATION 6

That principals participate in continuing education that includes issues relating to parents who have a disability, with an emphasis on their leadership role within the school in developing a culture of acceptance and on the legislative requirements of schools.

### LIAISON AND SUPPORT

Many parents expressed their dissatisfaction and frustration that they have to repeatedly explain themselves and their disability to teachers, principals and school administration staff.

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I explain my situation, but they forget quickly. I have to remind them all the time and it's embarrassing.

– **Bernice, mother who has a vision impairment and an acquired brain injury**

It's too hard to educate a new teacher every year.

– **Phillipa, mother who has dyslexia and a physical disability**

The issue of having a liaison person within the school arose a number of times during the consultation phase of the project. Some parents felt that a designated liaison person would make dealing with the school much easier for them and prevent them from having to repeat information and explain their disability to teachers over and over again – as one father put it,

A liaison teacher could be a go-between between parents and the system.

– **Mark, father who has a mental illness**

Other parents felt that such a role would set them aside from the general school community, when what they are working for is to be included in an ordinary fashion. They were also concerned that sensitivity to disability and cultural issues is not well established in schools and that they may be treated as 'second class' parents. This is particularly true for parents who have linguistically and culturally diverse backgrounds. This issue links closely with that of disclosure of disability to the school, which is addressed in more depth on page 20.

The roles of year coordinator/advisor and school counsellor were both brought up by parents as logical places where information could be channelled and communicated to other teachers and staff in high schools who need to know information about the child or their family. It was suggested that these teachers should receive extra training about working effectively with people who have a disability and be supported to provide a useful resource and support to parents with a disability in being involved in their children's education.

One mother stated,

I deal with the year advisor in high school, rather than individual teachers. It depends a lot on the individual teacher or advisor, as to whether they could be bothered to put the extra effort in. It should be part of their job, not seen as extra.

– **Victoria, mother who has a vision impairment**

School counsellors were also seen as a possible useful resource, but again, parents expressed concerns that an unskilled or unsympathetic counsellor could leave them isolated from the rest of the school community. One mother described that experience,

My son was being bullied by other kids earlier this year, but I found out pretty much straight away and I contacted the school counsellor and suggested we sit down and talk about it, but he referred me on to Community Health because I've got a mental illness... Yeah. And I thought, well it's a school thing and he's the school counsellor and we need to talk about it at school.

– **Jill, mother who has a mental illness**

### RECOMMENDATION 7

That a liaison and support role be developed within every school, with the aim of supporting interactions between parents who have a disability and the school in a range of activities. This role could be linked to the existing position of school counsellor or year advisor. It must be adequately resourced in terms of time allocation and resource support.

### RECOMMENDATION 8

That additional training that includes issues relating to parents who have a disability is provided to staff filling the liaison and support role.

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## 3. SCHOOL ADMINISTRATION

I'm sure there are no procedures in place and no policies for saying how do you deal with a blind parent, how do you deal with two blind parents. I don't think that they'd look it up in their manuals! And it could be quite challenging if I were to encounter individuals who were not too receptive, because if you make too much of a fuss, is this going to get taken out on the kids?

– **Angus, father who is blind**

The issues addressed in this section of the report cover the areas which are not the responsibility of any one individual. These include access to the school, the ways in which information on a range of issues is provided to parents and the ways in which schools respond to suggestions for change.

### ACCESS AND INFORMATION

Issues of access cut across all areas of participation in the school for parents who have a disability. This section of the report focuses on physical access, on access to information and on the opportunities that parents are able to take to gain better access to their children's school community.

#### Issues related to Physical Access

Physical access into the school is an obvious issue for people who have a range of disabilities. The general feeling of parents involved in this project was that physical access is improving, due to the increasing numbers of children with physical disabilities who are attending schools. However, there were still instances where schools were completely inaccessible to parents. More common were situations where parents could get into the school grounds, but not into their child's classroom or into the hall where speech nights, concerts and functions are held.

Because I'm in a wheelchair and that is a big issue, because most of the classes you can't even get into, you know, when you've got parent and teacher nights, you can't get to the classroom, you can't actually get inside, so most of the time you don't get invited to take it in... most of the time, you have to sit outside and look through the window.

– **Costas, father who has a physical disability**

Problems with physical access were certainly not restricted to parents who used wheelchairs. A number of parents who participated in the project had difficulty with vision or balance that made using stairs difficult, and parents who are blind noted that they were not able to find their way around the school without assistance. Some people had physical pain that prevented them from walking a distance.

Parents who have an acquired brain injury expressed their frustration that schools aren't better signposted, as they had difficulty remembering the location of various classrooms within the school.

There really is a lack of signs around the school to help with directions – I forget from one visit to the next.

– Alison, mother who has an acquired brain injury

Schools responded in a range of ways to parents raising access problems with them. As has been discussed earlier in the report, these responses have ranged from being open and accommodating to being actively discriminatory against parents due to their disability. There did not appear to be a systemic response to identifying issues of access at any school. A useful strategy may be for schools to conduct regular access audits with the assistance of people who have a disability, similar to those conducted by local council access committees.

One point that was strongly made concerns the focus that is placed on the disability of the parent when problems with physical access are not addressed. It was felt that this becomes the primary focus of people's attention, rather than the fact that parents are there to support their child's learning or to participate in school activities.



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Arrangements [for physical access] should be made before you come, not waiting around for someone to find the ramps, so my child's educational needs are the focus of attention, not my disability.

– **Gwen, mother who has a physical disability**

## **Information provision**

Without access to information in appropriate formats, it is impossible for parents who have some disabilities to participate in their children's school communities effectively.

Most information that schools provide for parents is in written form. Newsletters, notes from teachers, P&C reports, invitations to parent teacher interviews – if parents are unable to read this information, they are often not able to access the event or information.

All of the information that's sent home to communicate between the school and the parents is in written formats, even things like the offer of an interview with the teacher is conveyed in a written or printed invitation.

– **Angus, father who is blind**

Missing out on information impacts on parents with a disability and their children in a number of ways. Parents who have a disability do not have the opportunity to participate in a range of activities that support the school, such as accompanying children on excursions, being involved in the tuck shop, being a part of the P&C and so on. Importantly, parents also miss out on curriculum information that they need in order to effectively support their children's learning. For example, one mother stated,

I never had input into the boy's HSC, because the information is inaccessible to me – it comes home in big wads of stuff and I actually don't understand what it means. That sort of stuff is quite difficult and it means you don't have much of a say or much understanding of what's going on.

– **Alison, mother who has an acquired brain injury**

As another parent pointed out, there are a significant proportion of the population who have low literacy skills. These difficulties are compounded for people who have linguistically and culturally diverse backgrounds. It is not too much to ask of schools that their information is given to parents in a range of formats, including plain English and non-written formats.

Deaf parents also have enormous difficulty in gaining access to information from their children's schools. One mother describes her current situation,

My son is in kindergarten at a new school. When I drop him off in the morning they have an assembly with announcements five minutes before class starts. I don't understand what is being said. Many parents from an nesb background tell me they don't understand either.

– **Madeline, mother who is deaf**

Of the seventeen deaf parents we spoke with, who had thirty five children between them, only two had ever been offered an interpreter without having to ask for it to be provided. When parents did ask for an interpreter, schools did not always agree to provide one. The occasions that schools did recognise the need for an interpreter and organised for one to be provided stand out in people's memories. One mother stated

I asked for an interpreter and they said 'OK, yeah, we never thought about that.' They arranged for one and going back to the same meeting this year they automatically arranged for one. So that was really great.

– **Monica, mother who is deaf**

Providing information in large font was the most common response that schools made to requests for information to be made clearer. This is an effective strategy for people who cannot read smaller print, but does not address the complexity of the language that is often used in school documentation. Access to modified newsletters and other material was also raised as an issue.

Things come home in 10 font and they won't make it bigger because then they have to use another sheet of A4 – or you can get it at the front office, but a school kid won't go to the front office and say 'my mother needs it in font 14' – so it is available, but only under certain conditions.

– **Alison, mother who has an acquired brain injury**

Written information is not accessible to parents who are blind. We were not told of any strategies developed by schools in order to ensure that blind parents were kept apprised of information they needed in order to support their own children in school. Parents themselves suggested that providing newsletters and other written information on disc or by e-mail would help, as they could then apply the appropriate software to either read out or translate material into braille. Phone calls to advise of parent teacher interviews, excursions and so on was also raised as a strategy which would be effective.

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There are a range of access processes in place across a number of different agencies. For example, local councils across NSW have access committees that advise on issues concerning physical access and access to information for people who have a disability. It would be of great benefit for schools to link into these existing networks to gather information on how they can make their school community as open and accessible as possible.

#### RECOMMENDATION 9

That schools conduct regular access audits. Access audits consider both barriers to physical access and access to information for parents who have a disability. People who have a disability are involved in the audits, and a budget is allocated for responding to issues identified in audits.

### RESPONSIVENESS TO SUGGESTIONS FOR CHANGE

There was a wide range of responses from schools to suggestions by parents for changes that would accommodate them better. Again, the goodwill of particular individuals appears to provide the impetus for responding to problems and access issues with efficiency and sensitivity. Some schools have been open to suggestions and quick to make changes and alterations which accommodate parents who have a disability. Other schools have not been as positive. The following two examples clearly demonstrate that the reactions of individual schools vary enormously.

I had trouble with the front steps – I couldn't see where each step began and ended. There was no handrail and I was frightened of falling down them. I rang and asked if they could paint some white stripes on the edges of each stair. They were very accommodating and it was done soon after.

– **Nicole, mother who has a vision impairment and an acquired brain injury**

My daughter goes to a large school, which is on a hill. There is a lot of red dirt and brown asphalt, which makes it hard to see steps. I asked the school to paint white lines on the edge of the steps, but they wouldn't, even though a child at the school has a vision impairment. Eventually, they did paint some steps, but not all – and it took four years.

– **Victoria, mother who has a vision impairment**

The mother whose request was promptly responded to is closely involved with her daughter's school through participation in reading groups, on the School Council and in a range of school activities. She felt that the positive response that teachers and the principal had towards her when her daughter first started school fostered her interest and her involvement in the school has been a source of pride for her. The mother whose request was denied and then delayed for four years, has not felt that opportunities existed for her to become involved in the life of the school.

Another person told of their experiences with a school that was both responsive and proactive,

I remember turning up. First, they had a step to get into the office to have a meeting with the principal. Anyway, the principal helped me up that step and I got in and the next meeting I had there, there was a ramp. So, I made a suggestion that the doorbell and the doorknob was too high and they really needed to either lower the doorknob, or put a bell so someone could ring for help at the door. So, the next time I went, they had a doorbell at wheelchair height. So, every time I've had a request of the school... they've been very quick to make changes and fix it up.

– **Jamal, guardian who has a physical disability**

#### RECOMMENDATION 10

That principals ensure the school's complaints policy is available and accessible to parents in a range of formats.

### SYSTEMIC RESPONSES TO PARENTS WHO HAVE A DISABILITY

I think there should be some discussion on a policy level of how schools can be structured, or how the life of the school can be structured, so that if there are parents with a disability within that, the whole structures don't have to change. For example, if you buy the right computer software, it's easy to make the newsletters and so on available in a non-printed form. If you buy the wrong software, it's very difficult.

– **Angus, father who is blind**

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There does not appear to be policy within the Department of Education and Training that specifically refers to parents who have a disability. Policies concerning students and staff who have disabilities are in existence. There are a substantial number of policy and philosophical documents about parent participation in schools. Much of this material focuses upon the importance of parents as partners in their children's learning experiences.

The experiences of parents with a disability who were involved in this project indicate that there has not been a connection between these two policy areas in schools. Meetings with the Department of Education and Training, the Association of Independent Schools and the Catholic Education Commission confirmed that there is no documentation, either within schools or on a broader policy level, acknowledging parents who have a disability, or stating that schools needed to develop a systemic response to involving parents who have a disability. Independent schools develop their own policy frameworks and we are not aware of policies in Catholic, private and independent schools that directly address parents who have a disability.

The development of a policy framework around the participation of parents with a disability in schools would assist schools to recognise that there are in fact a significant number of parents who have a disability in the general community and give school personnel some guidance about how they could make the school environment more accessible and encouraging of parent involvement.

#### RECOMMENDATION 11

That the NSW Department of Education and Training Disability Action Plan be amended to include reference to working with parents who have a disability.

#### RECOMMENDATION 12

That policy is developed that directly addresses issues relating to parents who have a disability, including non-discrimination, strategies put in place to support involvement, the liaison and support role, and complaints mechanisms.

This policy needs to be developed and implemented at school and regional levels in public, private, independent and catholic schools.

### RECOMMENDATION 13

That funding is allocated for the development and distribution of a State wide resource kit for schools which includes issues relating to the participation of parents who have a disability in their children's schools.

### RECOMMENDATION 14

That professional development and continuing education concerning issues relating to parents who have a disability is developed and implemented for teachers, principals and other school staff at a regional level.

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## 4. PARTICIPATION IN SCHOOL ACTIVITIES

Reading groups, school concerts, committees for organising fetes and so on are all inaccessible. They might seem very trivial, but they are an important part of the fabric of the school community.

– **Gwen, mother who has a physical disability**

Participation in school activities is a concrete way for parents to measure their involvement with their children's school. This section of the report considers the experiences of parents who have a disability when participating in a range of activities within the school community, ranging from the governance of the school, to other parent committees, to classroom based activities, to whole school activities such as speech nights and sports carnivals.

There are issues which cross over all of the various school activities in which parents are commonly involved, including the degree to which parents feel they are able to volunteer their services and the reactions of other parents when they do offer assistance.

A number of parents felt that it was not wise for them to volunteer to be involved in parent activities in the school, as it might upset a delicate balance and cause discrimination against their children. The impression these parents had was that while disability was tolerated within their school communities, parents with a disability were not encouraged to become actively involved.

I wasn't really involved in tuck shop or committees. I tended to back off in case it turned against my children.

– **Elaine, mother who has a physical disability**

One of the common experiences of parents who have a disability was that their offers of assistance were met with refusal. One mother describes this,

It's a sort of false kindness – being involved will be too much trouble for you.  
'Thanks for offering, it's very kind of you, but we can manage without you'.

– **Gwen, mother who has a physical disability**

## GOVERNANCE

### Parents & Citizens Committees

I think the P&C is the crux of the school, where parents should be involved and I see that as a real fight for people with disabilities, just that real barrier around it. If you can't get in there, you have no real say.

– Alison, mother who has an acquired brain injury

The Parents and Citizens (or Parents and Friends) committee was seen by many parents as an important part of the school and a primary way in which parents could participate in decision making about school practice and policy. A small number of parents spoke warmly of their involvement in the P&C and felt that they had been welcomed and heard in the forum.

I have been involved in the day time P&C – was warmly welcomed and involved in cake stalls and so on.

– Phillipa, mother who has dyslexia and a physical disability

It was a far more common experience that parents who have a disability were not able to be a part of the P&C, for a number of reasons. Simply getting into the meetings was an issue for a number of parents who have a physical disability.

The P&C meeting were always held upstairs. They were not willing to hold the meetings somewhere accessible, like the community centre close by, even when they were directly asked.

– Gwen, mother who has a physical disability



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Another parent told of a disturbing incident when he went to a P&C meeting at his son's school, which reinforces the impact of attitudes to people who have a disability.

When I went to one of the P&C meetings, I went to go to the meeting, I dragged myself inside the hall, which had half a dozen steps, with the wheelchair behind me.

Nobody offered to give me a hand, not any of the teachers or anything.

**– Costas, father who has a physical disability**

The attitudes of other parents who were involved with the P&C committee played a big part in how welcome and supported parents with a disability felt in being part of that group. Where other parents were not comfortable, or where they held ambivalent or even hostile attitudes to people with a disability, participation was made almost impossible for parents who have a disability.

I would like to get more involved in the P&C, but you've sort of got to do so much...you've got to contact the person, explain the situation, get someone to meet me when I get there, then go through all the business about helping other people feel comfortable, you know, there's just so many things.

**– Angus, father who is blind**

I quit the P&C, because they didn't make me part of it. When you've got a learning disability, they treat you differently.

**– Tanya, mother who has an intellectual disability and a hearing impairment**

Another barrier to participation in the P&C which was identified by a number of parents was the way in which information is provided by the committee. Access to information in formats other than small font typed material was a barrier for parents who had vision impairments or who were blind, for some deaf parents and also for parents who did not read.

I would go to P&C meetings, or policy meetings and say 'this needs to be written in plain English' – and they say 'yes, yes, yes' but it never changes.

**– Alison, mother who has an acquired brain injury**

School Councils were not mentioned by many parents, but those who did discuss them raised similar issues to those above relating to the P&C committee. One parent who was part of the School Council felt that her involvement was respected and that she was a valued member. She went on to represent the school on FOSCO, the Federation of School Council Organisations, which she felt was also an opportunity for her to have influence on the way that issues relating to people who have a disability were dealt with. Another parent described the reaction of the School Council when she returned to her position on it after acquiring a brain injury,

It was a bit of a ‘gulp! How do we handle this lady?’, but they developed strategies to support my participation, such as frequent reminders about past events.

– **Joanne, mother who has an acquired brain injury**

## **Other committees**

A number of parents were involved with other committees at their children’s schools, such as fete organising committees, fund raising committees and ladies auxiliary groups. One mother stated

Being involved with committees has been good, because you get to know some of the other parents. You’re recognised as someone interested in the school.

– **Brenda, parent who has a vision impairment**

For some of the other parents who raised their involvement with committees, the sorts of issues that prevented involvement in the P&C were named as reasons that they were unable to either join committees or maintain their involvement. Not only do parents miss out on the business of those committees, but also on the opportunities to get to know other parents who have children at the school. One parent stated

There is a lot of interaction going on between the parents at an informal level, like taking notes and they swap ideas and if you’re not part of that, you miss out on that, the nuances, if you like, you know, the subtle things... and I think that if you’re not part of that interaction, then I think it is harder.

– **Angus, father who is blind**

### **RECOMMENDATION 15**

That principals ensure the resource kit and other relevant information concerning parents who have a disability is available to the P&C and other school committees.

### **RECOMMENDATION 16**

That the NSW Federation of Parents and Citizens Associations provide training on issues relating to parents who have a disability for office bearers of P&C committees.

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## PARENT RUN ACTIVITIES

This section of the report concerns the every day activities that are run or supported by parents within schools, such as the tuck shop, uniform pool and so on.

The most common activity for which parents had volunteered was the tuck shop or canteen at their children's school. Experiences in this setting did vary, but by far the most common experience for parents with a disability was one in which they felt they were not really welcomed or included.

I only did tuck shop once. Because I was slow reading the lunch bags, the lady in charge suggested I go home. I think she responded differently to ordinary questions because of my disability and she had no confidence that I could do the job.

**– Brenda, mother who has a vision impairment**

The attitudes of other parents who were also working on tuck shops or other voluntary roles and also the attitudes of students significantly affected the opportunities for parents who have a disability to participate in an ordinary way in these everyday school activities.

I did work in the kitchen, rather than serving, but I found it frustrating, I felt like a child as I couldn't communicate with any of them. The children would come and say 'hey that's your mum, she's deaf' and it actually made it worse for the kids. I got upset and my kids got upset so I decided not to do that... It's a different world for hearing parents and deaf parents.

**– Lena, mother who is deaf**

I was in the tuck shop, but got a lot of criticism from the kids and the other parents, because I had to say I didn't understand some things. I felt that I had to quit.

**– Tanya, mother who has an intellectual disability and a hearing impairment**

## CLASS AND GROUP ACTIVITIES

Reading groups, education days, sports coaching and accompanying excursions are all areas in which schools traditionally rely on parents for support. A number of parents who participated in the project had been actively involved in these activities in their children's classes. However, there were often barriers to their participation which meant that they were not able to be involved in the same way as other parents in the school.

I did participate in reading groups, but we had to have them outside [because the classroom was not accessible], so if it was raining or cold, I couldn't go.

**– Penny, mother who has a physical disability**

Preparation for participating in everyday activities was sometimes a barrier to involvement for parents too. One father describes his reluctance to take part in education day activities, due to the extra work and attention required.

On education day, they have a program where fathers go and read to the kids for half an hour. I have never done that, because I would need to talk to the teacher, she would need to talk to the kids, I would need advance notice to organise a braille book and it all just seems to get too hard.

**– Angus, father who is blind**

Some parents chose to focus on a particular area in which they could confidently offer support. A number of parents felt that this strategy allowed them the chance to fully and actively participate in the school activities in a particular area. However, the frustration of being subjected to the negative attitudes and judgement of other people in the school community was also expressed.

I did reading before the accident and afterward I didn't – because I didn't feel I would be able to cope with it without looking silly. I was quite involved with the school before the accident and after – that's the nature of acquired brain injury – people drop off, they can't cope with you, you're different – and so I then stuck with sport because I knew about that, so I just stuck with that... And the rest I don't do, because I'm actually quite scared of people's perceptions of what I have, you know, being with a disability and stuff... So I did tend to drop out.

**– Alison, mother who has an acquired brain injury**

A number of parents needed to make sure that they were able to offer support to their children, support the school and also manage their own health and wellbeing. For some people, this placed limits around the things that they were able to take on.

When I go out and do something at the school like that, it takes a lot out of me.  
So, yeah, I have to choose carefully.

**– Jill, mother who has a mental illness**

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It's good to get involved, but I can't commit 100%, because you don't know how you'll feel the next day. You could wake up in a flaming black hole and it's very hard to climb out of it.

– **Mark, father who has a mental illness**

This situation was expressed by parents as being frustrating and they were concerned about the perception of their children's schools that they were not interested in being involved. One parent stated

I sort of feel out of it, because I can't do much. Teachers think you don't care.

– **Irena, mother who has a physical disability**

## WHOLE SCHOOL ACTIVITIES

Speech nights, school concerts, sports carnivals and fund raising functions such as trivia or fireworks nights are an opportunity for parents to be involved in the life of the school community without having to perform a particular task. Part of the value of these sorts of activities is the opportunity that parents have to meet other parents and develop the informal networks which are so helpful in supporting the learning of their children and in encouraging their own participation in the school.

Access to information is critical for parents to be involved in events such as presentation days or school assemblies. When this information is not provided in an accessible format, it is impossible for some parents to participate in the event as fully as they want or need to.

Over 11 years I have realised how much information I have missed out on. Every year, at the school assembly, Christmas events, presentation day and so on, I'd always go along whether my children were receiving an award or not. And every year I would sit for 2 hours not being able to access anything that was going on. I'd miss out on so much ... It's disappointing as I want to know more about the school and what was going on. All my four kids seem to be doing very well at school and they are very happy but I don't actually know what they are doing at school, what is really going on.

– **Catherine, mother who is deaf**

Speech nights were another area where a number of parents expressed disappointment that they were not able to participate easily. On a number of occasions, parents described speech nights held in inaccessible venues, so they were unable to get into the room. Other parents found they were able to physically participate, but it was very difficult to make maximum use of the event to interact with other parents and develop informal networks.

It used to be agony for me to go to speech night, because I wouldn't want to go, this ongoing exhaustion [and they are pretty boring at times]. Yeah, which was good, because I could just sit there and stare into the air, because everybody else was doing the same. But also that meant that I didn't have any interaction with the other parents, which I think is very, very, very common. You don't want people to know, you can't talk to them anyway, you don't want to put a stigma on your child, you don't want to tell the other parents.

**– Julie-Ann, mother who has a mental illness**

When strategies are put in place which enable parents to fully participate in the event, it is clear that the benefits extend past the conclusion of the event.

They did get an interpreter when my daughter was receiving an award, a scholarship, a performing arts award. The Principal actually posted me a letter saying that they were inviting the parents along to this function, dinner etc. So I contacted the school and they did arrange for an interpreter. I insisted how pointless it was to not have one there. It was great. I had access to the whole event which was nearly four hours and I was interested to find out about various students and the awards they were receiving. It was really, really very interesting. So, I wrote to the Principal thanking him for providing access to an interpreter and telling him how I had enjoyed the opportunity to attend, hopefully encouraging them to provide more interpreters in the future.

**– Fiona, mother who is deaf**

#### RECOMMENDATION 17

Information that schools regularly provide to families, such as policies and school orientation materials, include information supporting the involvement of parents who have a disability.

#### RECOMMENDATION 18

That in the planning and implementation of school activities, including parent activities and committees, both physical and information access issues related to parents who have a disability are considered.

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## 5. DEVELOPING THE SCHOOL COMMUNITY

The system needs to change, rather than relying on particular individuals to accommodate your disability.

– **Alison, mother who has an acquired brain injury**

In this chapter of the report attention is given to the broader considerations of how a culture of acceptance of people with disability is created or prevented from developing within the school.

The culture and ethos of the school was a point that a number of parents raised in consultation. There was a distinct feeling that the culture of the school has a strong impact on the number and sort of opportunities for participation that are offered to parents who have a disability.

The school culture is a critical factor – a positive milieu at the school and a social justice emphasis makes a real difference.

– **Andrea, mother who has a mental illness**

We are not able to make any broad statements about which sorts of schools might support parents with a disability better than others. The degree to which parents with a disability are still reliant on the goodwill of particular individuals within the school and the lack of a coherent policy framework within which to measure school performance masks the development of any clear trends.

A number of parents found that smaller, community oriented schools were more open to acknowledging their disability and providing opportunities for them to be involved in the life of the school.

When my son was in primary school, it was great. It was a small school and it was easy to be involved and good for everyone. We were all on a first name basis and it was less institutional.

– **Mark, father who has a mental illness**

Similarly, primary school was found by many to be easier to deal with than high school, as there was only one teacher to deal with at a time. However, some parents did find that their interactions with their child's primary school teachers were quite negative and found they had very little support or assistance to deal with these problems on a day to day basis.

High school was seen by many parents to be harder to deal with than primary school. The number of teachers who have interaction is much higher and information was not communicated between teachers in a number of instances parents described. One mother stated that

I have to explain to the school, to the principal, to the teachers, to their seven teachers, to the year seven coordinator, that I was disabled, that I was in a wheelchair, every year for the last three years. And it's the same school.

– **Anna, mother who has a physical disability**

## CREATING A CULTURE OF ACCEPTANCE

We have... 256 cultures in our area and some of the schools have got so many cultures in one big melting pot and then you throw in a couple of disabilities and it becomes a real, excitement really, when it's dealt with in a really good positive way.

– **Jamal, guardian who has a physical disability**

Further to being proactive in involving parents who have a disability, schools need to work towards creating a culture within the school that respects and values difference. A school culture which is open and accepting of people with disabilities does not appear to be common, gauging from the experiences related by parents who participated in this project.

I do think it requires some ideological commitment to it if it's going to work. And these are the sorts of things that can always get put aside by people because they're always too busy and they haven't got time and so you can't do all the things you'd like to do, so you have to focus on certain things and neglect other things. If kids see people with disabilities being actively involved in the school, then they're going to develop a positive attitude towards people with disabilities, so they're much less likely to leave the education system never having had contact with someone with a disability or having very negative attitudes.

– **Angus, father who is blind**

This means that schools need to think clearly and strategically about the groups of people who are involved in their community. It means going beyond the reliance on the goodwill of individual teachers and principals. Parents who have a disability should be able to expect the same opportunities to participate in the education of their children as any other parent in the general community does. Without considered and articulated support strategies being put in place, many parents with disabilities will continue to be marginalised within their children's school communities.

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Central to this commitment needs to be the involvement of people who have a disability in a range of ways. Education is an obvious tool to use in challenging the attitudes and practices of people who are not supportive of people with a disability.

## EDUCATION AND AWARENESS RAISING

The majority of parents who participated in the project indicated that they felt education about people who have a disability was very much needed in schools. Their ideas for effective education strategies ranged from awareness raising sessions, to 'disability weeks', to an embedding of education about disability in the curriculum.

### **Awareness raising sessions**

There are a range of community and school education programs which are in place across the state, which provide information and raise awareness in many schools. Many of these programs are linked to disability advocacy and support organisations. A number of parents who were involved in these sorts of projects spoke about the effectiveness of these sessions.

We used to do that sort of thing [awareness raising talks in schools] ... A person with a mental illness and a parent of someone with mental illness. They loved it. You could hear a pin drop. It really was an eye opening program.

**– Jill, mother who has a mental illness**

The initiatives that are being done by the community access programs about school... and teaching schools about brain injury... It's incredibly valuable, the positive response to that sort of action.

**– Renata, mother who has an acquired brain injury**

One of the points made most strongly about awareness raising sessions was that they must be conducted by a person who has a disability themselves. Further, the person conducting them needs to be someone who can offer the school community a realistic and positive view of living with a disability.

There is no point people knowing the tragedies that have happened in my life or your life unless there's a solution and an educational component because without an educational component the story is going to be devastating.

**– Margaret, mother who has a mental illness**

Awareness raising sessions were described as highly valuable to school children and also to teachers, principals and the school administration staff. Some parents felt sessions were particularly effective when they were linked to specific calendar

dates, such as Pedestrian Safety Week for talks on acquired brain injury, or the International Day of People with Disability for more general awareness raising talks, when children could focus on the issues in their formal class work too. The other time that they were seen to be of particular value by the participants in this project was when they themselves had joined the school, or had returned to the school after an accident or injury. Several parents described how speaking to the school helped everyone to understand about the person and their disability and broke down many barriers.

### **Focus days/weeks**

A number of parents described initiatives that their children’s schools had implemented, where disability was discussed and learnt about over a day or week specifically set aside in the school calendar.

One of things they’ve got is a really good program, they have a disability awareness week and I’ve been asked a couple of times and I’ve actually done it, gone in and spoken to a class about people with a disability and it’s actually really helped to break down the barriers with the people in the community. And the children actually ask questions, quite private questions too, you know what teenagers are like. And I find it quite interesting... I find it very helpful generally and I put it down to that program, where they have a week for the children to learn about disability and they actually go and speak to someone they know, or find someone in the community with a disability and then report back to the class.

– **Jamal, guardian who has a physical disability**

#### **RECOMMENDATION 19**

Principals ensure that a range of awareness raising educational activities related to people with a disability are structured into the school calendar at the commencement of the school year. These activities should be made available to students, school staff, other parents and volunteers.

#### **RECOMMENDATION 20**

That issues relating to people who have a disability are integrated into the school curriculum across all years K – 12, at State, district and school levels.

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# CONCLUSION

Throughout this report, parents who have a disability have described many instances in which they were treated differently and often less fairly than other parents. A number of times during the project, parents commented upon the fact that they are often reliant upon the goodwill of particular individuals in order to be actively involved in their children's education. They have also detailed many experiences where schools have responded to them effectively and appropriately.

The publication of this report provides schools and parents with the opportunity to build upon these individual and to create a culture in which parents who have a disability are valued and respected within the school community. We hope that this report will be seen as a tool and a resource for making changes that benefit everyone who is involved in their school community

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