# Isolated parents' perceptions of the education of their children with disabilities

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#### Abstract

Commissioned by the Department of Employment, Education and Training with The Australian Association of Special Education as grantee, this Project of National Significance was designed to gain a comprehensive insight into the provision of educational services to students with mild or moderate disabilities living in geographically isolated areas of Australia. There were two main groups whose perceptions were sought: parents and service providers.

In general, parents report a reasonable level of satisfaction with the quality of the services their children are receiving and with the educational and personal development of their children. It would be misleading, though, to assume that there are no complaints. Areas which need attention include better training of teachers, more special education teachers available, more teacher aides and teacher aide time and more access to allied health specialists, particularly speech therapists and physiotherapists. The parents recognise the educational disadvantage their children suffer from geographical isolation and they emphasise the need to resource educational programs for their children at a more effective and realistic level.

# Background to the Study

Australia is a vast continent where the very large proportion of the population of 18 million lives in a narrow coastal strip and clustered around five main cities. Services for children and adolescents with disabilities are comprehensive in the well-populated areas of Australia but the more distant one travels from the larger population centres, the more sparse are the resources and services for children and families. This study was commissioned by the Department of Education Training and Youth Affairs (DETYA) with The Australian Association of Special Education as grantee. The investigation was designed to collect data on the perceptions and needs of service providers and parents in relation to the education of isolated students with mild and moderate disabilities in the age range 0 to 18 years. The definitions from the survey instrument provide the frame of reference.

For the purposes of this study, isolation refers to living in an area which is very distant from services, in which travel to receive those services is extensive and/or expensive. We are interested in students whose disability requires an adapted or specialised instructional program. While we are including 'mild' disabilities, because of the large numbers of students in this category, we are expecting people to respond about those students whose disabilities are more towards the moderate end of the mild-moderate range. Students may be in the age range 0-18 years, may not be attending school because they are too young,

Education in Rural Australia, Vol. 10 (2) ... 2

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may be on distance education (correspondence, School of the Air etc.) or may be attending a small isolated rural school of 2-3 teachers.

#### Aims of the Investigation

The general objective of the investigation was to map the provision of services and resources to children and adolescents with disabilities in the more remote areas of Australia. Of particular interest for this paper was the identification of the parents' perceptions and evaluation of the provision of services for their children with special needs and to identify sources of special education assistance currently available to students with mild or moderate disabilities. An indirect aim was to collect information that could be useful for government policy development and action, at both state and federal level.

#### Literature

One of the difficulties of finding literature on this topic is that there is only a small body of Australian research on 'rural' education and virtually none on disabilities in the bush. In the USA, there is considerable interest in rural education and rural schools but services to many children are delivered outside the context of schools. In their 17th Report on IDEA to the US Congress, the US Department of Education (1995) laments the lack of a widely accepted definition of 'rural' and makes the point that this lack has interfered with research in the area. They regard population density and remoteness as two key criteria in a definition. They then use the US Census Bureau definition, that is, a non-urban area, a population of less than 2500 in the area or place, with fewer than 50 000 people in the surrounding territory. Clearly, geography, demographics, land use, population size, and culture are all factors likely to shape a nation's view of 'rural'. Australia has a landmass about the same size as the USA, but has one fourteenth of the population.

The figures cited in the US Report mentioned above suggest that there are nearly one-half of a million school students receiving rural education. It is also asserted that the prevalence of students with disabilities in rural America is virtually the same as that for the population at large, however, data from their National Longitudinal Transition Study suggest that a very large proportion of these rural children live in poverty. Naturally, poverty adds an additional challenge to serving students in the bush.

The themes that arise from North American literature on rural education include the impact of the terrain and the isolation on the students, economic problems in rural regions, and government under-funding (Freitas, 1992, cited in US Department of Education, 1995). The usual problems referred to in the literature relate to recruiting and retaining teachers, and access to and the need for in-service education, specifically for disabilities and remoteness (Hicks, 1994). Besides in-service training for teachers, there is also a need for leadership training for school principals, many of whom are not trained in special education. Indeed, in a study of the attitudes toward inclusion of students with disabilities of principals of Queensland state schools, one of the strongest responses was for training of teachers, teacher assistants and principals in developing inclusive education programs (Bailey & du Plessis, 1999). There is a small literature on rural education training models, one in particular promoting the value of the Individualised Education Plan (IEP) in this process (Brown & McIntire, 1995). But there is virtually none on parents' perceptions of services to their children who are disabled.

Some studies assess the attitudes and aspirations of teachers regarding teaching in rural areas. Bell (1993) found that less than one-fourth of undergraduate special education students preferred a rural placement, and, not surprisingly, those who grew up in rural areas were more likely to

express a preference to return to the country. A study by Westling and Whitten (1996) gives encouragement. More than half of 158 rural special education teachers planned to be in their same jobs for the next five years. This continuity is extremely important in the bush where there is a high turnover of professionals. Interestingly, the two factors influencing retention in this study were to do with the requirements of the job and administrative support.

One of the major enriching possibilities for all children receiving their education in isolated areas of Australia is the emergence of communication technology. The Internet changes the way people access the world. On-line chat facilities, email pen pals, email shopping (likely to be the curse of the 21" century), the use of voicemail using free software like Purevoice, the ability to be able to send digital stills and videos, the possibility of Internet teleconferencing using small, inexpensive cameras, Internet phone calling at reduced rates are some of the facilities that will change the face of isolation. For teachers, technology should be a wonderful augmentation of traditional teaching. For tutor parents accessing distance education at home, the learning packages can be delivered instantly over the Internet rather than having to wait for snail mail delivery. A 1996 study (Nelson, 1996) does not give a great deal of hope though as a survey of 141 rural special education teachers knew little of this technology and its educational potential.

But what of Australian literature on education in rural and remote Australia? When undertaking such a review, the most likely source is the one specialist journal concerned precisely with that topic - this journal, Education in Rural Australia. Of the 72 articles published in that journal from 1990 to 1999, there are none on disabilities and parents. There is one on teachers' perceptions of inclusive education in rural schools (Fields, 1993) and two on parental perceptions (Baker & Andrews, 1991; Hard, 1997). These parent papers are on choosing rural school or a boarding school and perceptions of preschool education. There are plenty of articles on various aspects surrounding teachers and teaching, for example, there are nine articles on teacher concerns and 10 on curriculum matters. Searches of the Australian ERIC database portray a similar picture. What is interesting for the purpose of this paper is that there appears to be virtually no studies on the education of students with disabilities in the bush - either in terms of teacher perceptions of the adequacy of those services or parental perspectives.

#### Resources for Rural Education

A search of resources for isolated students in Australia gives cause for encouragement. Of course a major political force in rural and isolated education in Australia is the Isolated Children's Parents Association (ICPA). This body is extremely knowledgeable, mobile and influential. They have a very powerful role to play in influencing government policy and funding. In response, there have been some wonderful examples of services to isolated children through Priority Country Area Programs (PCAP; NSW's Country Area Program website is www.cap.nsw.edu.au) and similar support schemes, through Schools of the AIR (SOTA; see for further information Katherine, NT's SOTA's website www.ksa.nt.edu.au). There are also many distance education example, Dubbo Distance Education Centre; (for their www.dubbosde.nsw.edu.au). One particularly impressive service was the Queensland Department of Education's Isolated Children's Special Education Unit. It is also interesting to note that a group of retired teachers have formed a support group for isolated children. The association is called VISE (Volunteers For Isolated Students' Education; website www.vise.org.au). These people provide tutorial support in several ways as described on their

Obviously, the picture about education for children with disabilities in isolated areas of Australia is a mixed one - with considerable gaps in information about parental evaluation of services to students with disabilities. While we have little Australian data on the incidence or the problems,

the sparse literature identifies the main themes to be concerned about in research and services to children with disabilities in the bush. Clearly, every child is entitled to high quality education regardless of the locale in which that education is delivered. A government cannot claim that it is promoting social justice for its people when the needs of a specific population are not met merely because of distance.

This study was designed to fill in some of the gaps about education to children with mild and moderate disabilities in isolated areas of Australia. In particular, we wanted to know what parents thought about a range of topics of particular importance to them and their children. The actual details of the study are described in Appendix A (the questionnaire) and in the tables below. The main aim was to take an audit of as many isolated and rural parents as we could reach who had a child with a mild or moderate disability. Information on resources in the home, services provided, the level of help their children required, and problems caused by isolation in terms of service provision and education development constituted the focus of the inquiry.

#### Methods

#### Sample

This study, based on survey questionnaire research, was of parents who live in isolated' areas of Australia as defined above and who had a child or adolescent aged 0 to 18 years who had a mild or moderate disability. No attempt was made to confirm the diagnosis of disability, nor was an effort made to confirm the estimated severity level because of the distance and complexity involved. Parents of children with disabilities are extremely familiar with the nature and degree of the disability and, for inclusion purposes, were regarded as expert in their judgment.

The major problem with the study was to try to find the parents. There does not appear to be any database held in Australia relating to children with disabilities living in remote areas of Australia. Clearly, even using the definition of 'isolated' one encounters problems. For example, how 'distant from services' does one have to be to be isolated? What if one is living on a fishing trawler that comes into port infrequently? What if one's parents are itinerant workers in, say, the fruit picking industry? What if a parent is psychologically isolated, that is, endures agoraphobia and feels unable to leave the house? In the end, we accepted that 'geographical' isolation was the issue, and, in a sense, if people believed themselves to be isolated, for them this was sufficient. We also recognised that some of the parents we would try to reach would be living too far from schools for their children to be able to attend on a regular basis. As well, we knew that there would be parents living in fairly remote communities who were close enough for their children to attend small rural schools. The real issue, of course, was convenient access to services to meet their special needs children.

Having pointed out how difficult it was to actually draw up a sampling frame to recruit participants, we were confronted with yet another problem. How did we find these people? We relied on groups like the Isolated Children's Parents Association, an enormously competent and well-organised group of parents. We also relied on teachers and administrators in the various schools of the air or distance education centres (depending on the state). In some cases, we relied on members of AASE who live in remote areas. Ultimately, we were able to get a reasonably large mailing list of people who appeared to fit the criteria of being isolated and having a child with a mild to moderate disability. In some ways, the sampling was skewed in that we may not have accessed those populations of people who were not in any known networks, and/or had few resources to be able to be recognised. This is a major limitation of this study.

#### Instrumentation

A survey questionnaire was developed specifically for this investigation (see Appendix A). With support from an AASE reference committee, a final survey form sought information on the clusters described in Table 1. No statistical efforts were made to ensure that this instrument had strong psychometric properties as the purpose of the survey was to conduct a reasonably comprehensive audit of parental resources and perceptions.

#### Table 1:

# Parent Questionnaire Items Used in the Survey of Special Education Provisions in Isolated Areas to Students with Mild or Moderate Disabilities

- demographic details on the respondent and the child
- · location and type of educational services
- · details of programs and professionals providing the programs
- distance from schools and services
- · educational and related resources to which the family has access
- · disability aids the child needs to use;
- an evaluation of the level of help the child needs;
- · educational and developmental problems confronting the parents of the child;
- funding assistance;
- an 18 item rating scale seeking parents' perceptions of the impact of geographical isolation on the education of their children;
- a request to indicate the areas in which additional support and resources are needed.

It should be noted that the expression 'regular education' refers to those schools that have a preponderance of enrolled children without disabilities.

#### Results

Despite the difficulties of finding participants, 122 surveys were returned from parents around Australia. Table 2 shows the distribution of respondents by the states and one territory.

Table 2: Distribution of Parent Responses by States

	NSW	Qld	Vic	SA	WA	NT	Tas	Missing Data	Total
N.	26	25	12	17	21	10	8	3	122
%	21.3	20.5	9.8	13.9	17.2	8.2	6.6	2.5	100.0

The Australian Capital Territory was excluded from the study because of the small size of the territory and because advice received from members of the Steering Committee was that geographical isolation is not a problem in the ACT.

Table 3 provides some demographic detail on the respondents. The bulk of the respondents can be described as mothers between the age of 32 and 44. In terms of residential mobility, virtually all of the respondents (98.4%) were fairly stable in terms of where they live.

Table 3: Gender, Age, and Role of Parents

	N	%
Gender of Respondents		
Females	112	91.8
Males	10	8.2
Missing data	0	0.0
Age of Respondents		
Mean Age	38.4	
Standard Deviation	6.1	
Lowest Age	26.0	
Highest Age	57.0	
Missing data	5	
Role of Respondent		
Mother	107	87.2
Father	9	7. <del>4</del>
Grandmother	1	0.8
Grandfather	0	0.0
Guardian	2	1.6
Other	3	2.5
Missing data	0	0.0

#### Information on the Children with Disabilities

The parents were asked to describe their children with disabilities. Table 4 shows the gender and age of the children. There were fewer females than males, a common fact of disability prevalence studies. With an average age of 10.1 years, the population tended to be primary-age children.

Table 4:
Gender and Age of the Children Reported on by Parents

	N	. %
Gender of Children		
Females	56	45.9
Males	66	54.1
Missing data	0	
Age of Children		
Mean Age	10.1	
Standard Deviation	3.2	
Lowest Age	4.0	
Highest Age	17.0	
Missing data	0	

Table 5 shows that there were more children with a moderate disability than a mild disability. What is more interesting, though, is the range of disability types.

Table 5:

Degree and Type of Disability of the Children Reported on by Parents

Degree of Disability	N	%
Mild	46	41.4
Moderate	65	58.6
Missing data	11	44.4
Type of Disability		
ADHD	3	
Agoraphobia	2	
Articulation Problem	2	
Asperger's Syndrome	2	
Autism	2	
Behaviour Disorder	0	
Cerebral Palsy	8	
Down Syndrome	10	
Foetal Alcohol Syndrome	2	
Hearing Impairment	6	
Intellectual Disability	2	
Language Disorder	0	
Physical handicap	1	
Psychiatric Disorder	2	
Spina bifida	2	
Visual Impairment	2	
Missing Data	<i>7</i> 5*	
Total	122**	

<sup>\*</sup> missing data occurred because of the layout of the question on the survey form

# **Education Provisions, Programs and Professionals**

One of the main aims of the study was to find out what sorts of programs were being provided in isolated areas. Table 6 describes the programs, their source and the professionals involved with the 122 children with special needs identified by their parents.

<sup>\*\*</sup> one child had intellectual and physical disabilities

**Table 6: Education Provisions, Programs and Professionals** 

	N	%
Location of Education Provisions		
Home	2	1.6
Distance Education	9	7.4
Small rural school	73	59.8
School of the Air	4	3.3
Other	31*	25.4
Missing data	3	2.5
Provider		
State Department of Education	115	94.3
Independent School	1	0.8
Catholic Education	3	2.5
Other	2	1.6
Missing data	1	0.8
Professionals Providing a Program		
Regular Teacher	88	
Special Education Teacher	56	
Psychologist	6	
Speech Therapist	37	
Occupational Therapist	28	
Physiotherapist	15	
Early Intervention Teacher	5	
Teacher's Aide - Special	4	
Teacher's Aide	9	
Others	19**	
Child in an Educational Program		
Yes	86	81.1
No	20	18.9
Missing data	16	

includes special schools, large rural schools, pre-schools etc

Three-fifths of the students reported on in this study attend small rural schools. Virtually all of the students attend state schools. This could be an artifact of the distribution system used but it is more likely that it represents reality. There are virtually no independent schools in isolated settings and the number of Catholic schools in isolated communities has decreased over the last several decades. It is interesting to note that of those responding to the question asking whether their children received a special program, 81% (N = 86) indicated that their child receives a special program. This is very encouraging information.

<sup>\*\*</sup> a range of other professionals is involved in the education of these children as well. These include school counsellors, other counsellors, Kumon specialists and part-time instructors.

Table 7: Home Tutors and Parent Involvement

	N	%	
Home Tutors			
Yes	6	4.9	
No	115	94.3	
Missing data	1	0.8	
Parent Involvement			
Mean Hours per week	8.7		
Standard Deviation	9.1		
Range	40		
Lowest Involvement (hours)	0.0		
Highest Involvement (hours)	40.0		
Missing data	25		

In Table 7, we note that only six families employ a home tutor but many parents spend a great deal of time working with their children at home. The average amount of time spent weekly with their child is nearly nine hours but the standard deviation shows that there is a very wide spread of commitment. Some parents spend up to 40 hours a week tutoring their child while others indicated that they now leave the extra support to the school and they provide little direct school support at home. The stress on parents of children with disabilities, particularly mothers, must be a cause for concern. Similarly, there will be displaced effects, for example, there will be less time for the mother to spend with the siblings and even with her husband. These additional pressures are well-recognised in the field of disability generally but, given the lack of available specialist resources and the often large distances involved in getting to centres which have the services parents needs, isolated parents have an additional stressor.

#### The Extent of the Remoteness

While some parents travel vast distances or are too far away from a school for their child to attend daily, many live near small rural schools as Table 8 demonstrates.

One of the disappointing outcomes of the method used to gain respondents was that the very large proportion of the parents lived within 30 kilometres of their local school. Some who lived within metres of their small rural school saw themselves as isolated because of the distance of the school from a comprehensive range of services. Quite a few respondents lived considerable distances from their schools, for example, one is 550 kilometres from the nearest school. It is not clear whether those who cited a flying time did actually fly their children to school on a daily basis. Many of the respondents spoke of the great burden and considerable expense of driving their children long distances to school. Having to drive even the average distance, 30 kilometres, twice a day, is a significant cost, for example, for a normal school year of 200 days this is 24,000 kilometres.

Table 8:

# Distance from School

Kilometres by Road (Mean)	29.4
No. of respondents	102
Standard Deviation	<i>7</i> 7.0
Range	550.0
Shortest distance	0.0
Longest distance	550.0
Hours by Road (Mean)	1.0
No. of respondents	55
Standard Deviation	2.3
Range	15
Shortest time	0.0
Longest time	15.0
Flying Time in Hours (Mean)	0.2
No. of respondents	15
Standard Deviation	0.6
Range	2.0
Shortest time	0.0
Longest time	2.0

# Resources and Aids

It is often assumed that people in remote areas have few resources to assist their children educationally but this is not the picture painted by the information in Table 9.

Table 9:

# Resources Available at Home

Resource	N	
Generator	5	
Mains Power	94	
Telephone	108	
Radio Telephone	16	
Computer	50	
CD ROM - on computer	20	
Modem	4	
Mail Service	varies	
Electronic Mail	2	
Cassette Recorder	106	
Television	112	
VCR	96	

Those resources commonly used in isolated areas where there is no electricity or landlines for telephones include the use of a generator for electricity and a radio telephone. Most respondents, however, had mains power, telephones, televisions, cassette and video recorders and regular mail. Nearly one half of the families have computers and one-sixth have CD ROMS.

Clearly, each of the families has a wide range of resources that would be of great value in educational programs. The computers, and particularly CD ROMS, lend themselves ideally to instruction. With the advent of a great deal of teaching material on CD, and with the possibility of cutting CDs for less than \$5 for each disc, the potential of these huge and flexible data storage devices would make a great difference to isolated parents. In their 'wish lists' many parents spoke of their frustration at not being able to get suitable software, particularly in terms of borrowing such materials from educational service providers. Clearly, this is an area that could be addressed very readily through a centralised computer software borrowing system.

Table 10: Aids to Assist the Students

Aid	N	
Glasses	33	
Walking Aids	8	
Communication Board	6	
Hearing Aid	8	
Wheelchair	6	
Other	12	

While many of the children wear glasses, there are few other specialised aids (see Table 10). Four children have a communication board and six use wheelchairs. The other aids used provide an interesting picture: catheter; pencil grips; lenses; standing frame; medication; special shoes; splints; visual aids and braillers.

#### Support by Teachers

Only eight respondents get regular visits from teachers. The number of times reported for visits in any one year were 1, 1, 2, 3, 4, 40. In terms of visits to teachers, 12 of the parents reported visits and they were 1, 2, 4, 4, 10, 40, 40, 40, 120, unlimited. Clearly, some parents are having a great deal of contact but the bulk of the families have very little contact with the teachers, a source of concern for many of the parents. The major differential is, of course, whether the children are attending a school. Obviously, if they attend a local school and parents drive them to school, there is daily access to the teacher. Those who receive their education remotely are in a different category.

# Levels of Support Needed

One of the things we wanted to know was how much help the child needed to be able, in the parents' eyes, to function appropriately. We identified seven areas, as shown. The first five had equal relevance on the basis of degree of disability (mild or moderate) but the curriculum areas produced a significant difference in response on the basis of degree of disability. Table 11 shows the area in which support was needed, the means and standard deviations. The anchors for the scale were 1: Needs no help; 2: Needs a little help; 3: Needs a lot of help; and 4: Unable to do it

alone. The smaller the mean, the more likely the child would be able to complete the task independently. The larger the standard deviation, the greater the variability of response.

Table 11:
Levels of Support Needed (4 point scale)

Skill Area	Mean	Standard Deviation
1. Self-help Skills	1.8	0.86
2. Large motor activities	1.6	0.82
3. Language use	2.1	0.85
4. Social Skills	1.9	0.82
5. Self-control	1.9	0.77
6. Reading	2.8	1.07
7. Mathematics	3.0	0.98

The first five skill areas were reported around 2.0, that is, at the level where a 'little help' was needed. This is, of course, a reasonable and somewhat comforting outcome. The area in which there are additional problems and more help is needed are in the two basic skills areas - reading and mathematics.

# Parents' Perceptions of the Impact of Isolation

Table 12 employs the same skill areas used to assess the level of support needed. Respondents were asked to rate how much of a problem being isolated caused them with regard to the educational development of their child with a disability. The anchors were: 1: No problem; 2: A small problem; 3: A large problem; and 4: A very serious problem. The larger the mean, the greater the negative impact of isolation on the child's development.

Table 12: Impact of Isolation

Skill Area	Mean	Standard Deviation
1. Self-help Skills	1.4	.66
2. Large motor activities	1.5	.69
3. Language use	1.9	.89
4. Social Skills	1.8	.92
5. Self-control	1.7	.87
6. Reading	2.3	1.12
7. Mathematics	2,3	1.09

The parents report a small degree of problem caused by isolation in self-help skills, large motor activities, self-control and social skills. The level of impact rises in language use, reading and mathematics. One of the problems of isolated families where the children do not attend school is socialisation. Social skills, motor behaviour and language all develop through interaction and, as one reduces the interaction, there is an expected increase in concern about proper development. The general conclusion, though, is that isolation in itself is not causing a major problem for parents. This is not to say, of course, and this will become obvious later, that isolated parents do not perceive many shortcomings in their child's education because of their geographic location.

#### **Program Funding and Allowances**

There were very few families receiving special funding and allowances. Typical funding was provided by State departments of education, and this was mainly for the provision of teacher aides. Other funding schemes mentioned were TALFU, the child disability allowance and special integration funding. Very few parents received special allowances and, for those who did, the only one mentioned was the Department of Social Security's disability allowance.

# Parents' Indications of Inadequate Services and Programs

An open-ended item asked parents to comment where they felt they were not receiving adequate programs or services. This question provided a very large amount of data. In some ways, the best way to appreciate the comments would be to read all the data but space does not permit, so the following summary covers the main concerns of parents. No attempt is made to indicate the frequency of responses, instead, the descriptions are allowed to stand for themselves, whether one or many made the statement.

Parents were concerned about their children's achievements in basic skills. They indicated that there was a need for better training of teachers. Some recommended improvement in teachers' attitudes, willingness and ability to work with children with disabilities. There were also suggestions about the need to emphasise social skill development and Physical Education. A continuing concern was funding for home support. Besides these areas, there was overwhelming support for improvements in three areas. These were, firstly, increasing support to the parents to facilitate the development of their children, particularly in one-on-one teaching and the availability of teachers trained in special education. A second dominant theme was the need to improve services to their children by increased provision of teacher aide time. The final area for improvement related to the provision of specialists, mainly speech therapists and occupational therapists, although some mentioned physiotherapists and psychologists. The problems for parents with regard to specialists were that there were either no or very limited therapy services. Some parents suggested these therapists should be assigned to the school.

#### Parents' Wish List for Improvement of Services to their Child

A second open-ended item asked them to indicate what they might put on a wish list to improve services to their children. This was something of a Pandora's box and the extensiveness of the responses gave a clear indication of the deficiencies parents see in the provision of services.

In terms of basic rights to education and services, one parent expressed her concerns in the following way:

I believe that every child deserves an education. My daughter is not getting one. She has no special education teacher and "normal" teachers are not qualified to teach her. This is not their fault. Her rights as a human being give her the right to a special education teacher. This is not a privilege but a right. She has struggled for six years and no child should be expected to do that.

The issue of rights to proper services is a theme reflected in many of the wishes. Similarly, many parents expressed concern about the attitudes of specialists and children about their child with a disability. Of course, this is not simply a problem of isolation - it is a statement about how our

society deals with disability. One parent was concerned about the expectations of specialists and she phrased her concerns in this way:

Therapists of all types who have more humane and realistic expectations for disabled children, e.g., who don't have over high expectations for children to perform at an age group level. Some of the things expected of my son even normal children can't do well. This high expectation of therapists adds more stress than necessary to parents of disabled children making them feel they are failing their child (a good many other parents of disabled children feel this way).

Access was an important wish for many parents - access to school, to programs for self-esteem and sport, access to adaptive technology. Some parents wanted shorter distances to travel, another wished for a small bus to get the children out of the school to extend their experiences and some parents wanted more camps. Many made suggestions about being able to borrow equipment to assist home programs. Some parents were concerned about the poor quality of communication by the professionals. One person recommended the introduction of a 1-800 (free) help line for parents. In terms of programs, wishes include more written materials, more varied programs, specific programs in keyboarding skills and programs for siblings of children with disabilities. Respite funding was another wish.

The predominant wish was for increased funding for a wide range of program-related purposes, for example, for more reading and computing equipment, for more personnel in the schools, for increased hours of integration and teaching assistance, for more and better trained special education teachers (a common theme even in North American studies, see Berkeley & Bull, 1995), and particularly for more teacher aides. A major ambition of many parents was to have improved support by the allied health specialists (Occupational therapist, physiotherapist, speech therapist). More staff, better trained staff, more experienced staff, staff who would stay to provide continuity, more hours of service, more programs, and more regular access without long waiting times. Training of teacher aides (again, reflected in North American studies, see Passaro, 1994) and teachers was another item which was high on parents' agenda. Better funding for training, more inservice programs for teachers, more time for teacher and aide inservice were some of the suggestions. As well, there was a concern that there were not sufficient special education trained teachers available.

One parent summed up her needs for the right teacher.

Firstly, in a one-teacher school that you are given experienced teachers. Not given a teacher one year out of uni to teach 7 grades and 24 children. Then the next teacher we are given is a secondary teacher who doesn't have primary experience and lacks communication skills. It shouldn't be that because we live in an isolated area, what's left will do. We still want a good education for our children. I wish for an experienced dedicated teacher capable of teaching in a one-teacher school.

#### Statistical Analysis of the Data

There are many ways to analyse these data. The first is to review the descriptive data provided above. This gives a comprehensive picture of the perceptions and realities of these parents. Another more rigorous approach is to subject the data to statistical analysis. Some of the more

important of these analyses will be described below before drawing conclusions and making recommendations.

The first examination of the data involved a factor analysis of the 18-item 'Perceptions' scale. Table 13 details the items to assist in reading the analysis that follows.

Before undertaking a factor analysis (Principal components), it was noted that items 9 and 10 showed a very large number of missing responses. The reason is obvious: virtually all of the respondents do not employ governesses, nor do their children attend school of the air. Items 9 and 10 were excluded from the factor analysis. After forcing an analysis with two user variables, the following factor solution emerged. In the main, both factors had sufficient content cohesion to permit treating them as one data set. One content 'outlier' included in factor two was item 13: "Your child has sufficient contact with peers to ensure that they develop appropriate skills". This item was included but is important to note that this item had the highest mean (3.73), indicating a strong degree of satisfaction. It is possible that this resulted from the high enrolment of children in schools, particularly smaller rural schools that probably have a more supportive social environment.

Table 13: The Parents' Scale showing Response Means in Descending Rank Order

(Highest rank shows greatest satisfaction)

#	Item	Means
11	Your child's disability was identified at an early stage	4.12
13	Your child has sufficient contact with peers to ensure they develop appropriate social skills	3.73
3	The education professionals servicing your child have been trained adequately	3.37
8	Teachers serving your child stay long enough to ensure program continuity	3.28
1	In general, your child's educational needs are being met adequately	3.23
12	Early intervention programs were provided at an appropriate time for your child	3.11
	Response means less than 3.0.*	
14	Your child does as well educationally as his/her counterparts in larger non- isolated schools	2.82
10	Distance Education (School of the Air - SOTA) programs meet the needs of your child adequately	2.81
15	As a parent of a child with disability, you receive sufficient advice from professionals	2.79
16	Inter-agency cooperation (Health, Education etc.) is effective	2.79
18	In general, being isolated does not disadvantage your child educationally	2.78
2	Adequate physical resources for program purposes have been made available by Government departments	2.71
4	There are sufficient speech therapists available for your child	2.33
17	Staff turnover of allied health therapists (speech, physio etc.) is not a problem for the continuity of programming for your child	2.33
6	There are sufficient physiotherapists available for your child	2.19
5	There are sufficient occupational therapists available for your child	2.17
7	The therapists provide services to your child with acceptable frequency	2.14
9	Governesses/home tutors are adequately trained to assist your child	2.05

Factor 1: Program Features (items 1, 2, 3, 8, 11, 12, 14, 18)
Factor 2: Professionals and Peers (items 4, 5, 6, 7, 13, 15, 16, 17)

<sup>\*</sup> the shadowed break is a cut-off point for the less satisfactory perceptions (< 3.0)

The factor 'Program Features' includes questions asking whether the child's needs have been met, whether the child is disadvantaged by virtue of the isolation, whether teachers stay and are adequately trained, and whether identification was early and intervention programs were implemented. Professionals and Peers relates to the availability and sufficiency of therapy services, inter-agency co-operation, staff turnover of therapists and whether the child has sufficient contact with peers. These two factors provide useful dependent variables to measure the reactions and evaluations of parents.

Two other sets of responses were also useful in assessing how the parents feel about being isolated and about the education of their child with a mild or moderate disability. The first was the scale which asked for their appraisal of the level of help their child needed (Table 14) and the questions which asked parents to assess how much of a problem being isolated caused them with regard to the educational development of their child (Table 15).

Table 14:

Parents' Reported Level of Help Required for their Child

#	Behaviour/activity
1	Self-help skills, e.g., dressing, eating, using the toilet etc.
2	Large motor activities, e.g., walking, running, catching and kicking a ball
3	Using language, e.g., understanding directions, communicating verbally
4	Social skills, e.g., greeting people, making friends
5	Self-control, e.g., is able to behave properly, accepts discipline
6	Ability to read
7	Ability to do arithmetic

Table 15:

Parents' Reports of Problems caused for the Educational Development of their Child because of Isolation

#	Behaviour/activity	
1	Self-help skills, e.g., dressing, eating, using the toilet etc.	
2	Large motor activities , e.g., walking, running, catching and kicking a ball	
3	Using language, e.g., understanding directions, communicating verbally	
4	Social skills, e.g., greeting people, making friends	
5	Self-control, e.g., is able to behave properly, accepts discipline	
6	Ability to read	
7	Ability to do arithmetic	

These aggregations of data provide five dependent variables for analysis. These variables will be called Total Evaluation (all items in Table 13 except 9 and 10), Program Features, Professionals and Peers, Children's Needs and Problems of Isolation. The independent measures selected to analyse these dependent variables are: distance from school; degree of disability; age of the child; and gender of the child. In terms of the statistic used, single factor analyses of variance were conducted for all the nominal variables (degree of disability; and gender of the child) while simple regression analyses were used for those variables which were continuous (distance from school; and age of the child).

#### Distance from the School

None of the regression analyses was significant for any of the dependent variables, that is, Total Evaluation ( $\underline{r}^2$ =.003), Program Features ( $\underline{r}^2$ =.021), Professionals and Peers ( $\underline{r}^2$ =.002), Children's Needs ( $\underline{r}^2$ =.049) and Problems of Isolation ( $\underline{r}^2$ =.001). These findings seem to reduce the impact of distance from school on the development of the children or on the quality of the programs provided to them.

#### Degree of Disability

A reasonable expectation would have been that the more severe the disability, the greater the impact of the isolation on the child's disability. Degree of disability did produce significant differences in terms of perception of services. For total impact of isolation on children's educational development, parents with children with moderate levels of disability reported a greater negative impact than those with children with mild disabilities ( $\underline{df} = 1$ , 102;  $\underline{p} = .0029$ ). A similar result was found for the factor Professionals and Peers ( $\underline{df} = 1$ , 103;  $\underline{p} = .0072$ ). Clearly, parents with children with moderate disabilities are concerned about the availability and continuity of therapists. In terms of Program Features, there was no significant difference ( $\underline{df} = 1$ , 102;  $\underline{p} = .1933$ ).

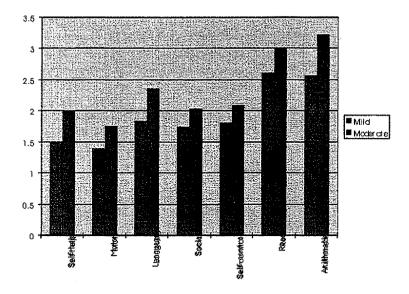
For the children's needs and the problems caused by the isolation in terms of impact on the child's educational development parents with children with a moderate degree of disability reported an expected greater adverse effect of isolation. For the child's needs, the results were:  $\chi_{mild} = 1.913$ , N = 46,  $\chi_{Moderate} = 2.330$ , N = 64,  $\chi_{Moderate} = 2.330$ , N = 64,  $\chi_{mild} = 1.105$ , p = <.0001. For the problems that isolation cause by degree of disability, the results were: :  $\chi_{mild} = 1.597$ , N = 45,  $\chi_{Moderate} = 2.040$ , N = 62,  $\chi_{Moderate} = 1.105$ , p = .0006.

While it is expected that a more moderate disability might require more attention to the child's needs, it is also interesting that the degree of disability increases the impact of isolation on the child's educational development. To make this finding more graphic, the following two charts (Figures 1 and 2) display the means for each group for both dependent variables.

A four-point scale was used in the questionnaire. The lowest point (1) had an anchor of 'Needs no help', while point 2 was 'Needs a little help', point 3 was 'Needs a lot of help' and the final anchor was 'Unable to do it alone'. Obviously, the higher the mean, the greater the degree of dependency of the child.

As would be expected, children with a greater degree of disability would have greater support needs. In each of the questions, those children described as having a moderate degree of disability had higher support needs than those with a mild disability. The progression of support needs is also interesting. The lowest scores were for self-help skills (question 1), large motor activities (question 2), social skills (question 4) and self-control (question 5). While children with a moderate degree of disability had greater support needs in language and communication (question 3), both groups need considerable help with reading and arithmetic. Again, this is not a surprising result but it does point to an area where parents are reporting a higher level of support need for their children.

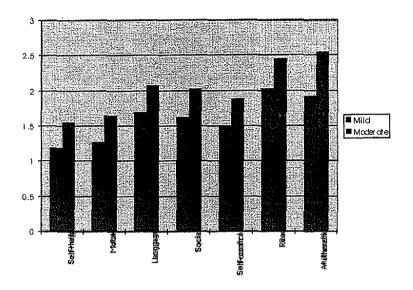
Figure 1: Comparison of the Needs of the Child Based on Degree of Disability



Of particular relevance to this study is parents' perception of the impact of geographical isolation on the educational development of their children. Figure 2 summarises the result for these seven questions. The items are the same as those described for Figure 1. The anchors in this case are: 1 - No problem; 2 - A small problem; 3 - A large problem; and, 4 - A very serious problem.

Given these descriptors, we can accept that any mean in excess of 2.00 is likely to be a problem that concerns the parents and requires some form of intervention. Those with a moderate degree of disability have the expected higher results but what is interesting is that the three areas of concern, language, reading and maths, are areas designated by these parents as being of great concern as a result of their isolation. This is not a surprising finding but it is an important result. One of the issues in the education of students with disabilities is the availability of experienced teachers to provide the level of curriculum support children with disabilities need. Besides level of support, children with disabilities need a greater frequency of services. It is quite likely that in these two areas isolation has its greatest impact on parents and their children with disabilities.

Figure 2: Comparison of the Problems Created by Isolation Based on Degree of Disability



# Age of the Child

None of the regression analyses was significant for any of the dependent variables, that is, Total Evaluation ( $\underline{r}^2 = .001$ ), Program Features ( $\underline{r}^2 = .001$ ), Professionals and Peers ( $\underline{r}^2 = .001$ ), Children's Needs ( $\underline{r}^2 = .006$ ) and Problems of Isolation ( $\underline{r}^2 = .001$ ). It would have been reasonable to assume that isolation might have caused more problems for younger children, particularly if parents were aware of the importance of early intervention.

#### Gender of the Child

None of the ANOVAs was significant for any of the dependent variables on the basis of the child's gender.

#### Conclusions and Recommendations

The foregoing information should have been interesting to persons who wanted to know something of the context in which isolated parents are working with their children with disabilities and it would have been helpful in understanding what it is that these parents feel and want. There are several areas that stand out when one is drawing conclusions and making recommendations.

In general, these parents are quite satisfied with most aspects of the education and development of their children.

While they might want a great deal more in terms of communication, educational programs, specialist assistance and educational instruction, they appear to be pleased with the quality of the programs provided.

Their major concern is for more regular contact with professionals of all kinds. Access is a continuing problem in the bush and parents of children with disabilities have great needs to meet with and be advised by professionals involved in their children's development.

4 It is clear that parents want significantly more teacher aide time. Teacher aides are vitally important personnel in helping to deliver educational services to children with disability. More time, better training and more specialised aides to facilitate integration and development are indicated.

The level of experience and training in special needs education are obvious problems for regular teachers in isolated areas. Assuming they have positive attitudes about working with children with disabilities, the regular teachers in isolated areas have an extra burden in that they too are distant from specialists who can help them and many teachers in regular education are inadequately trained in dealing with children with disabilities in regular classrooms.

There is a great need for more special education personnel for isolated parent to access. The special educators must also be experienced and well trained.

7 There are far too few experienced allied health professionals working and staying in isolated areas. The lack of continuity and inability to get to the specialists is a worry for many isolated parents.

Funding for equipment and programs is a major requirement for many isolated parents.

It is not only teachers who are the educators - parents are the primary educators for their children. Indeed, regardless of whether parents are the home tutors or are supporting education in local schools, they spend an enormous amount of time in an educative role. When one remembers that children in Australia go to school for six hours a day for 200 days per year, and when the calculations are done, one realises that children are in school for less than 14% of their year, then the notion of education outside of school becomes more important. But parents caring for their children with disabilities in isolated areas need more than educational information. They often need health, medical and developmental sources of information and support. Again, technology has the potential to be of great assistance in the bush. A simple example comes from researching the Internet. One site claims that they provide ongoing email support to all kinds of people on health issues and in the week preceding the search had sent 1.4 million advice emails to people inquiring from around the world. The British Medical Journal set up a site in April 1998 and they already have 40000 regular uses. Their site is rated in the top .05% of the world's seven million Internet sites. There are 'Virtual Hospitals' on the Internet.

In conclusion, this article provides basic audit data that should be a good start to more detailed investigations of some of the elements in the survey questionnaire. While the picture that emerges gives some cause for satisfaction, parents generally being happy with the education and development of their children, there are obvious areas for improvement. While it is difficult to get experienced teachers and health professionals to accept employment and stay in the bush, more must be done in terms of incentives. A parallel is occurring in medicine where, to attract doctors to rural areas, very generous inducements of elevated salaries, free car and housing and support for relief from duty are offered. In the interests of social justice for all children in Australia, politicians need to continue to support isolated and rural education generously.

In the longer term, we believe that the major means of improving access, communication and services without excessive travelling and expense on the part of isolated parents will be through emerging technology, particularly the Internet. The capacity to give instant feedback using web based learning programs, the opportunity to collect relevant information on aspects of children's development, the ability to receive social support through disability and parent support lists and chat lines, and the opportunity to use pc to pc closed circuit technology for 'telemedicine' and other 'tele' services are some of the ways the tyranny of distance can be ameliorated.

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Appendix A

# SURVEY OF SPECIAL EDUCATION PROVISIONS IN ISOLATED AREAS TO STUDENTS WITH MILD OR MODERATE DISABILITIES

### **QUESTIONNAIRE FOR PARENTS**

Dear Parents

This study, an initiative of the Australian Association of Special Education (AASE), is funded by the Department of Employment, Education and Training. AASE, an association for parents and professionals interested in service delivery to persons with disabilities, is very keen to obtain a national perspective on the extent and quality of service provision to students with mild or moderate disabilities living in isolated areas. There are two questionnaires - one for parents and the other for educational service providers. This questionnaire is for parents. We are very interested in receiving your views and comments. The study is important because it will provide a national perspective and will provide information which can be used to inform policy and improve the quality of service delivery.

For the purposes of this study, isolation refers to living in an area which is very distant from services, in which travel to receive those services is extensive and/or expensive. The focus of the study is on isolated students whose disability requires an adapted or specialised instructional program and who would be categorised by professionals as having a mild or moderate disability. Please remember that if your child is severely or profoundly disabled, do not complete the questionnaire. Students may be in the age range 0-18 years, may not be attending school because they are too young, may be on distance education (correspondence, School of the Air etc) or may be attending a small isolated rural school of 2-3 teachers.

Please feel assured that your responses are anonymous and confidential. We will not reveal the identity of any of the participants of this study and the data will be reported such that no individual can be identified. All data will be retained by the investigators and will not be given to any other persons or organisations. If you would like to receive feedback on the study, complete and return the Request for Feedback sheet below.

Please return your completed questionnaire in the envelope provided to the address below. We look forward to hearing from you. Thank you for your assistance.

<u> Ieff Bailey</u>	<u>Diana du Plessis</u>

1 3 4 5	Your nearest town  Do you change your place of the pour of the pour sex:  Your sex:  The pour sex is a sex and the description.	of residence fre , please explain e Male	quently? Yes	No		
6 7	Your age in completed year Your role: Mother Guardian Other: Plea	Father	Grandmother	Grandfather		
8	Sex of your child	Female	Male			
9	Year of your child's birth					
10	Your child's age in complet	ed years:	*******			
11	Your child's disability can					
12						
13	The location(s) in which your c					
		Small Rural Sch				
	Distance Education	School of the A	\ir			
	Other: please specify					
14	Your child's education is pr		Catholic Educatio			
	State Department of E Independent School		: please specify			
15	Please tick professionals cu	mently providi	no a program for vo	eur child:		
	Regular teacher	Special	Education	Psychologist		
	regular toucher	Teacher	2,72,74	1 Sychologist		
	Speech Therapist		onal Therapist	Physiotherapist		
	Early Intervention	Other: P	lease specify			
	Daily Milciventuon	Cure, I	cuse opecial			
	Teacher	Odder, 1	ease special initial			
16	Teacher  Do you employ a home tui	or for your chil	d? Yes	No		
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21 Does your child receive a special program 22 If the answer was "NO" please give reason			No			
23 Compared to other children of you				r to have any		
disability, please rate the level of help your c	hild need	s. Circle on	ily ONE 'x' for	r each item.		
# Behaviour/activity	Needs	Needs a	Needs a lot	Unable to do		
	no help	little help	of help	it alone		
1 Self-help skills, eg., dressing, eating, using the toilet etc	<u> </u>	0		0		
2 Large motor activities , eg., walking, running, catching and kicking a ball	0	Q	ם	0		
3 Using language, eg., understanding directions, communicating verbally	Q	Q	0			
4 Social skills, eg., greeting people, making friends	0	Q	Q	0		
5 Self-control, eg., is able to behave properly, accepts discipline	O.	Q	0			
6 Ability to read	a	ū	0	o l		
7 Ability to do arithmetic	ū	Q		Q		
Now rate how much of a problem be educational development of your child Circle only ONE 'x' for each item.	d in the ar			regard to the		
# Behaviour/activity	No problem	A small problem	A large problem	A very seriou problem		
1 Self-help skills, eg., dressing, eating, using the toilet etc	ā	a	q	ā		
2 Large motor activities, eg., walking, running, catching and kicking a ball	0	Q	Q	Q		
3 Using language, eg., understanding directions, communicating verbally	<u> </u>	G	O .	Q		
4 Social skills, eg., greeting people, making friends	0	0	a	Q		
5 Self-control, eg., is able to behave properly, accepts discipline	Q	0	ū	Q		
6 Ability to read	ū	<u> </u>	Q	0		
7 Ability to do arithmetic	<u> </u>	0	<u>q</u>	O		
25 If your child is receiving special progressive source the type of funding:  26 Do you get a special allowance(s) to he yes No	lp with y	our child's	education exp			
<ul> <li>27 If you do get a special allowance, plea which you receive assistance:</li> <li>28 Please indicate where you feel your ch</li> </ul>			_			
Please indicate where you feel your child is not receiving adequate services/programs:  If you had a wish list to improve services to students with disabilities in isolated areas, what would you put on that wish list. Please write your wish list below.						
you put on the water from a source willing	,					

Parents' Perceptions of the Impact of Geographical Isolation on the Delivery of Educational Services to Students with Mild-Moderate Disabilities

This part of the questionnaire seeks your responses on a five point scale from Strongly Disagree (SD) to Strongly Agree SA). There are two additional columns that you may use: No Opinion (you do not have the experience to answer the question) and Not Applicable - N/A - (the question is not relevant to you). The references in the items to 'your child' refer to your own child with a mild or moderate disability living in a geographically isolated situation.

#	Item	N/A	No Opinion	SD				SA
1	In general, your child's educational needs are being met adequately	0	a	ū	0	a	٥	ū
2	Adequate physical resources for program purposes have been made available by Government departments	<u> </u>	ū	a	۵	<u> </u>	a	۵
3	The education professionals servicing your child have been trained adequately	a	0	σ		a	Q	0
4	There are sufficient speech therapists available for your child	O .	0	O.	Q	<b>a</b> .	<u> </u>	0
5	There are sufficient occupational therapists available for your child	a	a	a	Q	0	ū	a
6	There are sufficient physiotherapists available for your child	a	0	a	0	0	ū	
7	The therapists provide services to your child with acceptable frequency	a	a i	a	Q	O	۵	0
8	Teachers serving your child stay long enough to ensure program continuity	O.	0	ū	O	a	Q	٥
9	Governesses/home tutors are adequately trained to assist your child	0	0	0	0	a	Q	a
10	Distance Education (SOTA) programs meet the needs of your child adequately	0	0	Q.	a	a	ū	a l
11	Your child's disability was identified at an early stage	Q	a l	۵	O	۵	a	0
12	Early intervention programs were provided at an appropriate time for your child	a	a	a	۵	0	Q	٦
13	Your child has sufficient contact with peers to ensure they develop appropriate social skills	0	0	۵	0	ū	۵	
14	Your child does as well educationally as his/her counterparts in larger non-isolated schools	a	a	ū	O.	a	۵	a
15	As a parent of a child with disability, you receive sufficient advice from professionals	0	O.	a	a	0	ū	a
16	Inter-agency cooperation (Health, Education etc) is effective	0	0	a	ū	Ö	0	
17	Staff turnover of allied health therapists (speech, physio etc) is not a problem for the continuity of programming for your child	Q	0	ū	a	a	٥	0
18	In general, being isolated does not disadvantage your child educationally	0	0	0	a	ū	a	9

Thank you for taking the time to complete the questionnaire.