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Māori Perspectives of Autistic Spectrum Disorder

Report to the Ministry of Education

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MĀTAURANGA MĀORI

WĀHANGA MAHI RANGAHAU

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Māori Perspectives of Autistic Spectrum Disorder

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Te Kunenga
ki Pūrehuroa



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Abstract

The purpose of this study was to investigate Māori perspectives of Autistic Spectrum Disorders (ASD). This was done by consulting with the parents and whānau of 19 Māori children with ASD. In face-to-face interviews, people shared stories of raising their children. They noted what had been both helpful and unhelpful and offered suggestions for how services could be improved in the future. While parents described many people, services and strategies that had been helpful over the years, they also outlined numerous barriers they had experienced including delays in diagnosis; disbelief and detrimental attitudes; lack of information, services, funding and qualified personnel; difficulty accessing services; assessment, organisational, system and procedural hassles; and financial strain. Suggestions for overcoming barriers included an increase in the provision of culturally appropriate, effective assessment, teaching and ASD-related services. A need for professionals to improve their understanding of ASD and Māoritanga was also identified. In addition, the research revealed that Māori children with ASD were being “culturally disadvantaged” in that the nature of this disorder limited their involvement in culturally valued processes and activities.

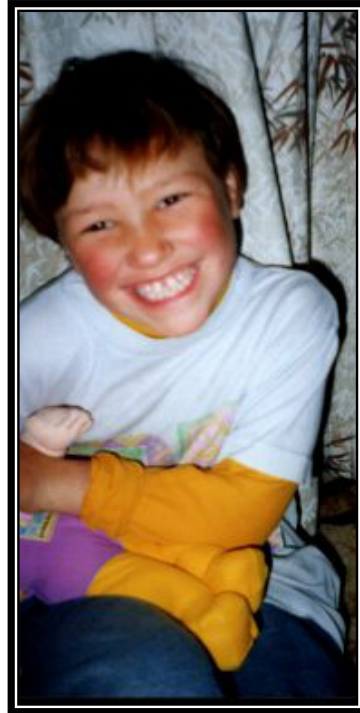
KEY WORDS

Māori, Special Needs, Autistic Spectrum Disorders (ASD), Autism, Asperger Syndrome, Culturally Appropriate Programmes and Service Provision.

DEDICATION

This report is dedicated to Waimirirangi Parker and her whānau.

He whakamaharatanga ki a Waimirirangi



He māngina te whakamaetanga

He mutunga kore te arohanui

Difficulties and pain are but fleeting

Great love is without end.

ACKNOWLEDGEMENT

I would like to personally thank and acknowledge the parents, whānau and children who participated in this study. I cannot adequately express how grateful I am that you opened your lives and hearts to me nor how moved I am by the stories you shared. The challenges of raising children with ASD are immense and it is difficult for people who have not lived through these experiences to truly understand them. However, you have provided a glimpse of what is involved – of the joys and sorrows, laughter and tears and I thank you for sharing this with me and others.

I also do not have words to express the admiration I feel towards you. The parental involvement and commitment to providing the best for your tamariki under often very trying circumstances, your expertise and your aroha are all remarkable – I salute you! My dream is that this research will in some small way contribute to future improvements to education and services for both Māori and tauīwi children with ASD. If this happens, know that your contribution was vital.

Ko koe ki tena, ko ahau ki tenei kiwai o te kete

With you at that and me at this handle of the basket

Seventeen whānau contributed to this study. While information within the report uses fictitious names to preserve the anonymity of individual comments, the following people opted for their participation to be acknowledged:

Sharon Pawson
The Potini Whanau
Mereti Taipana
The Te Rangi Whanau
The Wallace Whanau
Cathleen and Matiu Whiting

Executive Summary

This research investigated Māori perspectives of Autistic Spectrum Disorder (ASD). After gaining ethical approval for the study, an Advisory Group was consulted about appropriate questions and processes. Prospective participants were identified by paediatricians, Group Special Education (GSE) staff and the researcher's own networks. All those contacted agreed to participate and subsequently face-to-face interviews were conducted with the parents and whānau of 19 Māori children with ASD. People were asked to share their experiences of raising their children, to comment on what had been helpful and unhelpful over the years and to make suggestions for future improvements to services. Participants all lived in the central and lower North Island region. The children involved included five preschoolers, nine primary school children and five who attended secondary school.

The majority of parents became aware that their children had difficulties prior to age two. However actual diagnosis of ASD or ASD tendencies did not come until some time later due to a range of factors including: the difficulty in identifying ASD in young children; a cautious “wait and see” attitude amongst medical personnel; their long waiting lists; disbelief of parents; the existence of other disabilities or medical conditions; initial inaccurate diagnosis; and delays caused by “red tape” and rural location.

Parents' experiences at diagnosis varied from no help and information at all to informative explanations and support. The written information given at diagnosis varied in its usefulness. There was strong support for having a person visit parents, sit down with them to explain what ASD was, what services and entitlements were available and to assist them in obtaining these.

The concept of ASD that was described and discussed by parents was the generally accepted triad of impairments, heavily influenced by the medical model. Knowledge of ASD varied amongst parents, however most had a good understanding and six were considered to be experts. These people had attended conferences, read widely, sought out relevant research and were active members of various parent organisations. The world wide web played a major role in informing parents and was used by 11 out of 17 families.

Parents varied in their desire for cultural input into their child's education and service provision. This ranged from substantial input to nothing at all. Not surprisingly those parents whose children were in total immersion or bilingual education were the staunchest supporters of cultural input. Nonetheless, with the exception of two parents, all wanted the inclusion of some degree of cultural content. Impairments associated with ASD were identified as hindering children's involvement in cultural activities such as kapa haka, learning te reo and staying on the marae. Children were also disadvantaged because of difficulties experienced in culturally valued behaviours and practices such as group activities and whakawhanaungatanga.

Māori-medium education and Māori services were seen to hold both advantages and disadvantages for children with ASD. On one hand, the cultural content, wairua and inclusive, supportive attitude of staff and children in educational facilities and the friendly, approachable style of Māori service providers were seen as beneficial. On the other hand, there was considerable concern about the lack of ASD expertise amongst some Māori staff and service providers. Parents expressed a wish for more culturally appropriate assessment measures and procedures and for more Māori services, service providers and professionals.

Parents from ten families either had been or still were members of parent organisations. Reasons for limited or non-involvement were generally of a practical nature. There was some support for specifically Māori groups which involved whānau, fun and informative activities and operated according to Māori kawa.

Considerable variation existed in the degree to which parents received whānau support. This ranged from 24/7 help to none at all. It was quite typical for support to vary within whānau. Also typical was a general lack of understanding of ASD amongst whānau members. Siblings were reported to be helpful, protective, embarrassed, annoyed and sometimes “left out” as a result of having a brother or sister with ASD.

Parents described a wide range of helpful people and services. At a personal level many medical, educational, special educational and support service staff had provided outstanding support and assistance over the years. Other parents of children with ASD were also praised for their help and knowledge of available resources, services and entitlements. Strategies that had proved particularly helpful were: careful preparation and transition activities; visual strategies; firmness and perseverance; activities involving music and rhythm; computer use; one-on-one assistance; social stories; and explanatory class and school visits. Respite care was also mentioned as a service that was much appreciated.

On the other hand, parents also described a variety of barriers they had encountered. These included: a shortage of information, services, funding and qualified personnel; difficulty accessing services; assessment, organisational, system and procedural hassles; financial strain; personal and family stress; detrimental attitudes of professionals and society in general; and a lack of knowledge of ASD amongst professionals leading to inappropriate, ineffective programmes and provisions and incorrect decisions.

Typical of children with ASD, those in the study had difficulty developing social relationships and learning appropriate social skills. A number of strategies were being used both at school and at home to facilitate social development. Some of these were: the formal teaching of social language and skills; buddy systems; involving other children in therapies; community experiences; providing opportunities for socialization with family and friends through outings, visits and family gatherings; and fostering an interest and involvement in sports, games and other recreational activities. Parents’ dreams for their children’s future were for them to be happy and to live as independently as possible.

The research revealed a pressing need to:

- increase the number of personnel in existing services and expand provisions for parents, whānau and children with ASD to ensure they have readily available, on-going assessment, information, assistance and support;
- increase ASD-related, financial assistance available to parents;
- reduce the “red tape” involved in accessing relevant services and develop user-friendly, culturally appropriate administrative and funding procedures;
- adopt friendly, personal approaches to service provision which include providing information to parents, assisting them to access resources and entitlements, and supporting them during transition periods such as beginning, changing and leaving school.

- increase teachers' and other professionals' knowledge of ASD and Māoritanga to enable them to provide culturally appropriate, effective programmes and services;
- upskill personnel employed in existing Māori provisions and increase and expand these services;
- increase the bicultural and bilingual expertise of personnel in mainstream services;
- provide more ASD-friendly, safe, assessment and learning environments;
- financially assist parent organisations to enable them to effectively perform their dual function of informing and supporting parents;
- introduce media programmes to facilitate awareness and understanding of ASD and to improve detrimental attitudes amongst the general public;
- provide services and facilities for adults with ASD to enable them to live with dignity and as much independence as possible; and finally;
- listen to and be guided by parents.

Chapter One: Introduction

BACKGROUND TO THE RESEARCH

In 2002 the Ministry of Education (MoE) initiated a participatory action research project on effective educational practices for children with Autistic Spectrum Disorders. This project aimed to raise interest and awareness about children and young people with ASD and to investigate how their learning could be assisted. As part of this project it was considered important to gather Māori-relevant information. To this end one of the local project teams chosen was based at a kura kaupapa Māori. From the outset it became evident that there were cultural factors that influenced both the research questions and process and that these needed to be taken into consideration in the kura kaupapa Māori project. Sadly, in April 2003 the girl who was the focus of the Māori project died. As no appropriate replacement site was available it was proposed that alternative means of gaining Māori perspectives of ASD be sought. The mentor of the kura kaupapa Māori project was consulted about how this could best be achieved. She recommended that parents and whānau of Māori children with ASD be consulted to learn about their experiences of raising their children, to discover what had been both helpful and unhelpful over the years and to find out how services for their children could be improved in the future. Subsequently, she was commissioned by the Ministry of Education to conduct this research.

THE RESEARCH PROCESS

This research was conducted over a period of seven months from January to July 2004. Names of people willing to be interviewed were supplied by paediatricians and Group Special Education staff via the Ministry of Education. In addition, the researcher used her own networks to obtain the names of prospective participants. After approval was obtained from Massey University's Ethics Committee, invitations to participate and information sheets (Appendix A) were sent to all those identified. This was followed up by phone calls to further explain the nature and purpose of the research. Everyone contacted agreed to participate.

An Advisory Group was established to provide the researcher with guidance and feedback. Kahu Stirling, a respected kaumātua, member of Ngāti Porou Rūnanga, lecturer in special education and uncle of a child with autism was approached to lead the Advisory Group. Using whānau networks, two parents of Māori children with ASD were identified and invited to join. Fred Potini and Cathleen Whiting accepted this invitation.

The Advisory Group met to discuss possible research questions and to recommend an appropriate interview approach. They were not in favour of an interview format consisting of a series of questions but preferred a more user-friendly approach where people were invited to tell their stories of raising children with ASD. It was believed that this approach gave people the opportunity to share experiences and opinions meaningful to them. However, to ensure that a wide range of information was obtained it was suggested that an interview schedule/prompt sheet (Appendix B) be used. If important topics were not covered naturally in the course of the interviews, the researcher would pose questions relating to them. The two parents in the Advisory Group agreed to “pilot” the interview process and schedule. These trials showed that the recommended approach was a successful means of gathering information.

Research participants were asked to nominate an interview time and venue suitable to them. Fifteen interviews were conducted in people's own homes and two were held in the researcher's office. The length of interviews varied between one and five hours. Notes were taken in one interview, the remainder were taped. After being transcribed, the interview transcripts were returned to participants for verification, possible amendment and approval to include the information provided. Interview transcripts were then analysed, summarised and written up in a draft report. This report and/or a summary of key findings were given to research participants, Advisory Group members, Ministry of Education personnel and members of their ASD Advisory Group for consideration and comment. Based on the feedback received amendments were made and a final report submitted to the Ministry of Education in September, 2004. Copies of this report were also sent to all research participants.

THE PEOPLE INVOLVED

The 17 interviews involved parents and whānau of 19 children with ASD or ASD tendencies. (Two families had two children with ASD). In total 51 people were present during all or part of these interviews. This included 15 mothers, seven fathers, one grandmother, one friend, 14 siblings and 13 of the 19 children with ASD. Only one of these children (a 15 year old youth with Asperger Syndrome) took an active part in his family's interview. Similarly, while siblings contributed the occasional comment they did not participate to any great extent. Although 51 people were present in the interview situation, other family members contributed indirectly. In a number of cases participants specifically mentioned consulting with their partners and seeking their input prior to the interview.

Of the 51 people, five were Pākehā – the Pākehā partners of four Māori men and one Pākehā grandmother. Of the 17 families involved, 13 were two parent and four were single parent families. They were all presently located in the central and lower North Island region. However, as a number of families had shifted from other areas in Aotearoa/New Zealand, their experiences related to a much wider geographic area in both the North and South Islands. Participants lived in the city, suburbs and in rural locations.

THE CHILDREN AND THEIR EDUCATION

The 19 children involved were all diagnosed with ASD or ASD "tendencies". Children with mild, moderate and severe autism and Asperger Syndrome were included. In addition, a number of the children had other disabilities and medical conditions. They ranged in age from two to 19. Five were preschoolers, nine attended primary school and five were at secondary school.

The five children under five years of age were all attending fully integrated early childhood centres. Of the nine primary age children, six were in the mainstream, two were in special class/units and one child was being home-schooled. Three of the five secondary age children were in special units, one was in a residential special school and one was in the mainstream.

Four children had previously attended kōhanga reo, one was presently at a kura kaupapa Māori, one had previously been in a bilingual unit, while another child who had attended a kura kaupapa Māori was now in the rūmaki (immersion) unit of a secondary school. A further child who was in a special unit of a secondary school was also a valued member of the school's whānau class.

Chapter Two: Past Experiences, Present Understandings

THE RESULTS

From the outset a word of caution should be sounded. This report does not claim to represent “the Māori view of ASD”. Māori, like any other people, are a diverse group. They differ in lifestyle, beliefs, values, socio-economic circumstances, religious and tribal affiliation, geographic location, degree of acculturation and knowledge and practice of their Māori culture. Therefore, a single Māori viewpoint on ASD cannot exist. However, this report does contain the thoughts and experiences of 17 different Māori whānau. While their “stories” cannot be generalized to all Māori, they can enrich our understanding of what life is like for a number of Māori children with ASD, their parents and their whānau.

In reporting the information shared in interviews, parents’ quotes have been heavily relied upon. This approach has been adopted to ensure parents’ “voices” remain central and their experiences are not “summarised out”. Parents are the experts on their children and professionals need to listen carefully to what they are saying.

Using the ratio of positive to negative comments made by parents as a rough guide to their overall satisfaction with the health, education, care and support services received, a fairly even picture emerged in this research. Four parents were generally happy with the services they have received, four were generally unhappy and nine were “divided”, that is, they were very satisfied with some services and highly critical of others. The following chapters elaborate on this situation and provide parents’ descriptions of what went right, what went wrong and what improvements can be made.

THE EARLY YEARS - DIAGNOSIS

The great majority of parents knew that their children had some type of problem prior to the age of two. Prolonged crying or lack of crying and sounds; slow physical development; lack of mobility; reluctance to be held; no eye contact; tantrum throwing; sleeplessness; unusual mannerisms; and making little or no effort to communicate, play with toys or interact with others were all frequently mentioned causes of concern that prompted early visits to doctors. However, in most cases a diagnosis of autism or Asperger Syndrome did not come till a number of years later. In a few instances diagnoses are still inconclusive with children being deemed to have ASD “tendencies.” Children with Asperger Syndrome and those who have/had additional disabilities or medical conditions have taken the longest time to be diagnosed.

Reasons for the delay in diagnosis are many and varied:

1. Parents believed that the difficulty of diagnosing ASD at an early age and a reluctance to prematurely “label” children led many medical personnel to take a cautious “let’s wait and see” approach.
2. For children with additional disabilities or medical conditions their ASD symptoms were attributed to pre-existing conditions, earlier medical problems or where no pre-existing conditions were identified, the existence of dual/multiple disabilities complicated the diagnostic process.

3. Parents reported being labeled “over-protective” or “neurotic” and their concerns not being taken seriously. When one mother took her son to the doctor because she was concerned about his lack of speech, “The doctor brushed it off and said, ‘maybe he’s got nothing to say!’” Another mother reported:

It took 15 months to get a diagnosis for Manu and during that whole 15 months they just kept saying, “No, he’s OK, he’ll catch up, he’s normal,” but he’s not, he’s not normal. As soon as you say this it’s like, “I can’t hear you.” He was just not doing things that my two year old son was doing...with kids like ours it’s kind of, “You’re neurotic” until they get diagnosed and then they bend over backwards.

4. An initial inaccurate diagnosis was a further reason for delays. For example two children were diagnosed as deaf. A parent relates this experience:

We were quick to put hearing aids on him but we knew there wasn’t something right about it. We knew it wasn’t [deafness]— my description that I used to say was that Raymond was in a glass dome, and he is on one side and we were on the other, and we just couldn’t communicate. But, we knew that he was totally able to, but just unable to get out. We knew he could hear, but it was like he was shutting us out. And, I kept saying that to him, “It is like you are shutting us out.” But, they put hearing aids on him, which he didn’t want to have anything to do with. We started learning sign language and started to teach him sign language.

... They told us his hearing would never get better, then all of a sudden they discovered that his hearing was getting better ... but in the meantime they were traumatising this kid, and they weren’t listening to us, and I think if anybody knows him better than anyone else, it is us.

5. Delays in diagnosis were also caused by long waiting lists to see medical personnel, “getting through all the red tape” and the rural location of some families. For example one mother noted that the paediatrician came to her country town once a month but because the waiting list to see the paediatrician was so long, it took approximately two years before her son was seen. However, it was reported by some parents that when they eventually were seen, a diagnosis was given reasonably quickly.

It is of interest that in three cases parents reported the onset of ASD occurred within days of receiving a vaccination. In each instance the child seemed to be developing normally up until vaccination. The following stories told by two different parents are strikingly similar:

He did develop normally until not long after his sister was born. Probably at about 18 or 19 months, he stopped talking. He used to say about eight words and then he stopped talking and stopped looking at me, eye contact was gone... In about three days [after having the vaccine] he stopped talking and he was squawking. He hadn’t been sick. They say that it’s quite normal for autistic children to do that. I don’t understand how that would happen.

We went through to Tauranga for my brother’s wedding when he was eight months old. He was looking at the camera, he was gorgeous, a normal happy little baby. Then two weeks later I had him vaccinated, and although everybody assured me at the time that it had nothing to do with the vaccination, and that the vaccinations were safe ... it seemed a very strong coincidence that he’d stopped smiling. He was eight and a half months at

that stage, that was within the same week as the vaccination and we put it down to him not being well or he might have a cold or earache. Then I noticed that he stopped looking at us at the dinner table and stopped following the conversation. It was within two weeks that he was totally disinterested in people and things around him. Within a month he was getting more and more withdrawn... I phoned the Plunket nurse and said, "I think there is something wrong with him," and she had a checklist and asked me what he was doing, and there was "No" to 18 out of the 20 questions. Like the looking, showing him pictures, no interest in anything. You couldn't show him the dog or something outside. Prior to that he was very alert and interested. She said, "Go to the doctor, use your mother's intuition and keep pushing." I went to the GP and he told us it was definitely not autism.

Delays in diagnosis understandably caused great frustration to parents. They were anxious to learn exactly what was wrong with their child and to have some assistance and guidance in helping them. Many felt unbelievably, unlistened to and unsupported. One couple told of "rushing off and doing parenting courses" as they felt sure they must have been doing something wrong for their child to be behaving as he did. Others talked of periods of depression, confusion, sleeplessness and anxiety. Another point raised by one parent who waited years for a diagnosis was that for this time she was denied the child disability allowance which would have been helpful given the extra financial demands of raising a child with ASD.

On receiving a diagnosis parents reported being devastated, sad, bewildered, unbelieving, frightened and/or relieved to have finally got an explanation for their child's behaviour.

Only one parent reported having knowledge of ASD prior to diagnosis or to their search for a diagnosis. This parent had a family member with ASD and as a result she had read a book on the subject. One other parent reported having a relative with autism but as he had died at a young age she had not developed her understanding in this area. The same parent reported being thoroughly confused with the diagnosis she received for her own son. Letters sent to her appeared to contain conflicting information:

I got a letter and I actually looked at it and it said, "Diagnosis: Autism," and some of them would say, "Global developmental delay," and some would say, "Behaviour problems,"... So, I actually went to Doctor Jones down here and said, "Look, what is his diagnosis?" and he said, "Autism," and I said, "Well, I have got all these letters and some say behaviour issues, some say...what is wrong with him? You tell me his full diagnosis" and he said, "Mild autism, global developmental delay and behaviour problems."

Five parents mentioned that they were not given any explanation or information about ASD when their child was diagnosed. One mother related how after being told her son had definite autistic characteristics, the paediatrician commented that he would not need to see her again because her son had no physical problems. "When I said to him, 'what can we do?' he said, 'Basically, there's nothing you can do for autism.'" However, she added that she had since changed paediatricians and that the new person has a particular interest in ASD, "Kids do stay on the books now. You are not automatically dropped like we were."

On the contrary, two parents reported that paediatricians had provided helpful explanations of autism when their children were diagnosed. A further six parents mentioned that on diagnosis they had been

provided with pamphlets, books and contact details of supporting organisations. However, this information varied in its usefulness:

I was sent a two page booklet in the mail but it really didn't tell me a lot about it.

...He [the medical professional] said to me, "You can read books and books about it but the best way to learn is just as you go along each day" and he told me, "All kids are different, all autism cases are different."

I think we might have got some pamphlets but it was like reading in a foreign language. It wasn't stuff that told us much because we didn't understand ...I'm sure they tried their best.

It was helpful. The SES [Specialist Education Services] gave me some pamphlets as well about the same time and it was really informative.

They gave us a lot of written information ...and there was so much to read about it. You can't take it all in, it is too much. It was enough to give you autism! It was so technical, you couldn't understand it.

This parent remarked that she would have really liked to have had a good talk with someone who knew all about autism. She added that taped information would also have been helpful. In a similar vein another mother said that a Directory of contacts and services would be useful:

As long as it is not too wordy, because I think when you initially get diagnosed you get a million things thrown at you, and which all just goes "arrgghhh." I guess for me I would have liked to have had someone come along and make me a cup of tea, and say to me, "Look," and then have your little booklet. Because I think we are great orators, we love our kai and we love to talk.

Interviewer: So it is a Māori process?

Exactly. Yes, I really wouldn't want a book given to me, "Here you go," because I have had enough stuff thrown at me. Whereas it is somebody to come along and ... just to sit with me and really to have a physical support... I think there needs to be something, some physical – somebody.

Interviewer: That can touch base?

For sure, yes, just touch base. Because, there is a huge process that goes with a diagnosis – the family has to go through a grieving process, you have to go through the self blame, you know all of that stuff, and so I think it is hard enough without being thrown into this system, that really doesn't want you to be there anywhere, because it certainly doesn't welcome you.

PRESENT UNDERSTANDING OF ASD

Parents varied in their present understanding of ASD. The least understanding was exhibited amongst parents whose children's diagnoses were inconclusive. However, most parents had a good understanding. Over the years they had learnt through raising their children, talking to medical professionals, teachers and other parents and through reading relevant material. The concept of ASD

that was described and discussed was the generally accepted triad of impairments. Understanding was very influenced by the medical model.¹

Six parents are considered by the researcher to be “experts” on ASD. These parents have attended conferences, watched videos, read widely, met and talked with international experts, they are/were active members of support organisations such as Parent-to-Parent and Autism New Zealand, and have used the internet to locate relevant, up-to-date information and research on ASD. Their attitude and approach is typified by this comment:

I was floored by it, and I have my crying days and I think, “How am I going to handle this?” But then, I thought, “No okay, my baby needs help I better go and find out what this means,” because I didn’t know. So, I got pro-active, and I have got friends and family that have got the Internet, so I said, “Get me all the stuff you can.” And, they came home with pages, a lot of them, and I got in contact with the Autism Association, and I said, “Look, I want as much information as you can give me – updated stuff” and I just started reading. And, that is basically where I learnt.

THE WORLD WIDE WEB

The world wide web was identified as playing a major role in informing parents. Eleven out of 17 parents specifically mentioned using the internet to locate information. One parent located the latest research on the effectiveness of various drugs and used the information gained to question her son’s treatment and suggest the use of a different drug – a suggestion that was reluctantly acted upon and proved successful. Two parents log on to the Cloud 9 chat room to talk with New Zealand parents of children with ASD while another uses Oasis, (a web site set up by a parent of a child with Asperger Syndrome) to chat with parents from around the world. She noted that she has gained some really helpful answers to her questions posed in the Oasis chat room and has been able to keep abreast of the latest and on-going research which is regularly posted on the site. A fourth parent used the net to investigate the special needs facilities in an overseas city they were shifting to. While a fifth parent, “Spent many an hour on the computer” and used other resources to prepare a case to present to her paediatrician. She believed her son had Asperger Syndrome and amassed ample documentation to support her opinion. After waiting a long time for an appointment she went armed with this “evidence” but found the 10 minute session was not long enough for the doctor to look at her son let alone discuss her background research!

Although providing a useful source of information, the world wide web was viewed as a mixed blessing.

There’s so much stuff on there, you don’t know what to believe. They all say different things. It’s confusing.

We were going hard out [using the net] for a while. Once again, we were overloaded and there are not enough pictures for me!

However, the worst scenario was related by a mother who used the URL provided to her by a medical professional to search for information on Rett Syndrome. She was contacted by someone from the University-run site and asked whether she was interested in donating her daughter’s body

¹ The triad of impairments refers to difficulties related to social interaction, social communication and imagination. The medical model, in this instance, refers to the belief that ASD results from a deficit “within” the child which requires medical diagnosis and confirmation.

for research when she died. Although the person who provided the URL could not possibly have foreseen this situation, he was most apologetic when the mother reported it to him. This story illustrates that the quest to gain knowledge and understanding of their child's ASD can often be an emotionally fraught, confusing journey for parents. As another mother explained:

Doctors tell you all sorts of things, you don't remember it anyway. [We have learnt through books but] books can be really scary. A woman I know who has got a child like mine, got a whole lot of books out of the library and spent the whole weekend crying just reading them. They made her feel like it was hopeless. You have to learn it from books and reading about it. Then there are all these people that say it can be diet that has something to do with it and the paediatrician is saying, "No, it's genetic." You're never really sure. No one will tell you where you're going, what's at the end for you, they never say that cos they can't with autism - the children change. They could probably give you a general idea but they mightn't if it's not good in case you feel that it is a waste of time.

To summarise, in general parents were aware that their children had difficulties from an early age but for a variety of reasons diagnosis was often delayed. Explanations provided at this time varied from very helpful to nothing at all. Only one parent had prior knowledge of ASD. However, understanding had developed through their experiences of raising their children, talking to medical personnel and teachers, reading and, for many families, consulting the world wide web.

Chapter Three: Cultural Issues

A range of opinions, issues and recommendations specifically related to Māori culture arose in discussion with parents.

CULTURAL INPUT INTO CHILDREN'S EDUCATION AND SERVICE PROVISION

Parents varied in their desire for cultural input into their child's education and service provision. This ranged from substantial input to nothing at all. Not surprisingly those parents whose children were in total immersion or bilingual education were the staunchest supporters of cultural input. However, with the exception of two parents, all wanted the inclusion of some degree of cultural content. Of the two parents who did not want cultural input, one explained that they were not particularly interested in things Māori while the other noted that family members could provide the cultural input that was needed.

Obviously children who had been/were involved in Māori-medium education had the greatest cultural input into their special education programme. However there were a few mainstream schools that were doing an admirable job in this respect. One example is described by a father whose daughter was in a special unit at college and was also a member of that school's whānau class. He explains:

I always wanted her to be exposed to as much Māoritanga as possible, and we try to do that at home ... and she has had a lot of exposure in her family life, but at Leyton College they have been excellent. She is in TRK – Te Roto Kaupapa Māori has been her whānau group, always has been. They are really supportive of her there. They have karakia, and she has her turn at saying karakia, when she goes to whānau time. She has never been a part of the kapa haka group, but she didn't want to, or it didn't appear to me as if she wanted to be up there in the group as such. On Thursdays, for instance, is when they have the cultural day, third period, and for years someone from the Special Unit used to go with her and she used to sit there and watch them, and in the last few years she just takes herself over there and does it. She has been into Manu Kōrero... Anything that we would have liked her to be involved in she has been involved in. There is about two or three initiatives that are part of TRK, and they [children with special needs] participate as fully as they are able to.

At the other end of the continuum a few schools were providing no cultural input at all.

KAPA HAKA

Involvement in kapa haka was mentioned by eight parents. Participation in this activity was hindered for a number of organisational and ASD-related reasons. For example, at one school James was prevented from joining kapa haka because it was only available to children in the bilingual class. However when his mother mentioned in an IEP meeting that he performed kapa haka in front of the TV at home and that she would like him to participate at school, the teachers said this could be arranged. They commented, "What a good idea, maybe he can let his frustrations out in there." Another mother of a young musical child was keen for her daughter to begin kapa haka as she saw it as, "a means of encouraging communication and socialization."

One boy with Asperger Syndrome loved kapa haka but couldn't cope with it, "because of the noise of all the kids, it was too much and too many people, it used to make him seizure." He did perform wearing ear plugs on occasions and now, as an accomplished guitarist, he accompanies his college kapa haka group.

Another child also had problems with kapa haka noise. His father explains:

Hone used to find it noisy every now and then especially with the haka but I think he enjoyed being with the kids a lot more than he didn't like the noise so it was a bit different to earlier stages with similar experiences where the noise would be such that he just wanted to be out of the room. But because he enjoyed the kapa haka and he liked the kids, he didn't like the noise but he would tolerate it a whole lot more... Kapa haka is one thing that he used to love doing when he was in the bilingual class. He was not very good at it, he sings like his Mum! But he used to love doing it and the kids used to be happy with him up there as well and they'd perform and the girls would be in their lines and the boys would be in their lines and Hone would wander around, stand by the girls and sing, have a play with the poi, go over here, go over there, but the rest of the performers would carry on as normal and the kids were quite used to it and quite happy. When they performed in front of the rest of the school, the rest of the school got to know him as well so they didn't think much about it. The ones who were more concerned about that sort of thing were probably the teachers who were watching which was a shame because he used to love doing it.

Hone no longer participates in kapa haka at school because he has moved from the bilingual class although he has other opportunities available to him:

He knows his kapa haka, he comes to kapa haka with me quite a lot, same as his sister although they don't so much train with us. What kids do is run around while their parents are doing the kapa haka and on the way home you'd hear them in the back singing all the songs and so he knows his kapa haka and he knows what to do. He'll do it when he wants to.

Another child's problem was not the kapa haka noise but the "hype" associated with performing. His mother explained:

He was in the kapa haka – over exuberant ... I had to take him out, calm him down cos they were kinda losing the plot with the rest of the group. They were getting out of sync because of Raymond and a few of his little mates [with special needs.]... They just take him out for a little while and then bring him back in.

One mother whose child was at a residential special school noted:

They try, when they get something from the Māori community like maybe Queen Vic have kapa haka, they try to see if they can take their children along and I know they are doing it specially for Moana. The houses do it – social time for the kids.

TE REO MĀORI

The inclusion of te reo Māori was mentioned by eight parents. The main issue raised was that although parents would like their children to learn to speak Māori, they were concerned that because they had communication problems, learning a second language might prove too confusing.

Being bilingual may be challenging when communication is a major problem

I'm trying to get him to learn to talk and if I try to bring the Māori culture into it now, the language, I'm going to confuse the heck out of him and me.

Because Duncan has not long been verbal I have actually kept away from using any other languages aside from English but now we are starting to introduce, "Sit there" and "Go" and "Haere mai Duncan" and he was like ??!!! We are putting in more.

Because Reti had problems with his speech we decided to go mainstream [as opposed to bilingual class] to get his speech up.

However Reti's mum also noted:

He has got a Māori teacher and he uses a lot of Māori – just basics – e tū and Reti has actually been bringing it home with him and that is when I sat back and thought, "Yes, kids do pick up a talent now and then and when they do you actually notice it." Yes, he has been using it a lot.

One mother who was not enthusiastic about cultural content in her son's education did mention that she "would like him to speak a bit of Māori." While another chose not to put her son in a bilingual class because:

My attitude is if I want my children to speak Māori I'll do it myself. I'm not paying for someone else to do it. There are enough in the family that can speak it.

An Asperger-related problem of a different nature was raised by one couple.

We still do speak quite a bit of Māori to the kids and I still remember one time at kindy when I was watching Karl looking at the fish tank and he was pointing to the fish and he was saying, "Ika, ika" and I still remember his kindy teacher thinking that he was just speaking garbage and trying to correct him saying, "No, it's a fish, it's a fish." He was right. As far as he knew, that's what it was because that's all we used to call it.

When he got funding from about four I think, we started getting a teacher aide for him and one of our stipulations was like, "Could you look further afield and find somebody that speaks Māori," because his language skills were very very limited until he was six but with that situation he does understand Māori and words that come out, you've got to be able to try and interpret it whether it's gibberish or English or Māori.

When he started school we had a book to write up in the front anything that happened at school to give us an idea and in the back I put the vocab of common Māori words that we used for them to be aware of and listen out for. Not everyone who's had him has tried but it hasn't been a natural thing for them. They've had to learn it.

STAYING ON THE MARAE

Two parents noted that having ASD impacted on noho marae. One mother explained:

The other thing is that the marae we stayed at had a really good kaumātua room...[The principal] had been down and sussed out the kaumātua room, because she knew, not only Arama, but some of the other kids, needed quiet times, somewhere quiet to go to, and so Arama wouldn't eat all of his meals with the kids. Usually by the end of the day he would go off to the kaumātua room by himself. He didn't want anybody with him at

that stage. He just needed to shut out noise and be by himself, and so we were able to accommodate that, it was cool.

Another example was recounted:

The autism side of that is like in the whare the babies are sleeping in there. You can't go in there because there are babies. With his sister there is no problem but with Pataka he just wants to go and see them so he'll just lie down beside them or on top of them. There are all these different things... When we went down New Year's day he was going shake hands, here clap my hands, and this was with a two month old baby!

However the same mother also noted:

I remember an instance very distinctly. We were going to his grandfather's tangi and we were getting welcomed on and a cousin and Pataka were playing, cos his dad's up the front all the time so I'm sitting with the kids and they were playing away. Hohepa will go to the front and he knows not to go any further. Pataka knows too but, "I'm having a game and I don't care about the rules." And he went running through, right up the front and he had this big apple, it was a rocking one. He went up and sits beside this kaumātua who was sitting on the paepae, gets quite comfortable, then he moves on to some one else and they don't all know Pataka and all I could see was this apple being thrown around!

Interviewer: But there was no problem with that?

No. there wasn't. They might all be going, "Who the heck is that?" But it was so funny and I just felt, "Oh well, we can't do anything about it!" Everyone works out later on who he is. Luckily an old aunty grabbed him before he got too close but there was that tolerance there. We went back to the marae two weeks ago and we're sitting in the hall having a meeting and the kids are coming in and out but because we were on our home marae and everyone there was our whānau, I could just relax and not be worried about him coming in and out or making a noise and coming up and asking me something because, like I said, everyone else there doesn't care, it's all part and parcel.

CULTURAL EXPECTATIONS

Staying on the marae, learning te reo, participating in kapa haka are just three culturally valued activities that are adversely affected by ASD. In addition, one mother pointed out a host of other ways Māori children with ASD can be culturally disadvantaged. She explained:

If you are looking at the education of Māori children with ASD it's important to know what the "cultural expectations" are, what we look for in our children. 1. Whakawhanaungatanga – knowing their family and connections, their whakapapa – where they belong. 2. Being able to socialise well anywhere. 3. Being able to communicate well in all ways – verbally, visually, socially, written, culturally in appropriate ways... 4. Good physical prowess, sporting ability and participation in competitive, team and individual sports. 5. Imagination in most things, being innovative. 6. Academic ability, achieving to the best of your ability. 7. Participation in cultural activities – hui, kapa haka, wānanga, kura, kōhanga reo etc. 8. Individual pursuits, being able to stand tall in your own rights 9. visual, kinaesthetic, aural, tactile, emotionally compatible learning styles. ASD children, especially moderate to severe, either classic autism or severe Asperger have "difficulties" in all these areas

except perhaps individual pursuits. An education approach therefore would have to take these factors into consideration because these are cultural expectations that most Māori are socialized into. How can these children be helped in these areas? How do they learn? What can they achieve if encouraged? Who would/should be involved in their education? Māori teacher aides? So when you work with Māori children and their whānau you need to know that most of the cultural expectations and givens are not met because ASD children have “deficits” (for want of a better word) in these areas. To develop these children is to go with what they have and work with them towards meeting “cultural needs.”

MEETING CULTURAL NEEDS

So how can these cultural needs be met? Some successful strategies have been mentioned in the preceding discussion and parents suggested others. For example, one mother suggested “whānau involvement to show children connections, whakapapa, belonging.”

Another mentioned the inclusion of taiaha lessons and noted that it could possibly have the same benefits that classical ballet had given her son. Certainly it has many similar ASD-friendly attributes including rhythm and unchanging routines. It was noted that taiaha lessons needed to be given by the right person in the right way and that because of safety issues, one-on-one teaching may be needed. Henare, the 15-year-old boy with Asperger Syndrome, remarked that he would be keen to learn the taiaha and that one-on-one teaching “would probably be better because it would be quicker and if I had to go with a group then sweet as but if I get one-on-one, then go for it!”

Another suggestion was to hold the child’s IEP meeting in their home rather than at the school:

I see a lot of IEPs happening at schools but they’re in the wrong environments. They don’t include everybody that’s around that child, that supports that child... You need to bring the whole whānau into it. It is probably the best thing you could possibly do. [I would have the IEP] in the home, where the child is safe, where they are happiest. I wouldn’t have them in schools. Schools are foreign environments and it puts the parents on the back foot all the time because it’s not their environment.

While not specifically a “cultural” consideration, one mother suggested that parents have the opportunity to talk to someone outside the school staff prior to the IEP meeting. She explained why this is needed for her:

We always seem to be pushed for time. I remember bringing up something and I got bogged down but if I talk just one-on-one I’m a lot better than talking in front of lots of people. If you could talk to a person prior then you’ve got somebody advocating with you rather than you trying to explain it. I get flustered in front of heaps of people.

Three parents mentioned the inclusion of karakia in their child’s education programme and one commented that the use of rongoā deserved investigation. It was noted that the environment must be physically, culturally and spiritually safe for the child. One suggestion for ensuring cultural and spiritual safety was for teachers to find out about the values, practices and priorities of the child’s family and then to incorporate these, where appropriate, into the school/centre programme.

One mother recommended a holistic approach to service provision which included not only academic work but also the development of life skills – “Learning by doing, by living it.” Also suggested was the inclusion of Māori myths as opposed to European folk tales because “they haven’t

got time to know all that. They can only know so much and understand so much.” Therefore, time would be better spent on Māori-relevant content.

It was noted by two mothers that although children with ASD were meant to be uncomfortable with touch and displays of affection, their particular children were not like that, in fact, one child “absolutely mauls you!” One of these mothers put her child’s “soft” nature down to having a “sensory diet” that included a “real strong emphasis” on touching and stroking.

THE EDUCATION OF CHILDREN WITH ASD IN MĀORI-MEDIUM SETTINGS

Four of the children had been/were presently involved in total immersion education and one had attended a bilingual class. Discussion with parents highlighted both benefits and disadvantages in this respect. A major benefit is the opportunity Māori-medium education provides for cultural and reo development. In addition to this, parents were strong in their praise of the inclusive, supportive environment provided and the awahi and aroha of staff and children alike. For example, one mother explained how supportive and protective the children at her daughter’s kura kaupapa Māori were. Her daughter spits when she talks and also spits at other children. “In the mainstream the kids would go ‘oooo germs!’ but in kura they just say, ‘hei aha’ and wipe the spit off themselves and Josephine.”

Similarly, parents of a child who had attended a bilingual class noted:

One thing is that all the kids that are in the kapa haka that were in his class in the bilingual classes in earlier years, I don’t know whether it’s a Māori thing or not but they get very protective of each other and we used to see that out of the classroom as well, even just down the street or in town. The older Māori kids, he ignores them but they’d be saying, “Kia ora Rihari” and talk to him and he’d be carrying on playing just like Asperger kids do, not really acknowledging anything but they’re still quite protective of him with other kids. That was one of the good things about him being involved with the bilingual class.

The inclusive philosophy of a kura kaupapa Māori is demonstrated in a parent’s story:

The environment was conducive to being included and accepted. I can remember when he was 11 ... we did this big trip up the mountain... It wasn’t until we were getting them down and we had them all at the bottom and I remember turning to Bernadette saying, “My God, look what we have just done.” Four of them, and Ameria, lifting her out of her wheelchair, Hone seizing all over the show because he was so excited, and each with an adult holding on tight, and Rawiri and Hepa who at the time had two legs in plaster because he had just had another operation for his club feet, and is severely Down Syndrome and deaf. They had a good time and we had two kids in wheelchairs and we did it. We sort of looked at each other and said, “That is what being inclusive is all about, thank God we didn’t have an accident” because I think I was Chairperson at the time! ... It was really noticeable when Hone hit High School that his socialisation was streets ahead of the kids that had been mainstreamed, and his ability to function academically was streets ahead of the kids who had mainstreamed because kura had always looked at the child holistically, still do, at every child, and had worked to meet his needs - teachers up-skilled themselves, we all fought like stink to get teacher aides and the right teacher aides for him, and it was a team effort, and it was hard work. But no, he would have fallen through the cracks ... had he been mainstreamed, what

happened for him could not happen outside of kura [kura kaupapa Māori] It was the philosophy, it was absolutely the tikanga thing, the whanaungatanga, manaakitanga, absolutely, and it made a hell of a difference.

However, a down side of Māori-medium education was also mentioned by three parents. One father noted that the staff at his daughter's kōhanga reo had little special education knowledge. Similarly, a mother had a real concern about the lack of special education expertise amongst the staff at her child's kura kaupapa Māori. While she was more than happy with the awhi and aroha of the staff, she felt that her daughter was not getting her special needs adequately attended to. A teacher aide had been hired for her daughter but the mother noted that whenever she visited the school the teacher aide was helping other children. When teachers were absent the teacher aide took over their class leaving her daughter unassisted. When the mother mentioned this situation to teachers at the kura they replied, "This is the way we work – we don't have any one person responsible for her, we are all responsible for her, this is kura tikanga." The mother was concerned that her daughter was not making progress because she did not get enough one-on-one teaching. When her daughter's GSE worker raised this concern with kura staff she was given the same explanation and was "reluctant to push it" because of the claim of collective responsibility and kura tikanga. Tension existed between the kura and the GSE worker and the mother felt she was stuck in the middle. She noted that IEP meetings were a waste of time because what was written down never happened. For example, her daughter had a switch device that she had previously used at kōhanga reo but this had never been set up in the kura. The mother was considering putting her daughter in a mainstream school where she felt her special needs would be better provided for. However, she loved the cultural input and wairua of the kura and thought her daughter would miss out on this if she shifted to a mainstream school. She felt she was being forced to choose between meeting her daughter's cultural needs and her special needs and was in a quandary as to what to do.

A third parent noted that:

Teachers tend to treat children all the same in Māori immersion education – the "tātou, tātou" attitude but they are not all the same. There is a need to recognise impairment and use appropriate, specialised teaching methods with these children.

Further problems raised were inappropriate assessment tools, procedures and resources. An example of the latter was the computer provided to one child complete with word predictive software in English and no macron software or Māori dictionary. An example of the former was provided by a parent who objected to the process and content of an IQ test her son was given. In an attempt to be culturally appropriate the person conducting the test had begun with a karakia but she believed it was not an appropriate choice for a child who attended a kura kaupapa Māori. She explained:

She was a really lovely person ...whose notion of being Māori was very tied up in her Christianity....She didn't understand that wairua Māori did not mean Jesus is the Saviour da, da, da, ... That is not unusual, but that is changing – a lot of young Māori don't do it that way, because they have come through kura kaupapa Māori, and it is different for them. They [christianity and wairua Māori] are separate. So, that was an issue, the fact that she had not a clue was a really big issue.

The test itself was also criticized:

The only thing she knew to do was throw a WISC [Wechsler Intelligence Scale for Children] at him, which she did, but she hadn't even modified it for New Zealand

conditions, much less Māori kids [for the Māori language] ... I was absolutely horrified – how many stars on the bloody American flag? Like an 11 year old out of kura kaupapa Māori is going to know that! What is the capital of Brazil? – how useful is that! It was just so inappropriate, I mean, Hape knew a lot of the stuff she asked simply because we live in a household where we look at stuff like that, but how many 11 year olds who are in kura kaupapa Māori know who Charles Darwin was – in fact how many 11 year olds in New Zealand know who Charles Darwin was, they don't hit that till high school ... I just couldn't believe the inappropriateness of it ... She did actually try on the spot to change some of it, which is why she changed some of the math mental questions, where working out distance between places, so she made them New Zealand place names instead of the American place names, but the way she asked it was really bad, and so he got the answers wrong because he actually answered what she asked, not what she meant to ask. I can't remember the exact question, it was a distance one, it was about, if it takes you six hours to get from Auckland to Wellington and, Palmerston North is a third of the way, how long would it take you to get there? and Hape said "a third of the time," and it was the wrong answer. It was actually the right answer, she just wanted the hours, but that is not what she asked him, and there were quite a few that came in like that and he actually did not score very well in the way she tested him.

A final issue relating to Māori-medium education was raised by one mother. When checking out schools to send her son to she was faced by the following situation:

London School, I walked in there, they saw I was Māori, they would not put him in the unit, they wanted him in a bilingual class. That was their exact words, "You are a Māori, why do you want him in a special unit, he goes in a bilingual." And I turned round and said, "No, I don't speak Māori at home, I speak basic Māori, he's never been to a kōhanga, he does not go to a marae unless it's a funeral, you'll just be wasting my time, I want him to learn English"... There was no choice and I turned around and said to them, "Bilingual units, you earn money per head for having Māoris in there and you'll earn extra money having a special needs child in your school. My kid is not a cash register, we're going." They earn money on both sides of the fence.

MĀORI SERVICES, SERVICE PROVIDERS AND EDUCATORS

Seven people specifically mentioned the need for more Māori services and service providers. For example, one mother asked for more Māori staff to support Māori in residential, independent living and hospital situations. She told the following story to illustrate this need:

For example, going to the hospital it would have been nice to have Māori nurses. We had all tauīwi nurses and doctors and there were things that really peed us off because at one time she had a staph pneumonia infection on the lung and she went in and I had been staying with her and then I had to go home ... When we got back to the hospital her head was shaved and she had things sticking out of her head, and my husband really flipped his lid. So that was one breech for us

Interviewer: Was this because of the tapu of the head or because of putting things in her head?

It was a bit of both. Another time when she had that seizure, I feel that if there had been a Māori nurse there, I'm only guessing, I'm sure that she would have intervened in some way. Nobody did anything.

Stories from two other mothers support the need for Māori workers and services:

I had a support nurse, she's a Māori - just as a support, cultural, that was helpful. She came home for a chat to make sure everything was alright, did I feel intimidated or was I getting help appropriate for me? I was a bit shy and I was a bit ... well nobody wants to know that their child has autism, especially Māori. I wanted to know whether I did something wrong or was it just one of those things that did happen. ...

Interviewer: Was it because she was Māori you could relate to her?

Yes and as time went on I felt, "Well hey, everything is alright, kei te pai," so I didn't need her as much as at first but at the beginning she was very supportive.

I remember there was once and I was walking through town and I was feeling really low. We were going through something with Raymond and I walked through the mall and there was a sign, a sandwich-board and it said something like, "Help and support for Māori who were going through issues" and I thought, "Great." So I walked up the stairs, went up there and it was Women's Refuge. I thought, "Well I feel abused!" If there is anything [Māori services] available I haven't heard of it and I'm reasonably well informed. Again I'm not sure what difference it makes, [having a Māori service provider] it just makes you feel better and makes you relate to them a bit more and you feel a lot more relaxed.

A similar opinion was expressed by another mother:

Some of the organisations I have dealt with are Māori. I have found them really lovely, it is their approach. Because you get a Pākehā approach and it is very formal, very straight forward, to the book. The Māori approach is more relaxed and more understanding of the whole whānau and respecting the views of others... I don't like people coming in here, and they are all, "Yes, we are this and this and we are going to do this," and I'm sitting here thinking, "Yeah, whatever, if you are not going to be friendly!"... When you have a Māori person come in they talk to you like they have known you for years, and that is the sort of people that I like... I don't like the formality as to them sitting there and they have all the answers and you are sitting there like this meek person. I don't appreciate that – it doesn't wash with me very well, because as far as I'm concerned I know my son better than anybody because I'm with him all the time... I'd have a Māori organisation in here any day of the week because of their approach. Generally, most of the Pākehā I do deal with are really nice, they are grouse, I wouldn't replace them for the world, but I find that the organisations that I do deal with that are Māori, their approach is very whanau-orientated, and I like that – I like their friendly approach, and their relaxed approach, and I like it how they are willing to sit and talk – just take things one step at a time, and not rush in and expect you to have all the answers or give all the answers within a set time. It doesn't work that way.

However, another parent pointed out that being friendly and Māori was not enough - the service provider also needed to have the required expertise. She told the following story to support her claim:

They contacted us when they got the referral and said, "Did we want to go through ABC Services, or did we want to go through DEF?"... And I said, "I want to go to the person who knows about Asperger's, I don't care which service it is, I want the expertise on the condition." So, they sent us off to DEF because we are a Māori family, to somebody who had never met someone with Asperger's before, much less knew anything about it, who was Māori, but had not been brought up as Māori, and was

trying really hard to pick up that knowledge and really wanted to know, and was a really lovely person ... The fact that she had not a clue was a really big issue ... what point is there going to a Māori service if the only thing that is Māori is the fact that it is a brown face. There is no point for me, and if it is a totally inexperienced person, who had no idea, who should have been heavily supervised, but there was no money to do that of course. And, I have to be honest, in health, hospital services as soon as they say they are Māori services, I know they are second rate basically, that they are under-funded and they are not supervised closely because suddenly everyone throws in tikanga and says, “You can’t talk to us about that because you know it is tikanga,” and so they get away with doing crap all, and I think they do a lot of damage. They have got to have the expertise, the expertise is more important than the culture, although having said that, we have had expertise from people who were really culturally inappropriate, which made them useless as well, and so you actually do need both.

The need identified above i.e. the requirement for Māori service providers and educators to have a sound knowledge of ASD and expertise in their discipline area, was repeated throughout the research interviews. Workforce development in this area was seen as being very important.

In discussing special education services, one mother made the point that while:

We need Māori staff in Special Ed Services – if not Māori staff we need people who are very sympathetic to Māori, to things Māori, and I don’t just mean the surface stuff – the take your shoes off at the door and the dropping a Māori word in here and there, I’m talking about the wairua...[We need] somebody who comes to you. It is hard enough going out there seeking services and seeking help, and just seeking knowledge is hard enough, without being given another phone number and, “Look, here is Māori Health Services, give them a ring, they might be able to help you out” ... I really believe that the moment you touch the hospital, or if your child ends up in the hospital or something – and I’m not sure where the starting point is, but there needs to be somebody who goes along and rings up and says, “I’m so and so, and I have heard that your baby is not well.” Maybe it is just an impossible dream. ... Just somebody who is able to talk our language, I’m necessarily meaning Māori, to be able to say to us, “What do you think, how do you feel?”

Interviewer: And this is this wairua that you said is missing from the services at present?

Absolutely, in all of the services, just somebody to come in and make you a cup of tea and say to you, “Do you need to know anything? Can I help you out?” I mean I know I have sat there heaps and thought, “Where the hell do I go from here? Who does this? Who helps me with this?” ... Maybe there needs to be a key person, as a Māori, and as a Pacific Islander, somebody who knows the system, because that has been, and still is, my thing.... It would be nice to have somebody educated enough to know about the whole Autistic Spectrum Disorder, but also to know what is out there and to know what all these people – exactly what they offer. GSE I believe, you can get toys and things like that, and puzzles – I did not know this. Support Links apparently have a fund there for buying things like trampolines and things like that for the kids but nobody tells you these things ... or how to tap into them.

In discussing the services her son had received, one mother concluded:

We need someone who knows what they were doing every time, because the kind of practical stuff that we as parents need when we are getting and accessing services for

our kids, if people don't know what they are doing, they can't help us. But, because Petera is complicated with the epilepsy, we have had so many people touching his head inappropriately, and he doesn't like having his head touched anyway – haircuts are a bit of a mission, without the whole cultural thing about head touching, so that sort of stuff everybody should know.... In my ideal world at Early Intervention, when they first came to kōhanga reo, it would have been absolutely brilliant if we had someone who spoke Māori ... that would be my first ask. I actually think that everybody working in the system, in the GSE system, should have both languages. In my ideal world, we wouldn't need specialist Māori Service Providers. Everybody could provide appropriate services to anybody because they had both, and had both skills, but those people are fairly rare, unfortunately. ... I don't believe it means setting up Māori services. I think it means that in the field of Autism what we need are services for Autistic Spectrum children that includes people with expertise who can work in a culturally appropriate way with Māori children.

Interviewer: What is wrong with Māori specific services if they know what they are doing?

Nothing, except that we are such a small percentage of the population. I think it spreads it too far and they become too isolated from the wider issues that are going on, and it is too easy to become out of date and practice very quickly when you are isolated like that – I think isolation is a really bad thing when you are dealing with this sort of thing.

Seven people specifically mentioned that they had never been offered a Māori service, service worker or educator. For two of these people this was not an issue. One stated that she was quite happy with her child's present providers while another explained:

I'm not racist or anything, what we're living in now, is today, it's not back 150 years ago. Not all Māoris think like that either... I don't really see any problem as long as the person is going to do the right thing and be there for the job that they're meant to be doing but as to whether they be Māori or Pākehā or Asian or whatever, it doesn't matter.

One Māori mother thought she might not have been offered Māori services because she is fair although she noted she always ticked the Māori ethnicity box when filling out forms. Two Pākehā mothers hypothesised that they might not have been offered Māori services because they were Pākehā and their children were fair, although one added that given their Māori surname she thought her children's ethnicity would be recognised.

Another person who was not happy with their family's present case worker because she believed her to be racially prejudiced, noted that she would like a Māori worker but she would not make a request to change because she had been advised, "Not to go down that road because you will be waiting forever."

While supporting the idea of Māori personnel in general, a couple added that as their son did not appear to identify people as Māori, it might not matter whether the person who assessed, taught or supported him was Māori or not.

The need for Māori in special education services especially psychologists and speech- language therapists and more Māori teachers, teachers aides and specialist teachers was a reoccurring request.

My biggest bugbear is I'd like to have somebody who's not part of the school to actually talk to...I've seen these guys come in and they're males which is helpful and

they're both Māori and they come in and they are from GSE and I think, hang about, my son is Māori, why don't you come and talk to me?

One mother suggested that teacher aides who work in total immersion settings should be paid more. She gave her reasons:

Māori-speaking teacher aides are like hens teeth, they don't pay enough money to retain them. Wiremu has just about single-handedly staffed several kura, because they do a year with him and then head off to Teacher's College – I think we are up to five or six of your teacher aides who are now out teaching ... Basically we don't pay them enough. There should be a special rate for Māori-speaking teacher aides because those people are working bilingually all the time, well they are working in immersion most of the time, but then they have to be able to be coherent in English as well to be able to cope with all the meetings and bureaucracy and all the stuff behind the scenes. We can't attract and retain them, so that has to happen, and that, I'm afraid is an Education Ministry responsibility. They have to make that happen.

INAPPROPRIATE RESOURCE ALLOCATION PROCEDURES

The procedure for allocating ORRS [Ongoing, Reviewable Resourcing Scheme] funding came under fire from two parents. One explained:

Getting kids ORRS funding in the first place, the way the system works now, absolutely and completely totally disadvantages Māori kids because it is all on paper, because it is a series of questions that you have to answer, and it is no face to face talking, meeting with us as a community. It is totally inappropriate, and because parents have to do so much of that filling out and chasing up of the supporting documentation we know Māori parents don't do it – I have personally supported several parents who had children to be ORRS funded. I have chased up and got all their supporting evidence, because they couldn't, because there is a whole lot of issues about confidence and so the system screws them straight away. The fact that it is all written – it's not necessarily a comfortable medium for Māori parents, and the fact that the people making the decisions you never meet them. ... It is more difficult for someone Māori to access, absolutely, because for starters they have got to go through all these hoops that are inappropriate, and foreign, and you have got to read the system and work the system, and these guys, many of them, they haven't got a hope, because the system changes.

PARENT SUPPORT GROUPS AND ORGANISATIONS

The parents from ten families had been/still are members of parent organisations such as Autism New Zealand, Parent-to-Parent and Cloud Nine Association. Some attended meetings while others played a more passive role using the organisations as sources of information only. Those who no longer attended meetings cited reasons such as time clashes with other commitments, neurotic parents and hassles within the organisations themselves rather than any cultural reasons. Those who never joined said they either had no time available due to solo-parenting and young children, had whānau support so did not feel the need to, had not yet located their local organisation but were interested in joining, had to travel too far to meetings, were “in denial” or were not interested in belonging to a parent group. Although over 50% of the families interviewed were/are members of parent associations, three mothers who were parent organisation members were Pākehā. Their Māori husbands reported that while they had attended occasional parent meetings it was their Pākehā wives

who were the active meeting-goers. Three Māori mothers who were members of parent organisations specifically mentioned that they were not “your typical Māori Mum.” Two of these mothers explained:

You now, for someone like me who is a bit bull-headed and stuff, those sort of things are okay for me because I will go out there and say, “What are you going to do?” But, I’m not the average Māori, I’m not the average Māori woman, and we are not the average family, but I think that the average family is going to fall through the cracks. That worries me, that worries me that there are so many Māori out there who need so much support. I mean, we need it, and we are okay, we are doing okay. There must be so many out there who are just falling by the wayside because they are not able to advocate for themselves... And, I remember saying to Aroha from Support Links, “Where are our Māori?” And she said, “Oh they are there.” – Where? Where are they? Parent to Parent have support coffee mornings and Lollipops Playland groups, and that is awesome, but for us it is a bit harder to do that, in terms of resources and going to coffee mornings is not really our thing. We like it but if you go along to the average Māori mum and said “There is a coffee morning,” they would say, “That is a bit flash, isn’t it.” You know what I mean? So, it is kind of like we are intimidated by the fact that there are all these Pākehā women sitting there talking about their children and they have this diagnosis and that diagnosis and this paediatrician – the word paediatrician is too big!

I’m reasonably assertive and if I don’t know something I go where I need to find out the information and to push for it but I know plenty of families and people through school and through meeting the other families who just don’t have those sorts of resources so it worries me that there aren’t the advocates available, that there aren’t the people standing up for them, that they get told something and they just accept it because they don’t know any other ways.... [A speech-language therapist told me about] these two Māori kids who had problems and the hospital was saying, “No it’s not our responsibility, it’s SES” and SES were saying, “No it’s not our responsibility, it’s the hospital.” So neither would work and she said the parents just don’t know how to push the envelope and she said when you’re told, “No” by a professional they just accept that and they think. “Ok then.” In the end I phoned Parekura’s office and said, “This is the issue ...” This family had not been receiving adequate services or any services for three years and this child had been a huge problem. It was sorted out within a month after that phone call from Parekura’s office. It is a shame that a lot of the parents just don’t know where to start... If you’ve got some people who are very outspoken and very articulate, they get given the hours because they’re sitting in front of the Minister complaining but you have Māori families like at our school who don’t have those resources or are able to do that and yet their need is probably as much and they miss out.

One mother suggested having a support group specifically for Māori families and others agreed this would be a good idea. Someone who had never joined a parent group because this did not appeal to her said she would be interested in joining a Māori group. She liked the idea of workshops for parents – “To give you ideas...hands-on strategies and activities.” These workshops would include the children and cultural content. Another mother also liked the idea of workshops where parents could share their experiences if they wanted to. She believed a reason Māori parents did not join parent groups was because the format of meetings was not Māori-friendly. She suggested that Māori

meetings would operate differently. One possibility was to have an activity where the whole family could be involved. There would have to be:

kawa and a set kaupapa... a whakawhanaungatanga experience and then after that you can get more into the fun stuff... There has got to be a big element of fun for Māori parents. There has got to be a kawa because we are used to that protocol.

This mother suggested information for parents to take away if they wanted. In addition to a Māori parent support group, she also saw a need for counselling facilities for parents.

I've met so many parents and I know from experience what they're going through, especially the Māori ones. They're grieving and it's obvious and it's either a sadness or it's an anger. For me, that kind of support is important for mental health, emotional, psychological well being ... I know Māori people like to do the whakawhanaungatanga and the wānanga about things and that's good and I understand that but sometimes people need to be on their own and talk through stuff on their own. Even in our society there's a place for individual issues.

One mother who was keen to join a group said that if she was the only Māori there she would not speak up because Pākehā women would not understand about wairua and her taha Māori side. She would prefer to join a group with at least three or four other Māori in it, an all Māori group would be even better. On the other hand, another woman mentioned that she was the only Māori in a parent-run play group and it was an excellent experience. While a third woman explained that the composition of the group would not matter to her:

As for a sea of white faces, I'm used to white faces because my husband is white, so that wouldn't put me off.

However, she explained what had put her off joining parent groups:

I think it's denial mostly! I didn't want to believe that he was autistic... It was actually them talking about autistic children and then showing me videos. It was frightening, I didn't want to see that. I wanted to work on- "He is at the end of the autistic spectrum and it's fixable" and that's what I stuck with.

One husband and wife came up with the following possible reasons for Māori not getting involved in parent organisations:

I find it easier to chat with somebody about autism when you run into them in town or on the side of the road as opposed to going to specific meetings. But whakamā does probably play a big part in why Māori don't go to a lot of meetings.

You have to be happy to sit round in a big circle and start talking about their child and I don't think a lot of Māori are happy to do it. It's not the kind of thing you do really.

Often it's that initial thing too. Maybe after they've been a couple of times they're happy to do it. If we're in a group with half a dozen other Māori who are in the same boat I think it would probably be a whole lot different because I think Māori would feel a lot happier to open up and talk about that sort of thing to each other and why's that? I couldn't really tell you. Maybe it's a whānau thing again, probably part and parcel why Māoris tend to, if there's a big group of people, why all the Māoris tend to flock together.

Well, it's a safety thing, it's an aroha thing.

Yes exactly, I suppose you know you're going to have a lot of things in common with that person.

Interestingly, while these culturally related reasons were hypothesized for Māori in general not joining parent groups, the previous reasons people gave for not doing so themselves were more of a practical nature.

WHĀNAU ISSUES

There was considerable variation in the degree to which parents received whānau support. This ranged from whānau who were on-call 24/7 to whānau who provided little or no help and support at all. It was quite typical for support to vary within whānau with some members being helpful while others were not.

On the positive side, parents talked of whānau who sought information, funds and services for the child with ASD, babysat on a regular basis and provided emotional and practical support. One grandmother provided respite care for her two mokopuna with ASD. In addition to this, the family had established a tradition of “Nanny day.”

We have “nanny day,” and that has been since we have first had our babies, since Horowaitai was first born, where she comes out and spends the whole day. Because they live quite handy my father-in-law drops her off in the morning at about 7.30 and picks her up at the end of the day at about 5.30 and she spends the whole day with the kids, and it is nice, and that happens once a fortnight.

A mother related another example of whānau support and involvement:

I mean he's brought up differently because we're a Māori family and the fact that everybody plays a part in Nathan's life from his grandparents to his aunts and uncles and he's made to feel secure no matter where he goes and he's included in everything. ... Yes, his aunty does a lot. My father has got to make [teaching display] boards up, he'll do that sort of thing. He's creative, he built our dark room and ... made felt boards for Nathan.... My Mum has said, “If anything happens to you, Nathan comes home” and my sisters are the same, “He's got to come here, he can't go anywhere else, he's not going into one of those homes” My family has all got the same point of view and I know that Nathan will be alright and no matter where we are he will be supported by my family. My dad wants to come with us to Perth. He's just got to talk the rest of my family into it because Nathan is his special boy. He and his grandfather have a great rapport. That's probably the difference is at the end of the day where they will go. Because Māori families see these kids as belonging to them, not something you farm out. And that's what my Mum was brought up with because she had a cousin with a disability and I've got another cousin with a disability and it was like they belong in the family. You don't send them anywhere else, they're ours. That's the difference.

Another person noted how her whānau, especially her mother, have supported her over many years but especially in difficult times:

When my husband left she was three and my boy was six ... I don't know how I managed but it was mum. I used to go around, sometimes I'd scream my head off in her kitchen, she'd just sit and listen.

A father told of his whānau's reaction to his daughter:

My whānau, they love Sophie, I don't go up to Eastbury very often and we went up there at Christmas time and they were sort of fighting over who was going to have her, and she was fine with it as well, and always happy.... My mother had 21 kids - she had 13, but she raised 21- whāngai, ... so there is always kids around. None of my family have an autistic child, or have any experience with autism, but none of them have a problem with it. Sophie would know. She is very perceptive towards people's feelings, she knows if people are angry with her, or don't like her, or are mocking her. She knows – she can pick up those vibes and those sorts of things, so she would know if any of my family felt that way. They have more to do with her because of the fact that she has autism. There are hundreds of nieces and nephews.

A high degree of acceptance and tolerance amongst whānau members was also noted by another person but she pointed out that this could sometimes be disadvantageous:

That's one thing I notice with your family when they say, "Don't worry," and I agree with that but I have to explain to them that I'm looking long term ... There are things that are funny now but would you laugh if he was 15 and doing it, so he has got to know.

Other participants did not report such supportive whānau experiences, in fact three participants said they received little or no support at all. A variety of reasons were given – no family living nearby; whānau avoidance because they felt uncomfortable; lack of interest; and concern about the “destructiveness” of the child with ASD.

Even with our families, they don't tend to invite us. We could have lots and lots of barbecues and they'd all come every time but we never get invited down there. They think our kids are going to wreck their house. A lot of our family members just don't even really want to deal with them. They pat them on the head but they feel uncomfortable around them. I give them lots of handouts to read but it makes them feel uncomfortable. Glen's family surprised me the most I think because I thought that in a Māori family that whānau is pretty important and he's got family that come down here and don't come and visit us and it's really hurtful to him. It's alright if your child is normal but if it's not normal it's different.

One mother mentioned the difference in support between her whānau and her husband's whānau:

My family are very very ignorant, they don't take Cory. They won't even take him to town to go shopping. They are very old book where there's something wrong with the child, it should have been locked away and out of sight, out of mind.

Whereas my in-laws don't care, he's part of the family. They helped out at Easter time, his grandmother flew him to Auckland and flew him home. They've been very good and the bad points are that they spoil him rotten because they don't want to admit things are wrong but they still take him. I've seen both sides of the fence, where my part of the family are “close the door” and help you when you're home and shut the door where no one can see. The other side of the family, they're in Auckland, he goes to the shopping centre and he'll run up and down the stairs and sing at the top of his voice and dance. They don't care. [My family] they're embarrassed.

One mother explained how they had shifted from a rural area to get better services for their child with ASD and better opportunities for the whole family. She told of being lonely sometimes but added that their shift away from the family also had benefits.

We have no one down here. And actually it is good, it is good being away from family, it gives me more independence to actually get out with Fraser, and actually find things for him. Yes, we don't rely on family now to get in and help... I have learnt to adjust, I have learnt to get out and find help like Barnado's Day Care for my kids.

Another mother echoed these sentiments:

Māori, 25 and up who start having their babies, they depend too much on their own families. They don't know what's out there and nor do the families to get help. I've found with a lot of Māori families, that's why a lot of women are too timid because they know mum is around the corner or mum-in-law. They know nanny is up the road, they come from big families like all of us, there's always someone there. The extended family can be a pleasure but it can also be a hindrance in a lot of things.

Probably the most frequently mentioned complaint about whānau was that many members had no understanding of ASD. This ignorance led to some hurtful comments. One couple explained:

No they don't understand anything at all. Like typical family, they always say the wrong things. "So and so's got children, they're only one and two and they are worse behaved than yours!" and "Look at Lee, she's so pretty, what a shame!"

And its both of our families – like saying, "They're still ill? Are they still sick?" No, no, they've got autism!

I really look around at your family and your family is so weird really and they think our children are weird and it's just not so. They say, "You must find it hard with John" but they have got a child the same age who is really naughty, and swears and is nasty and they think my child's got a problem, I don't think so! We got hurt at first but we don't really care anymore because there are a lot of people that are interested in our children that we're finding.

A mother noted some detrimental attitudes she has had to contend with:

It took us ages to be able to explain to our whānau, and they still don't really understand about the kids. Because, "Oh they look normal," which has always been the thing – they are normal, they just struggle with some things! ... I think too, when you have things like this, it kind of tarnishes the whakapapa a little bit. There is something wrong with your kid, they are special needs, so there is that to contend with as well. I think other people's denial is really strong and I have had aunties and things say to me, "But there is nothing wrong with him."

Denial was also reported for some fathers amongst the 17 research whānau. Four mothers reported that their respective partners took some considerable time to admit that their children had ASD. One mother explained her situation:

I remember my husband was saying, "There's nothing wrong with her" to one of the teachers at her school. The teacher turned around to him and said, "Your daughter has autism and I'm sure that your wife has told you about this before!" He believed it when

she told him but when I told him it was, “No, you don’t know what you’re talking about.”

Certainly there was strong support amongst participants for whānau members in particular and Māori people in general to learn more about ASD. One mother noted:

I look at our different kids and I think, “You know, if your parents were a little bit more on to it, they might have actually picked this [ASD] up.”

Another mother added:

I think Māori need to be aware of autism, there’s no need to be whakamā, shy about it and probably all get together, support each other.

Some participants believed that there was a tendency amongst Māori in general to dismiss or avoid talking about disability – a type of “she’ll be right” attitude that denies or minimizes the reality and is, ultimately, disadvantageous. A father explained:

I know with a lot of families they get very – they’ll hide it or put it away. “You don’t need to worry about it, we’ll put them over here with the other kids, they will be alright.” Which is probably not really the right thing to do because getting diagnosed at an early age is actually better for them so they can grow up with help. Where with Māori they put off going to the doctor - no they’ll be alright.

His view was supported by another participant:

What about disability though, that’s another story with Māori, they don’t like to focus on the disability aspect of things or impairment aspect of things. They’ve got this habit of, “Oh it’s alright, they’re just like the others. She’s just like the others, I’ve got a child just like her,” sort of thing. They’re just trying to make it look okay but they minimise, sometimes, the reality.

A different opinion was expressed by one mother. She believed that for Māori, children with disabilities are regarded as “special and precious” and that Māori values of aroha, kaitiakitanga and wairuatanga dictate a responsibility to look after and care for these children. Another person said he believed that Māori have a global acceptance of difference:

Again, in terms of my experience, Māori have tended to be more accepting of those conditions often than other cultures. Because when I was younger and living in Tolaga Bay and my second cousin had some sort of mental disability, and she was in and out of psychiatric hospitals and stuff like that, and when she was at home she was cared for by her mother, and we had a lot to do with her, but there didn’t appear to me – there may have been – the stigma that is attached to mental illness, that society have of mental illness.

Interviewer: Do you think that there would be any way that they would treat it differently, I’m not talking about the understanding of what it is, but from a Māori worldview?

I think Māori would tend to be, if anything, too soft on them, you know what I mean, tend to make allowances for them because they are different, and allow them to do things that they wouldn’t allow regular kids to do. I find this amongst my whānau.

Rosie will play up and they will give her something, and I'll say, "No, don't." An example is that she stayed at my sister's place ... and she rang up and said, "Rosie wasn't happy" because she hates cooking oil and they were having eggs, and she cooked eggs in oil and she got upset about it and went outside, and my sister said, "What should I do?" and I said, "Tell her to get back inside again," and "She wants to watch the video," and I said, "Don't let her watch the video if you want to turn on the TV, don't let her watch the video," but if it is up to them they would let her have her way all the time. So, I think that if anything they would be softer and let her do things that she shouldn't be doing just because she is the way she is, that is the only thing that I can think of.

However, this father added:

I don't even know if that is different to most people, I'm not really sure ... It can't be just assumed that Māori have the same view on it. They have different views just like everyone else has. You can't say that because of what I said that all Māori feel that way, and there are parents that you talk to that feel differently and that is just the way it is.

One couple reported problems with children in the whānau:

I find it difficult sometimes going to family with the kids because depending on the child and the children, some can wind him up, be sneaky, walk away and leave him to carry the can. Others will scream as soon as he might look at them. I know one day he was sitting watching telly happily and his cousin came over and pushed him for no reason whatsoever. I was standing at the door and he couldn't see me and then he ran away and sat on the sofa behind. Rawhiti got up and this boy looked up and said, "Auntie Lucy" and I said, "Don't say anything else, don't wind him up, I saw what happened, if you want to go and do that, you're on your own." But his mother would have come running and that's what I find really hard because it's happened a few times over the years. The child who yells the loudest will get the sympathy. "I'm not even going to go there, if I haven't seen the whole thing, both of you have nothing said to you or both of you get a growling." Then the other ones are sneaky and wind him up and take off and the next thing they'll come back in and he doesn't forget, he needs the closure and he'll push them over or do something and that's all we see, because we haven't seen what happened before.

A mother made the point that in order for whānau members to provide assistance in various areas, they needed to receive training. Two instances of this were reported:

They showed everyone – whoever who was willing. They showed me and then a paediatric nurse came to the house and she brought round the little dummy to teach the family CPR [Cardio Pulmonary Resuscitation] and teach the family how to put a tube down. They offered it.

I think it really depends on the family, some are comfortable with doing things others aren't. They did offer my family but they were too stand-offish because they were scared. So I showed them how to put tubes down.

Interviewer: When you showed your family, did they become comfortable with it or not?

Not comfortable but sort of, “Okay, this is what we have to do.” They weren’t comfortable at all and they tried to get other people to do it, but they would do it if they had to.

Although not specifically training related, other examples of whānau involvement reported were inclusion in the MAPS [Map Action Planning System] process and in IEP meetings. A mother explained how her son’s school changed the IEP date so that nana who was coming down from Auckland for a holiday, could be included in the meeting. They also offered to send her copies of her grandchild’s IEPs.

Involvement in various whānau gatherings proved problematic for some people. One mother explained:

Even going to barbecues because they have open areas and they don’t realise it’s very hard to take Renee to somewhere like that because she’ll just run. When they were both little it was terrible.

However, a similar scenario in another family was avoided with the help of whānau members:

We visited my wife’s brother down in Blacktown, and he has five Jack Russell Terrier dogs. Ruby hates dogs, and it would just be cruel to take her there with us, so we would say things to her like, “We are going down to Uncle Ray’s. You don’t have to come if you don’t want to,” and she is always more than happy not to. She goes to my sister’s place, or she goes to her brother’s place. She is going there on Friday to stay until Sunday.

SIBLING ISSUES

A number of participants mentioned the affect on siblings of having a brother or sister with ASD. For example, one mother noted that whanau members fussed over her daughter with ASD to such an extent that the child’s older sister often felt left out. A similar situation was related by a couple:

I sometimes feel sorry for his sister, like on occasions where she may feel a little bit left out maybe or wonder why he gets huge praise for something that she’s done five times. I pointed it out to her one day when she said something like, “Oh why do we have to do this?” and I said, “You know why,” and I added, “If it wasn’t for Rawiri you wouldn’t have gone to the special needs Xmas party” – she talked about it for months! We reel off the things she’s actually done because Rawiri is the way he is. And even though she was young she took it all in and I could see her thinking, “Oh well, it’s really not so bad” but I’ll have to remind her when she is getting shitty at him. When Rawiri goes on his respite day I try and do something for her.

Yes, take her away and have a mother and daughter thing, shopping, McDonalds.

She’s younger but a lot of the times we go somewhere she’s really got to be the big sister which is a lot to ask from an eight year old.

She said to me a while ago, “Mum sometimes I wish Rawiri wasn’t my brother.” I thought, “Here we go, I’ve been waiting for this.” “Why is that America?” And it was something really trivial like because he comes in and picks everything off my floor. I said, “Oh well, I don’t blame you, I would feel a bit annoyed about that too” and I was thinking, “Phew!!” She is really good with him. She’s learnt that if you wind him up

and mum sees it he's not going to get the blame. A lot of those things are just normal and you have got to remember that.

A father also commented about “normal” sibling relationships. When asked how his son Peter got on with his brothers and sisters he answered:

Normally – they all hate each other!! They do miss out a lot and they get a bit embarrassed. I will say, “Peter is going to the disco tonight” cos the disco is just across the road at the primary school and they’ll say, “He’s not coming, he’s not from Makomako school.” “No, he’s allowed to go” and they get all embarrassed. They say, “He’ll start clapping and yelling” and I say, “No, he’ll be alright” and he does behave, if you tell him to behave, he’ll just put his hands like this, it’s a hard case. They do miss out a lot and they have told me, “Dad we have to stay home because we have to watch Peter” and these sort of things. I have to try and balance it out. I say, “Well if you do this, then you can do that.” Cos kids they don’t want to have to handle that, they just want to have fun. But they do get more than their fair share [of good things] I think, more than what I got, that’s for real. They’re happy.

One mother reported that her older two children were very protective of their young brother with ASD. Her daughter was credited with teaching him how to hug. In another family, a mother reported how her younger son got quite angry with children who stared at his brother when they were out. A third mother mentioned that while her son had been very helpful as far as his sister was concerned, it had had a negative impact on him:

He’s just coming right now, he’s 19 though. He’s had depression, clinical depression and that was a real worry ... My daughter’s disability somehow affected him at school because kids used to tease him a lot that he had a mental sister and a handicapped sister and him being so sensitive he used to get really wild. Then I was reading the other day that sometimes siblings get depression from children with disabilities particularly autism.

DETRIMENTAL ATTITUDES AND BELIEFS

Māori parents reported a myriad of detrimental attitudes they were challenged to contend with. Some of these have been mentioned in previous sections and many more are covered in the chapter on barriers. In addition to these, a number of culture-related issues were raised. For example, five people mentioned incidents of prejudice, detrimental cultural stereotyping and patronizing attitudes. These included the case worker who after years of working with the family could still not spell their surname and passed comments such as, “I have coloured the people in your child’s book brown;” and the WINZ [Work and Income New Zealand] worker who publicly questioned the veracity of a mother’s request for financial assistance. Two other examples are:

Yes, I had to snap at him [the doctor] to make him realise that I’m not just here to come and get a tablet off you and not care about what it is for – because that is the way that he treated me at first. It was, “Here is a mother who has an autistic kid, she is not going to care what I give him.” He must have got a fright when I told him that, “I do care what you are going to give him, because he has never been on drugs before, and I do care what you are going to stick in his body.” Yes, I felt he judged me before he got to know me, and my husband, because my husband has got tattoos on his hands, but he doesn’t drink, he doesn’t smoke drugs - I felt they judged us before they got to know us.

Interviewer: And, do you think they did that because of you being Māori?

Yes, I think they just took one look at us and took an attitude they thought, "Oh they don't care about this kid, let's do this and this and this," and when I turned around and said, "No, I want to know exactly what you are doing with him. Why you are giving him that, and why are you giving him that amount?" he soon realised that they do care, they care very much about what we are going to do with him.

A second mother was visited by a social worker who said to her:

"We're only here because there's enough ignorant little Māori girls like you that want to play happy families and don't cope and with your son being autistic on top of it ... so more than likely he is a prime candidate to be abused." I said, "Well in the last five years there have been three autistic kids who have been killed, none of them were Māori." ... They tried using autism as an excuse to abuse the kid and that I was a young solo mother... He had expectations that I was a typical solo mother and on top of that the typical solo Māori mother that didn't know anything ... Kenny was actually home from school, he'd finished school for the day and he said, "Typical Māori, why isn't that kid at school?" I said, "Go and find me a school that will have him from nine till three and then you can say it." I had an answer for everything.

One father raised the issue of tokenism:

This is where I have a big problem when it comes to the Department of Education. They have a Statement of Intent and each Government Department has it and to me it is blimmin lip service ... I hate it because they just play it that you send someone out that can do a survey. This is what they do in regards to addressing the cultural issue side of things. We can tick that box. What they do with it is probably put it in the shredder. As long as they've covered their butt in regards to the cultural aspects of things, we don't know, we don't see any outcome.

In discussing their children's future, two parents expressed their concerns:

As far as I'm concerned, because they are Māori, and because they are Pacific Island children, they have obstacles that they are going to have to deal with anyway. As a Māori, as Pacific Islander, the expectation is that they are less likely to achieve ... they are more likely to be in a bloody jail cell.

In my experience they are looked down on.

They are, you are absolutely right. And so, everything that we do, every place that we go, - and this comes back to the physical thing - we carry that every day. We don't have a choice about being Māori, or Pacific island, we don't have that choice or that luxury. So everything that we come across - everything that we have ever come across and everything that they will come across - they will have to deal with that hurdle. I think that my children, without Asperger's would have had that challenge, Now with Asperger's, their challenges are even greater, and not only do you have to get passed that, they are in an education system that is not made for them. They are within a health system that is not made for them. The challenges that we as their parents and that they are going to come across in their lives are... scary. Every challenge that my children have is double the challenge, and then you have got your socio-economic stuff thrown into the mix as well. Their road is a lot harder, so yes I do see it as being a challenge and I'm not sure what the answer to that is.

To summarise, with the exception of two people, parents were supportive of some degree of cultural input into their child's care and education. However, the nature of ASD meant that often children's participation in cultural activities such as kapa haka, te reo and noho marae was limited. Māori-medium education and Māori services were seen to have both advantages and disadvantages. Whānau support varied from 24/7 to none at all and, in general, parents identified a need for whānau members to increase their knowledge and understanding of ASD.

Chapter Four: Helpful People and Services

Many different people were nominated as being helpful. They included a range of medical and educational personnel as well as disability service providers and parents. Certainly the stories that were told of their dedication, aroha and helpfulness were quite outstanding.

MEDICAL PERSONNEL

While parents found long waiting lists and “red tape” frustrating, the medical profession was often redeemed in their eyes by certain “individuals” within it giving outstanding service. Particular ear specialists, doctors, nurses, paediatricians, obstetricians, occupational therapists and neurodevelopmental therapists were described as, “very helpful, very open, supportive, knowledgeable, informative, inclusive, valuing of family, great advocates, easy going and non-judgmental.” Stories were told of medical personnel giving out their private phone numbers so that they could be contacted out of work hours. Two parents described occasions when they had taken advantage of this offer. In one instance, a mother contacted her paediatrician over the Christmas period. Her son had severe toothache and she had been told by emergency service personnel to give him a Panadol and come back at the end of January when the oral surgery unit would be open.

I phoned my paediatrician at home and he said, “Leave it with me.” He phoned back within half an hour. He had arranged for an oral surgeon to have a look at the tooth... He said Raymond couldn’t be anaesthetized if he had anything to eat or drink but ... he could book us in for 8am the following morning which is what he did.

Another mother rang the same paediatrician when she had hit her child and was distraught at doing so.

He did talk to me on the phone. He was good. He just said, “No, we will sit here and talk until you calm down” and he asked me how Jason was and how things were and it just got to the point where I calmed down ... He gave me an appointment straight away – that next morning.

Four parents told of the medical services provided to them:

The Mason Centre has been really great, yes. There have been endless offers of help for the children all the time no matter whether it’s for their autism or for anything else.

They’re very, very helpful. The paediatrician and I have got each other’s email addresses. The obstetrician and I have got each other’s email addresses for the hospital and home. They’re very, very helpful. Your kid has la la la the possibilities of you having another one are this, of anybody in the family having another one are this. If your family need verification and just want to ask questions, bring them in on the next visit, we’ll make another appointment. I’ve always found they’ve been good.

My GP really amazed me because he turned around and said, “You know, you were right Mabel.” He said, ‘I wouldn’t have picked that’ [When her son was diagnosed with ASD] ... He is really, really thorough when it comes to Maurice. He had him in hospital because he cried a couple of weeks ago. He was screaming and he couldn’t figure out what it was so he sent him straight to hospital. They knew that he was coming and he was autistic and he needed help now. He pushed it for us to get through. And, he is really, really grouse, I mean, I am really rapt to have a GP like him.

The hospitals here have been good especially the developmental therapists. They've made sure, like giving us a fire surround when Nathan was obsessing about getting into the fireplace because it looked so nice and bright. They had gates on the kitchen because he'd go into the kitchen and turn the stove on. They gave us a changing table for him and the toilet alterations for a wet room and a buggy for him to get around in. They found ways because they'd tried to tighten the loopholes... I've got no complaints about health, they've been wonderful, very on to it. They've bent over backwards to help Nathan. They've given him things like car restraints when he refused to wear a seatbelt, all those sorts of things... Health has been great. They've given him scans when he's needed them. They've tried to reassure him about being safe. When his brother was little and Nathan was in and out of hospital, his brother came with us. We all went as a family into the hospital all the time.

EDUCATIONAL PERSONNEL

Similarly, parents told many stories of outstanding teachers, teacher aides and early childhood centre and school staff in general. These people were lauded for a variety of reasons:

(1) Their aroha - Two parents of children who attended kura kaupapa Māori spoke of the awhi and aroha shown towards their children by the whole school staff. One parent spoke of how her son was “absolutely, unreservedly loved” by a kuia who continued to show interest, concern and keep in contact with him since he has moved on to secondary school. She also noted that at college the music teachers had “adopted him in much the same way that kuia had, in fact he is a very valued member of the Music Department.”

A similar story was told by a couple whose child's former teacher now provides respite care:

She offered respite care because she said, “I love having him around and learning from him.” So her whole attitude was, “You guys in his class are privileged to have him in your class, you can learn so much from him” and that was her whole attitude. She is wonderful and she has passed that on to the new teacher this year.

Another parent noted:

As soon as I walked into that place and looked around you could see the peace. There's a lot of aroha and a lot of dedicated teachers.

(2) Their support, assistance and advocacy – Parents told of how teachers had arranged for special educational assessment and services, fought to get resources for their children, arranged additional finance to top up teacher aide hours, accompanied them on visits to medical professionals and went out of their way to up-skill themselves.

One parent was impressed with the way her son's teachers consulted with her and took note of her concerns:

They know that Maurice is not up with the play. The school stamped it [bullying] out right then and there and he has never had a problem with it again. Whereas some schools would just push it aside but with him it was, “Find the kids, we deal with it and it is finished,” and it was all done within 3 days, it was all finished, we never heard of it again. I have had a lot of support from the school... The RTL [Resource Teacher: Learning and Behaviour] has been awesome. She has got him into everything. The school has been awesome with him. I'm glad I made the choice of bringing him to that

school. His principal is good, and his teachers, everything, they are bang on with him ... and I get my say too, whereas in Kahia I was always on the outskirts. I only heard about it, "This is what we have done with Maurice." Whereas here it is, "What do you want to do with Maurice?"

Another parent also praised the school principal and teachers for their attitude and effort on her son's behalf. When her son was diagnosed with Asperger Syndrome, the reaction was:

"We can deal with this" ... All the information I got went to kura and they all read it and Rachel who taught him in Form 1 and the principal both went to courses and they went to hear people speak and they were totally up-skilled. They up-skilled themselves because they needed to do the best for this kid.

(3) Their professional expertise – Teachers and teacher aides had not only taught their children well but had provided advice on teaching and behavioural strategies to use in the home. One parent sung the praises of teachers his daughter has had throughout her schooling:

She had some lovely teachers. I mean the teachers were really good, really supportive of both her and us as a whānau. They eventually drew more and more words out of her to such an extent that by the time she left there she could ... answer questions that you asked her and she could ask basic things as well.

She moved on to Intermediate, and again, they were really wonderful and she was really lucky because the first teacher she had is the teacher she loved the most ... She did well and progressed really well, her vocabulary increased and the amount of words and things and expressions she could say and knew just took off really. So, she had really good years there. But, at college she just really blossomed – her social skills, her vocabulary – those things mainly but there are a whole lot of other things. As a kid and as a person, as a young lady of 19, almost 20 years old, they have done wonders with her. Their programme is excellent there... Most of the positive things that have happened to her, definitely in recent times in our view, have mainly been as a result of the care and assistance that she gets at College. They just get to know the kids and they have obviously had lots of experience and have an interest ... They have all just done a wonderful job with her and you couldn't ask for more.

SPECIAL EDUCATION AND SUPPORT SERVICE PERSONNEL

For many parents particular special education and support service personnel stood out as being extremely helpful and supportive. This assistance came in many forms. For example, one couple recounted an upsetting school meeting where their son's misbehaviour was being discussed. The support of a GSE [Group Special Education] worker who challenged the teachers to examine the appropriateness of their teaching methods and programme was greatly appreciated. Another parent explained how an advisor on visual impairment had provided her with valuable resources, strategies, access to workshops and had accompanied her on a visit to Homai. Similarly, a support service worker had provided moral support to another parent by accompanying her on visits to the paediatrician. This mother also valued the information supplied by a second support service worker and the practical help provided by a third person. This worker "baby sat" her son while she was being interviewed. Additionally, he pressured for needed medical appointments, provided advice on behavioural strategies and helped research issues of concern.

A special education advisor received high praise from two mothers. They described what made her so special:

We had Susan, absolutely marvellous, all the years I've been under SES I could never fault her. She was good, it wasn't only work from 9-5, she would come around at the weekends. She'd ring me up at night and she came out during the day and if I was looking tired or Karl looked a bit touchy, she'd ring us up and say, "What's going on? You two don't look very happy." Karl has still got his desk that she gave him. She gave us a little school desk. She was lovely. ... Her friendly attitude, she didn't come in with the, "I'm SES and I know." She came in and made herself part of the family which relaxed Karl. I think that's really what I liked. There was no reading text books and saying, "That child should not be doing this, the child should be doing this." No looking down at us saying, "It's not normal, it's not this, it's not that." She let us do it our way and supported us.

One mother spoke highly of her whole early intervention team who provided her with support, ideas and resources:

I can ring them at any time I like and they will advise me over the phone if I need to or they will send me stuff. They are really good like that. I have got a really good team, I am fortunate.

In particular a number of parents mentioned how helpful their education support workers were. Not only did they provide assistance in their early childhood centres but also gave advice, provided ideas and made resources the parents could use at home. A few had become "family friends" who regularly visited the child and parents. One mother commended the supportive approach of her son's education support worker:

Yes, she's really good. She watches him. He's started to interact with other kids there, she won't get in the way, she stands back a bit. Some people are shadowing their kids, following them around. She's really good. She'll only intervene if he's done something wrong. When she first started coming she had to stop him quite a bit. Now he's learnt the rules she said she feels quite redundant. She just watches him all the time.

OTHER PARENTS

One of the most-frequently mentioned sources of support and information were other parents of children with ASD. In particular they were goldmines of information when it came to various entitlements and resources. A couple outlined ways in which other parents had been helpful:

She taught us a lot of things, more than what the Education Board did. I'm thinking, "She's just a parent and she's obviously looked into more details and finer points about how should I go about raising my son and she's passed it on to so many other parents. She has been wonderful ... She is a real bundle of knowledge.

Financially she knows where to dip into. She said, "Don't give up."

She said, "Ask for everything and you ask where it is and who it goes to and where it comes from." I don't think the Education Board like her. She came to a meeting we had one day and I don't think they were too fussed on her being there, she knew too much. Parents need to know. They don't need to just know this and this, they need to know everything... Parents have been our most useful sources of information I think. You can

talk to other parents whose children are in the same area as yours, you can relate to them... It's only through parents I've found out that you can get a disability allowance ... Special Education didn't tell me about it. I also found out about the travel allowance from another parent. I was never told about that. I found out about Dr. Joe Bloggs through another parent at school. He is really wonderful and so full of knowledge.

Similarly, another parent noted:

Other parents offer a wealth of information and support and stuff like that so that was really good, and they have been my key sources of information. There hasn't really been any other service that has stepped out and said, "Look, have you tried here, have you tried there?" It has all been other parents saying to me, "You need to do this and this and this, and this will happen." Even just getting to a paediatrician was another parent, they said to me, "No, get yourself a paediatrician's appointment." "How do you do that?" "Well you just go in here and tell them." ... And, it was only from other parents who said, "Don't take no for an answer." It was actually from another parent who said to me, "Do your research," that is what she said. "You go into a paediatrician and you say to him, 'This is why I think he has Asperger's. Now you tell me why he hasn't.' " So, I did, and that is how I have done it.

One mother mentioned how Parent-to-Parent had linked her with another parent with a child similar to hers. This parent had collected a whole file of relevant information which she shared. The mother found this very helpful. Another person who is a member of Parent-to-Parent mentioned how she and other members had supported and advocated for a mother who was going through a very stressful family situation. She believed this support was really appreciated by the mother.

Other parents were not only cited as great sources of information and support in difficult times but also in good times. As one mother explained:

One of the best things I've found about the Association is going out to an Association picnic with a whole lot of other parents and a whole lot of other kids that are in the same boat, where you can just relax and know that the sort of things that your son is going to get up to are things that everyone else around you is already familiar with so you don't have to be watching all the time or stopping him from doing something because you know that everyone else understands and you'll see other kids doing all the same things that your kid is doing. It's so good to be able to just let them do it around other adults and not be worried about what other people think. One of the things that annoys me the most is being out in public and seeing the things that he does and then thinking that people must think. "What useless parents, no discipline," and that sort of thing. So to go to an Autistic Association hui and to be able to let your kids be themselves knowing that no one thinks it, because they're all familiar with it themselves is good.

One mother believed that parents were a potential source of help that was greatly under-utilized. She explained:

There are a lot of educated people out there that they're actually not using. I don't think they're using parents enough. I know lots of parents that are sitting on a lot of knowledge and they're just not being accessed. Instead of saying, "Oh well let's go and train a few teachers," I would suggest they actually put a few teachers alongside some parents. There are parents out there, they have done ABA, [Applied Behaviour Analysis

Therapy] especially around this area that have paid for it out of their own pocket. Why aren't you using them?

Interviewer: Being the devil's advocate here, an argument might be that parents have already got enough on their plate without being used. What would you say to that argument?

I'd say poppycock! There are a lot of parents out there that have been through it and just don't want to see other parents go through what they've gone through and I know this for a fact. They want to make a difference, they want to change it. But if you leave it too late, the parents are so tired that they can't be bothered. If you can educate one teacher then you make a whole inroad. And I just think you can't send all these teachers back to teacher training college... They all can't afford to take a year or so off to do it. Why aren't you pulling parents in? Parents would do it. All they have to do is reimburse them for their time.

SUPPORT SERVICES AND ENTITLEMENTS

Parents reported a range of helpful services and entitlements, the most frequently mentioned being respite care (also known as care and relief). Of the 17 families interviewed, twelve said they used respite care, three people knew about it but had not used it, one person was not aware of this entitlement and one person never mentioned it.

Those who did use respite care were very thankful for it:

Yes it gives me a break, it gives me time with the other ones. He is a very one-on-one child and he likes attention all the time and sometimes I just don't have the time for him.

It was time to get some help – a lot of it, and actually now I don't think I could handle it on my own without the medication, without the Support Links [respite care]. Yes I probably would kill him if I had to go back to how it was, and I couldn't believe life could be so easy with a bit of help.

Just being able to pay for somebody to care for the kids and knowing that they are getting paid well, which removes guilt and just the ease of it really. We use Paul's mum, but it is so nice to be able to know that she can have the kids and I don't feel guilty about the fact because she is getting paid well.

Of those who used respite care the majority used family members. The reasons given were two-fold. Firstly, the children and parents knew and trusted family members and secondly, respite providers outside the family were often difficult to find. One couple told of going through three different providers, none of whom lasted long because of the challenges involved. Another mother explained:

It's hard choosing people to leave him with. When we first moved in here he was running down the road, he just takes off. So you can't take your eyes off him. If he's got an opportunity he'll take it to go. He was standing in the middle of the main road about two months ago. He was crossing the road and cars kept driving. You'd think someone would stop ... If he goes to a new place he gets a bit hypo and starts throwing stuff around.

Similarly, another mother who knew about respite care but had never taken it until her son was seven years old explained why:

For the first seven years of Dave's life I had him 24/7. It was finding someone I could trust to take him –Are they going to hit him? Are they going to treat him bad because he can't do his buttons up, and he can't do this and he can't do that? I knew what he could be like, and yes, I had to learn to let him go, and now he is with respite I have no regrets because I learnt that they are qualified, they are trained to look after kids like that so let him go, and I do. He has had a few cries on going, but it is just a matter of it is for his own good and for my own good too.

After family members, the most frequently used respite care providers were present or past teachers and teacher aides. Many of these people had become firm family friends over the years and stories were told of children looking forward to their stays or visits.

Of the three families who had not used respite care, two were not aware that family members could be used but on learning this, they said it would be an option they would be following up in the future. One mother had just recently found out about respite care and had not yet found someone to provide this service.

People also appreciated the flexibility allowed in its use. For example, respite care entitlement was used to have children cared for by friends, family members and caregivers; attend residential, daily and holiday care facilities and programmes; and to fund extra teacher aide and education support worker hours.

Apart from respite care, people also mentioned a range of other valuable services and programmes. These included therapy, recreational, support, financial, educational, resource and assessment provisions. For example, two parents were grateful for financial assistance to attend a conference on autism in Auckland and the life and leisure activities provided by the Summerville Centre. One mother described a “buddy programme” where a carer took her son swimming two hours each week. Another sang the praises of “Riding for the Disabled.” Two parents supported the ABA programme and one commended ISADD [Intervention Services, Autism and Developmental Delay], a one-on-one Early Intervention programme her son was involved in four times weekly. One session was conducted in the family home and the other sessions took place in the therapist's home. A wide range of activities were included and the mother reported that, “Jason gave eye contact, within three weeks of starting therapy he started looking at me. He probably says about six or seven words now.” Similarly, another mother was pleased with the progress her son made when he attended an early intervention programme in Christchurch. She described what was involved:

There might have been six kids in the group and there was a speech language therapist, a physio and an OT. Initially there were six kids and three therapists so you'd have half an hour here, half an hour break... They just worked on him and assessed him and worked on everything so it was pretty intense. He was very nackered after it...[They did] physio, cognitive, speech, computer and music therapies ... It was a busy place.

Notably both of these early intervention programmes were run by private organisations who charged for their services. However, parents considered their money was well spent.

A University Department that provided culturally appropriate assessment, Tautoko Services that helped with behavioural problems experienced in both the home and school and a Visual Resource Centre which provided resources for an autistic child who is visually impaired were also commended for the helpful services they had provided.

Parent and disability organisations were praised for their information and support and the work they did to inform teachers and the general public about disability issues. Specifically mentioned were Cloud 9, Parent-to-Parent and Autism New Zealand.

Two parents mentioned how much they appreciated having home help funded; a father of a 13 year old who was incontinent was grateful for the free nappies he received; the travel allowance was specifically mentioned by two parents as being beneficial; one mother was appreciative of having her section fenced for safety reasons; while a number of parents noted that the Child Disability Allowance was helpful

MISCELLANEOUS

Four people specifically mentioned listening and talking to Tony Attwood and reading his books as being of great help.

We found him the most useful man ever. It is a real shame that he's not available to everyone. It costs so much money to go and see him. I feel sorry for people that don't have access to money and don't have access to being pushy enough to push for appointments with him.

Certain politicians were also highly praised by one mother for their assistance in her fight for better services for children with ASD. In particular Ruth Dyson, Carol O'Dwyer, Parekura Horomia and Jill White were praised for their support and assistance but Steve Maharey was definitely her favourite!

Steve Maharey was fantastic. If it wasn't for him the Child Development Unit wouldn't have gone ahead... He was absolutely fantastic, he was very, very supportive and then when we were going from the other angle he actually let us use his rooms and when we would go into meetings, he would call Ruth Dyson straight away and say, "Hang on a minute, we'll just check that out." We'd say stuff and the Ministry of Health would come back with the answers and I'd say, "That is rubbish and that and that and that." So he'd phone them straight away. He was just amazing. He hosted the meeting.

Finally, Housing New Zealand were also praised by one parent:

Housing New Zealand were awesome. We were on the main road on Freeman's Street when we first moved here, and she was quick to pick me up and move me off the main street, closer to the school for him, because he couldn't walk unaided... She was very quick, she just said, "We have got a house here, it is close to the school," and it made my life ten times easier just in one day.

HELPFUL STRATEGIES

Parents described a range of different strategies that had proved helpful in the education and care of their children with ASD.

1. Preparation/Transition Activities

Activities to prepare children for various events and transitions in their lives were mentioned by seven parents. These took many forms, both simple and involved. An example of the former was

providing prior warning that kindy would restart two weeks before the event and then regular reminders until it did reopen. A more time consuming approach is described by another parent:

At the moment we're talking about different transport with him. All the things he will encounter in Sydney. We've found models about those sorts of things, we've found stories about different types of transport. We do our homework really well around here before we launch in.

Carefully preparing children to move from one level in the education system to the next was mentioned by a number of parents. In one case, the child's new teacher aide spent one term with him at kindergarten so that he could get to know her before starting school. In another case, the child's teacher aide from Intermediate moved on with him to college where he was employed for the first term. (The parent mentioned that she and the teacher aide would have liked him to stay on permanently but as the school already had their own teacher aides employed, this could not be accommodated.) Other transition strategies are described below:

We worked in really well with the school. They're great... They said it was okay that she [the teacher aide] came home for six weeks before he started school so that he could get used to her and that she could get used to the commands that he knew, like, "Don't stand on that," he wouldn't understand but "Get down" or "Come here," "Hands quiet," "Mouth quiet" are all of the commands that he knew but she was unfamiliar with. So they encouraged us. I did a gesture dictionary for them ... I laminated it too. I said that if he was walking on his tiptoes, holding the front of his pants, it means that he wanted to go and do a poo. So if they saw that, to take him to the toilet, give him a book and close the door! Or things that we knew and no one else would. I said that if he covers his ears it's either too noisy or it means that he's not coping with wherever he is and so to take him away or if there's a loud noise like a plane going over, just put your hands over the top of his hands and things like that... She came here for six weeks so she knew him really well by the time he went to school and then she just talked with the other teacher aides too and the other teacher aides had the gesture dictionary until they got to know him. Things like if he puts something in your hand it either means that he doesn't want it or take it away, he's had enough.

We started transitioning him into high school a full 12 months before he went, because I knew he needed that, so by the time he actually hit the place he was really familiar with it. In term one of his second form year he had three half day visits, and in term two he had fortnightly visits, and in term three he had fortnightly full day visits I think. Yes, everybody knew him before we got there, and he knew everybody and so it was okay.

The Sunrise organisation are overseeing the transition from school to community. At the moment she goes out on Friday mornings from school with Sunrise, and they do all sorts of things. It may be just a swim at the Lido, last week they caught buses around town at different points, and they ended up at Carlsdale and had lunch up there in the cafeteria. And, they do all those sorts of things to try and get them used to using public transport. And, next year, which is her last year of school, they will be organising things like once a month having a stay over at one of the houses that they have to get her used to being away from mum and dad and her familiar surroundings.

2. Visual Strategies

A wide variety of visual communication strategies and devices were described as being helpful by seven parents. These included flash cards used in teaching, matching and memory games and communication; visual story books that show a sequence of behaviours to be mastered such as going to the toilet and putting away equipment; and sticker books. Two parents used visual planners at home. One described it as “the best thing they ever made.” It was effective in teaching her son his daily routine although her present focus was trying to get him used to change so she had discontinued the use of the daily planner. Another parent described how she uses a visual planner with her two children:

It is a day planner ... What it has taught them is breakfast first, then you get dressed, after you get dressed then you are going to have a visitor. Then we are going to have some lunch, and then they can go and play, but we are staying home, and then in the evening we have dinner, then we brush teeth, have a shower and go to bed.... I say to them, “How are you feeling today?” and they say, “Great.” And they have got ... a whole host of little pictures that they can stick on there for different emotions, and the weather – it is a sunny day, if it is raining, if it is cloudy, and if the kids might feel cold, they might feel great, or excited.

They are brilliant ... it has been really excellent, it has taught them.

One parent explained how she used visual strategies as part of the total communication approach used with her autistic son who was visually impaired. This approach included Makaton sign, talking and tactile books, visuals and objects. She particularly recommended the use of objects to manipulate and encourage communication. Many of these are kept in a pouch which is worn around his waist. Being easily transportable the objects can be utilised on outings.

3. Activities Involving Music and Rhythm

Seven parents specifically mentioned that their children loved music and musical activities. One mother at a kura kaupapa Māori explained that the waiata sung there were too complicated for her daughter so she had given the school a tape with simple songs used at kōhanga reo. Another parent believed that one of the factors which contributed to her daughter enjoying her predominantly Polynesian kindergarten was the musical activities incorporated into the programme. While another mother explained her son’s response to classical music:

He loves music, he loves classical music which drives his mother nuts. I don’t like classical music much. I have got used to it because some of it I actually quite like now.... I bought him the baby Mozart and baby Bach videos. They have got toys on them. They are grouch videos for kids. And, they have Mozart and Bach playing in the background while toys are going passed and toys are doing things – it stimulates the brain. Mark has actually worn out one of them ... but he loves them – He is on to baby Shakespeare and that is poetry.

One mother explained that music in one form or other had a major influence on her son’s development. Piano lessons and classical ballet were two main contributors:

For motor coordination there are a number of things that you can do that we know works worldwide now. The research and certainly the anecdotal evidence from families shows it really works, and one of those is something really simple and that is piano

lessons... For fine motor coordination, in opening up new pathways in the brain and different ways of thinking, its piano, because you have got to use two hands and read two notes of music, and it is reasonably fine without being super fine and logical and it's a really good thing for Asperger kids in particular to do. And, if you look at the website, especially the Oasis website, it has got lots of parents there who are coming and saying to new parents who are coming on to the forum, "Take them to piano, it really helps." But, if you can't get music lessons, it doesn't have to be piano, piano is certainly the ultimate, but it might be guitar, or violin, or it could be recorder for goodness sakes. Those things make a difference, something about it and having to move your fingers to make notes. It is training coordination and training the pathways in the brain.

The other thing, you have to have is the right parent or teacher, you have to have the right person, somebody who has an understanding and who is willing to be flexible and who is willing to put up with some different behaviours and isn't going to get frustrated when things plateau as they do, who is not going to get frustrated when some people get obsessed on "Pop Goes the Weasel" and need to play it 60 times before they can move on to anything else! And so there are issues there, but we know it works, and lots of parents worldwide are saying it works.

Absolutely appropriate for Māori children, guitar in particular, well not even guitar, but percussion. One thing that it does is it helps desensitize the hearing sensitivity in a very gentle way and a kind way.

The same mother and her son explained the benefits of classical ballet:

Classical ballet was the best thing since sliced bread for gross motor coordination because it has got everything our kids need. It has got rules that never change, it's got gentle music that doesn't hurt their ears, it's got the right kind of discipline, is that when you stand at the bar to do plié and this is what a plié is and it is always what it is, and sometimes we might do it combined, this sort of plié and that sort of plié but there are only two kinds. There is the demi-plié, and full plié and once you have learnt them they stay the same and that is really valuable. And, it is all about body awareness and learning to centre your body so that you can control all of your movements and that makes a big difference and when you think about it, it makes absolute sense.

Interviewer: Yes, and have you enjoyed classical ballet?

Yes, last year I tried to play hacky sack, and I couldn't do it, and I'm actually getting quite good now. I can hit the hacky sack. I think the last count was 15 before it goes, and it wasn't that long ago where I could barely hit it twice ... I only started ballet this year, and at the beginning of this year I could only hit it twice.

One mother bemoaned the lack of music therapy for ASD children. She was willing to pay for this therapy but could not find any. She explained:

Music therapy is such a way in for an autistic child. Even with John, he's not like Lettie but music helps him to get the toning of his voice right otherwise he can sound a bit like Forrest Gump. It would be good for him and dancing would be good for him as well. And music wants to make you dance so it's all connected anyway... At kindergarten with the drums, the island drums, Lettie just loves it and the women up there just get down with her and into this music.

4. Firmness and Perseverance

Six parents mentioned firmness and perseverance as successful teaching strategies. The following quotes explain:

He always had to have the same pyjamas, top and bottom, same socks, but you know as kids, they lose their socks. I couldn't find the same pyjama top sometimes and same socks and so I just put it on him. "No sock, no, no, no," and he'd throw it away and I said, "Well, go bare feet!" So I put him in bare feet and then he goes, "My sock, my sock." That was really good. I can put two different socks on his feet and it's not a problem. A different top and a different pants on him and it's not a problem.

The ones that I do most is to be firm – be gentle, but firm. You need to not give in when he is fitting out. I find that really hard. Just for peace of mind, sometimes I want to give in but by me being firm on him and not cutting him any slack has actually helped him a lot, because he understands, "Okay, mummy says no..." and I always say, "No, because, whatever it is..." He is learning that there is certain things he can't do.

One mother explained a strategy she used to home-school successfully:

It was very strict. He got five minutes of work done and he'd get five minutes of play but I had timers going constantly saying, "Your five minutes is up, get over here or you're not playing." ... He loved his computer so the computer got switched off and packed away. We actually packed it away and said, "You don't want to do your work, you don't get a computer," and he just looked at us and we said, "You have five days to finish this bag, you do it every day, after five days and marked it on the calendar, you get the computer, otherwise, no." And we just never gave him any leeway.

As evidence of the effectiveness of this strategy the mother noted:

At Jamestown school they did a big survey and a behavioural assessment and he was having 30-40 non-compliances which they classed as, "Ken, it's reading time, let's do reading," and he said, "No" and walked away. He was having 30-40 within a two hour period. Violent outbursts were 15-20 within two hours and within a month of home schooling I had him down to three a week of non-compliances.

Another example of perseverance is evident in the following story:

At the supermarket, it is easier for me just to race in and leave him in the car but his sister says, "Mum, he toots the horn, he winds down the window, he does all this stuff," and then I take him in and he's terrible. I said, "Listen mate, I know you can behave yourself. We are coming back every day for two weeks until I know you can come into the supermarket and behave, so get used to it!" Well for the first two days he was pulling things out of people's trolleys, he was putting things in them, he was opening stuff but I thought I've got to stick with it so as maxed out as I was, when I got home I said, "Well that wasn't very good was it? We are going back tomorrow," and we did it and he was really good after that. By the end of it he was helping me empty the trolley and helping the next person empty theirs and I said, "You can leave that now son, we have to go." Next time I came back she said, "Where is your helper today?" So it is good to go to the same place and people get to know you... Yes, and it's not like an overnight or over a weekend thing, it's long term. And that's what I say at the school, "It might sound trivial now what I'm trying to do, but I'm looking at when he's fifteen, it's going to take three years, it could take a three year process to get this thing in, what

you're doing now, this is cute now he's eight, it's not going to be cute when he's 12 so we need to start the process now."

As the previous story illustrates, being firm and persevering can be an effective teaching strategy. However, parents noted that it was often difficult to maintain:

Yes I've had to do a lot more constant on that one thing. It's a constant thing. You run out of puff. If you run out of puff then you have to start all over again and I've done that. "I can't be bothered," and then I lose it for a couple of weeks and then I've got to start all over again, sticking at it. If I say one thing, I've got to stick at it and that's what I did and he's pretty good that way.

5. Computer Use

Five parents mentioned that using the computer was an effective learning strategy for their child. However there was a concern about the length of time some children would remain on the computer and some parents were strictly monitoring this. In addition to being used as a learning tool, the computer was also used to "baby sit," and to reward good behaviour. One parent noted that while her son had difficulty physically writing, he could manage to use the computer to express his ideas. Another parent explained how her son needed to participate in a story in order to keep on task. The computer was proving an effective means of achieving this:

We use different mediums to relate to the story. We'll put them on the computer and we'll put them into PowerPoint. We did one story which was about Boris the Pirate but we'd animated the story and he's actually helped read the story into the computer. We've had to look at different ways in which to adapt stories.

6. One-on-one assistance

One-on-one assistance was specifically mentioned as an effective strategy by five parents. One father explained how his son was able to produce neat homework when he took the time to work with him and insist on a high standard of work. He lamented that this degree of attention was not available in a busy classroom. In a similar vein another father attributed the pleasing progress his son made at a particular school to the amount of one-on-one attention he received there in comparison to another school he later attended.

One-on-one attention was seen to be important not only for learning but also for developing good relationships. A mother explained:

We have our real bad days, but we also have our good days. Usually about one weekend a month when he is home, I get my husband to take the other three. Usually on a Sunday he takes them to his place, and I get one-on-one with Justin all day. We don't do a lot, we usually go to the supermarket, we go for a walk in town, just so he has got that bonding – "I'm not feeling left out, I have got time with my Mum."

However, one parent also made the point that one-on-one attention could, in certain circumstances, be disadvantageous. She noted that she wanted her son to have as normal a life as possible and felt he could not have this if a teacher aide was always hovering around him. Consequently, her request was that her son have support available when and if it was needed, "but not to be hand and foot."

7. Social Stories

Four parents reported social stories as being effective although three people added provisos:

They are effective as long as they're short. You can't do them long because developmentally he's not at that level but it's like we adapted our own sort of social story. When he wasn't allowed the radio because he has a fixation on music and so I used the "No" sign on the front of the radio and said, "I'll try to remember, there's no radio when I'm doing my school work." And usually I put something at the end of it, "This is okay, I can have it later" or something. This worked very well. It's stopped a lot of William's bad behaviour, social stories. As long as you use them and put them in the right place and don't forget you've got them.

My wife has been to a few seminars where they use social stories and they are really good ... but when Jane gets herself so wound up nothing is going to work – certainly nothing like getting her to read stuff, or getting her to look at stuff when you read to her, stuff she just doesn't want to listen to. So, it is a matter of getting out of her face and doing what you have to do to get her to calm down ... and when she is calm, to talk.

We know that social stories or variations of that works. Music Therapy, we know that works. Overseas there is plenty of evidence, mostly anecdotal that I have heard off, but parents overseas they have been able to see really cool music therapists and in fact for Rawhiti, what we did was muck around with the social stories concept and set things to music, because that is what worked best for him, and that is an idea that I got from someone else... I made up little songs for Rawhiti, instead of stories because that didn't grab him and ring his bells. So we had a get up in the morning song, we had a getting into the shower song, we have that going on, and that worked. And, I just put rhyming words and that, because Rawhiti likes playing with words and we had nonsense words in there and silly words in there. I modified it to suit him. Now, I could do that, but if you are going to make social stories work for every child you are going to need to know the child really well, which is why they try to train the parents to do the social stories. But not every parent is going to be able to do that, and I'm very conscious of that, because I heard a lot couldn't, and not every parent is going to recognise that – "Damn this programme that they have sold us and it is so good and we are doing it and it is not working!" because that is possibly not the right format. For some kids rhythm works. I know a family where rhythm worked, instead of a story. It was little rhyming things to clap and that worked. And so it is the same idea, but modified to fit the individual.

8. Explanatory Class /School Visits

Three parents explained the importance of explanatory class/school visits. One mother told of how she had visited the kura kaupapa Māori prior to her daughter starting and had spoken to each class. She told children about her daughter's disability, what she could and couldn't do and how they could help her. A similar annual visit is made by a boy's parents:

One of the things we have done every year, at the start of the year, is to go into his new class and talk to the kids. Sit with the kids for half an hour and just tell them all about what Asperger's is and the sorts of things that he does that are a bit different. They understand so when they see him, if they've got a piece of fluff or something on their clothing or something out of place then he feels compelled to rectify it and so now the kids understand him and if he's tidying things up on their clothes, the kids will just

carry on doing what they're doing. They'll tolerate it. That's now. In the early days when the kids didn't know and even we didn't know, it was a lot harder.

One mother made a similar visit, not to her autistic son's class, but to her daughter's school. She explained why:

Year One and Year Two girls had gone through together but when she went into Year Three, four new girls went into the classroom and they were being a bit mean to her about Thomas so the teacher suggested that we take Thomas in and introduce him to the girls and talk about autism and what Thomas can do. He used to love the reading master pictures and he loved the flash cards so he knew all of the cats and all of the tropical birds and New Zealand birds off by heart. He knows the alphabet and numbers and all sorts of things and he really matched well. He knew the words of things even if he didn't know what they meant or what their functions were. So we went in and just showed them and he had a little talker so that they were able to see that when he wants to communicate he could use pictures or the talker and then he showed them how he could write his name and then they were able to pick up the card and he would say that was an Abyssinian or a Manx. That completely changed their attitude. So they were able to show that autism just isn't all him flapping and him running in and collecting everybody's pencils and putting them altogether, that he was intelligent and that something went wrong. One of the girls said, "Did his wires just fall out? Did the plug fall out when his brain was still developing?"

This same mother (whose son is prone to running away and entering neighbouring houses) has prepared an information sheet which contains a picture of her son, an explanation of his disability and her contact details. The police have advised her that it is appropriate to deliver these sheets to known neighbours but for safety's sake, she should not put them in the letter boxes of people she does not know.

9. Involvement in Choosing an Education Support Worker or Teacher Aide

Three parents explained how they had had direct involvement in selecting their child's education support worker or teacher aide. One person had sat in on the prospective employees' interviews while another got to select from people's job applications. In all cases people appreciated being involved in the decision-making and the person selected has proved a wise choice.

10. Miscellaneous Strategies.

Many other effective strategies were listed by one or two parents. These included: gym classes especially for ASD children; the use of a work station to minimize distractions and engender a sense of safety; flexible school starting times; placing emphasis on ensuring children feel safe and secure; a buddy system to assist socialisation; reward systems; learning games and physical activities; having patience and realistic expectations; talking to people to learn about new resources and activities; setting simple household chores to occupy the child during daily peak stress times; requiring three attempts before providing assistance; backward chaining; parents listening to their own instincts; getting parental counselling; inviting and transporting school staff to attend relevant workshops and guest speakers; using support people to help access services; holding IEP [Individual Education Programme] meetings at home; life skill outings; home-school notebooks; curriculum adaptations; incorporating and utilising current interests in teaching activities; sticking to established routines; thorough investigation into choice of school; using industrial ear plugs to reduce noise;

behavioural analysis; keeping a personal journal; making lifestyle changes; time out; and multisensory rooms.

The following quotes elaborate on the last eight strategies:

I remember a couple of times I took her to school, she was generally happy to go to school, but she was upset, she just wasn't herself. We couldn't work out why really, we just thought she'd had a bad day. But after a long time of this happening occasionally I worked out that the thing that was upsetting her was the way that I was going to school, because if I didn't go the same way to school it just threw her out. I didn't realise that because some days I might need petrol so I'd go this way, and those were the days that she was getting upset and so we worked out that if we went the same way she was fine everyday. And we slowly tried to make her get used to changes but it's taken years and years and years.

I had 38 questions prepared when I went around all the schools. So I checked out each of the schools with the special needs units and I also went over to the one in Weatherby and had 38 questions, just about the school policies and how they would deal with things and the programmes that they would put in place, all those general sort of things. I went to the schools three times. I went once to ask questions and to have a basic look. The second time I went at morning tea time so I could have a look at the dynamics within the school and how the staff interacted. The third time I took the therapist with me and I didn't influence them at all ... I just found some of the schools didn't walk the talk and some of the things, the programmes that they said that they would use I could see they weren't active. The other things we had to take into account was how busy the roads were around them and how many entrances there were and if he went missing, how easy it would be to find him and things like that.

When I was in kura one of the things I wanted to do, I think I actually did it once, was I took the earmuffs to school, and I actually wore them, and throughout the entire day the teachers kept saying, "Take them off Hone," you know, "Take it off, take it off," and thinking, "Oh God, he is not listening now," and I could hear perfectly. It just took out the background noise, and it was great – best day at school I ever had that day.

We went and got the industrial earplugs after that because they were more socially acceptable ... but now you are out of earplugs, about mid way through last year you were able to cope without earplugs

We'd looked into it quite deeply for obvious reasons and so we were aware of lots of little things that would trigger him off. Even down to hitting kids and then we'd figure out with Tipene ... if a rule was you couldn't wear your hat in the classroom and he was aware of it and as soon as he saw a kid who had a hat on, he'd go for them and try to take it off them because that was a rule. But with him it wasn't, "Can you please take your hat off?" it was a go up and grab the hat and so that would lead to other things and fracas and fighting because other kids wouldn't realise what he's doing and teachers wouldn't realise why he did it. Lots of little things like that and it's only because we'd see it happen here or other places, we'd be around him when a similar thing would happen so we'd know that's what the problem was... Once we've explained things to teachers and they've seen it and understand it then they're usually pretty good. The other thing with girls, he used to hate them having their hair hanging down their front, it always had to be around the back and so if one of the girls would come in

[with her hair in front] he'd go and rip her hair around. But because of things we've said to the kids as well as to the teachers, now everybody is trying to recognise these things and understand why, so they tolerate it because they understand.

He has even got his own personal journal that I write in that just says what his days been like – if he has been the hell child, if he has been really good, what he has learnt, where he has come from. Like I can look back from the very beginning and see how far he has come from then to now, and I think, "We really need to work on that so we will bring that here," or whatever [and I can see] a lot of progress.

I would have to say that lifestyle changes are your best strategy. Routines, making sure that he had places to put everything, and not stressing the little stuff. Actually working out what was important and the fact that it took him 10 minutes every morning to tie each shoe – 10 minutes per shoe, making sure that we actually remembered to build that into the routine so that things didn't spiral out of control. That is the most helpful thing is really knowing your child and working around it, work with it rather than against it. I think that a big one was working out what the priorities were and not trying to force the other things to happen, so I have stopped panicking that he wouldn't make his bed and couldn't make his bed, and we have just dealt with it a different way. We have stopped trying to make him fit into the wrong kind of peg hole, we modified the hole. That is the best advice I could give anybody, was modify the hole or stop having one.

He is still challenging, we have learnt a lot of things like time out – that is a big role in our household. I do have to physically put him in there, because he is a child who, "If I don't get what I want I will drop on the ground and kick and scream," so yes, I still have to manhandle him, but at least I know, "I don't have to hit you Phillip, I can just put you in the room, you can do what you like in there, I don't care," and it is just a matter of switching off. Whereas before if Phillip was kicking and screaming I would actually go in there and yell at him and end up playing a stupid arguing game, whereas now I ignore him, put him in there and say, "You can kick and scream all you like and no one will hear you" – apart from the neighbours I think. I can't even remember his name, but yes, they came in and said, "Try some time out - so many minutes for a certain age of the child." Yes, I told them we could put him in there and forget about him! But no, it does work, it was the best thing they could have ever brought into the home. I know now that, "I don't have to hit you, I can just put you somewhere and just leave you there for five or ten minutes till I cool off too." Yes, I just go outside and have a coffee and get over it and start again. And, usually by then he gets to the point now where he comes out and says, "Can I come out now?" and I will go, "Have you calmed down?" and he will say, "Yes" and I say, "Fine," and we will start again.

That's where we used things like the multisensory room. They taught him not to be afraid of the beach because we set up a beach scene. The roar of the sea in the background, we had material hanging down that represented the sea, go through seaweed. I would carry him through it to begin with because he was that scared of what was happening. We had a projector rotating on the wall with things in the sea and we pretended to swim with them and we did that for three weeks. Before Lance used to be terrified of the sea. He couldn't stand the sound of it, the vision of it was too much for his eyes and he was just petrified and we spent a whole week at the beach after this three week episode [in the multisensory room] and every day he was walking up and down that beach, he loved it, he couldn't get enough of it. Now the sea is his favourite

place to go. But that's only because I could manipulate the environment experienced in a safe place, then transfer it.

This section outlined a multitude of strategies which participants reported as being effective for them. However the last word should go to a participant who noted:

That's the problem with autism because you have so many strategies that you've got to use. I've spoken to psychologists before and they've said, "With autism it is a whole range of strategies, not one strategy that works, you've got to use everything in your arsenal." Then it's trying to remember them all. You've got so many and you suddenly think, "I haven't used that in a while." That's why you have to be very knowledgeable.

Chapter Five: Barriers

This chapter describes many of the barriers parents have faced in providing care and education for their children with ASD. A number of culturally related barriers have been described in the previous section on Cultural Issues. The barriers included in this chapter are more general in nature.

SHORTAGE OF SERVICES AND QUALIFIED PERSONNEL

A major barrier reported by parents was the shortage of services and qualified personnel. People talked of long waiting lists, of inconsistency between services offered in different regions and of staff burn-out and high turnover rates resulting from heavy workloads.

One mother reported that the lack of occupational therapists in her region meant people either had to go private or wait for ages to be seen. She also noted that this shortage of professionals meant work overload leading to burn-out. It was a vicious circle.

The shortage of speech-language therapists was mentioned most frequently. One mother explained:

They had the speech-language therapist going in there to do Ross. That woman has got 500 kids on her book ... He saw her three times in two years... It was cheaper for Basin School to fly a speech therapist in from Brisbane, put her up in a motel for three days. They had nine kids in that unit and she took the ones that needed speech therapy which is seven out of nine, an hour a day for the three days she was here every ten weeks. Every ten weeks they flew her in.

Another mother mentioned that when her children were booked in at the Kowhai Centre they said, "You could be waiting a year or eighteen months," and she said, "No, I'm not, I'm not waiting that long, these children can't speak." She explained that there was simply not enough people to cope with the demand. "When you try to sit there and work out your appointments with them, they're so pressed. There are so many people to see."

She had requested physiotherapy for her son "years ago" and was still waiting.

A father complained of the long waits at hospital:

You go in and you know he's going to be in all night. You go in there at seven o'clock at night and you're not out till eleven in the morning but that's how it goes.

One mother noted that long waiting lists for services sometimes meant that by the time your name came up the crisis was over and the service redundant. She had asked for assistance from behavioural experts when she was near breaking point because of her son's behaviour. On being notified of a one month waiting time, she remarked:

If I want to they've got all of these extra caregiver relief hours that they can throw me which means nothing to me because Glenn won't have anyone else. He wouldn't even have his father with him in the night time. I said, "I can have all these extra caregiver relief hours but I can't get time with Behavioural Services?"

Another mother was concerned about her daughter being hit by another child in her class. A behaviour specialist was asked in to help rectify the situation but:

he has still not helped with my daughter like he was supposed to last year. He still hasn't got there so she is still getting hit ... I think though that they have sat down with their staff and teachers because they were waiting for this guy to come in and help them with that sort of thing. Now they're just doing their own strategy, just intervening.

When people shifted they lost their position on waiting lists and were put at the bottom of the line in their new location. This situation also discouraged parents from changing professionals or services when they were dissatisfied for some reason. The attitude was- better the devil you know than nobody at all!

The high turnover rate of various professionals contributed to the problem. One father remarked that they had so many changes of key workers that he had lost track of who they actually had at present. While a mother explained that her son's key worker never stayed long enough for her to build up a rapport:

They keep changing them. I don't feel comfortable ringing them up to have a chat about things so if you don't do that, you don't know what's available or what you can ask for.

A similar situation existed at school:

The good thing about this year though is it's the first year his last year's teacher is still at the school. The last three prior to that had him for a year and moved on. They had files and stuff but we had to start again.

DIFFICULTY ACCESSING SERVICES

Parents complained that even when appropriate services existed, they were not always able to access them. This was attributed to a number of causes including organisational rules and regulations, gate-keeping, geographic locality and the health of the child.

A parent commented:

Lianne Dalziel actually said something really, really interesting that she released funds, or got funds in the budget, a few years ago for an extra 300-400 kids to go onto the ORRS funding, to get ORRS funding - if they had 3 moderate type disabilities that added up to a big one, which Bart falls into, and this other kid falls into - two or three, I think they said three, but they looked at the kids with two as well. And, only 50 kids were accepted under that criteria, so she canned the programme and she was talking about how that didn't work, and I wanted to say, "The reason it didn't work is because of the people you have got gate keeping." It is not that the kids aren't out there and don't need the help, they absolutely are. It is that the people who are gate keeping the system aren't listening and that is the problem.

The "health capture" of services also came under fire:

One of the things that really perturbs me is that services for people in the autistic spectrum have been captured by the Health System. And, there has been this whole capture and that includes within the Special Education system, there is this narrow view of what a specialist is and what specialist services are. You can't look outside that, and so if that narrow view isn't what your child needs, there is no support to access what is actually going to help, and I call that "capture." This small grouping if you like, have captured the money, and they are not necessarily the appropriate people, or the appropriate profession to help our kids.

Examples this parent gave were access to piano lessons and classical ballet. These activities had been effective with her son but despite this they were not funded because they are not “approved” therapies. Instead children are channelled into physiotherapy and occupational therapy which this mother claims are more expensive, less effective and less popular with children because in receiving them they are “singled out as different.”

A further point this mother made was that the “health capture” of services was inappropriate because:

the health system is looking after people who aren't well. Our kids are well and healthy, but there is something else going on there. It is medicalised, you can't get anything without a doctor's report. Your average doctor wouldn't know an Asperger kid, your GP, they don't know bugger all, they just don't!

This mother related an incident where the “gate keeper” GP would not give her a referral to a neurologist because he said:

“You have seen too many specialists, you can't see any more.” And so, I had a tantrum, literally actually cried and jumped up and down, and threatened violence, and I got to see a neurologist, but I shouldn't have had to do that. I should have been able to ask and have him say, “Yes, okay I'll write the letter,” but I had to have a hissy fit.

The disadvantages of living in a rural location were mentioned by two participants. One mother complained that the TIPS programme, which was proving beneficial because of its inclusive approach, was not available in her area while another mother noted the lack of services in her previous township:

The speech-language therapist only came once every six weeks and this wasn't enough for my son... He is going to correspondence now. I'm going to do correspondence with him because he can't deal with the level of work they are giving him. Yes, it is just a matter of new things every day. I wish Smallville had this, then I wouldn't have had to leave but I'm glad I did. It had it's pro's and con's, we left our families behind.

Four parents noted how access to support groups, play groups and parent organisations was limited because of where they lived. As one mother explained:

Well, it surprises me the lack of education out there, or even classes, or support groups in town. There is “Mums” in town but there is none over here and a lot of us can't get to town, or know our way around town for that matter.

Accessibility to various services was also limited by children's poor health. One father noted that he has not been able to make the most of respite care or have his child benefit from various activities because of health problems:

I've heard a lot of good things from IHC with these camps that kids go on. Things like that, I would love for him to go to something like that by himself with somebody that's going to look after him. I always try to figure out why he doesn't go to these things, why doesn't he do this? Why doesn't he do that? and it has only just recently come to me, it's because most of the time he's been in hospital or sick. They've been available but we've never been able to tap into them because he hasn't been well enough. This is how it is.

FUNDING ISSUES

Insufficient funding, lack of transparency in funding, ineffective funding systems, disparities and funding cuts were all issues that caused parents considerable concern. A number mentioned that they lived under the threat of their child's funding being cut - it had been in the past and they were worried that it might happen again in the future.

From the funding side of things it has been a battle. Every year from when he was five to about eight they'd review his funding. He was getting really good hours and then they cut them in half. That's what I didn't understand.

Parents were concerned not only that their own children's funding would be cut but also that of other children. One mother explained:

Two of the kids who are in Kevin's special needs unit... have applied for ORRS funding and been turned down. I couldn't believe it. One of them has huge behavioural issues. I then phoned the chairman of the Autism Association and said, "Have you heard similar things?" and I saw another parent and said, "How are you going?" and she said that she'd been turned down. Because I knew kids who received funding three years ago and knew her child very well too, I couldn't believe that her child had been turned down. It seems as though the goalposts have changed. I made some phone calls and one of the calls I made was to the funding agency and I was told, "Rachel, I can assure you that there are a lot of children losing funding, that Kevin will have a tick next to his name and his funding will be retained" and I said, "That's very nice but you don't get it, do you? The other children around him who need funding aren't getting funding, it puts Kevin at risk." Because he can't talk and because he can't express himself if he gets hurt or if something has happened, he's vulnerable and I said, "So if the other boy who is very violent and the other boy who has huge behavioural issues, if he's not funded then all of the children around him are at risk, so I'm not going to go away." ... I said [to the mother whose child lost the funding] "How do you feel about that?" She said, "Oh well, my husband is absolutely furious but we've been told there are kids like Kevin that need it more." I said, "If your child had asthma and they finally got the asthma under control, they wouldn't dream of taking away your inhalers saying your child is doing so well, we'll just take him off all his medication now." I said, "If your child and my child had leukaemia, there's no way they'd say to the parents, "I'm sorry there's just not enough drugs to go around to treat all of the children, so you'll just have to share it." I said, "That would never happen if it was a medical condition so why are you standing there? Why are you just taking it?" But then she said, "I just don't know what to do."

One parent told of how a severely disabled child's teacher aide hours were cut in half. When the funding agency was challenged about this, the parent was told that there was not enough money to go around. Undeterred she obtained the organisation's annual report (under the Official Information Act as the report was not freely given):

In the report, the previous year they had a \$1.3million excess and they had \$13 million invested in the bank. They were telling me that the teacher aide hours were cut from ten hours to five hours because there's not enough money in the pool ... They keep telling us there are not enough speech-language therapists, 13 million dollars buys you a lot of services and if you can't provide it that money should be made available so that services can be purchased in other ways but apparently that's just not how it goes.

Insufficient funding was frequently mentioned. Some children's teacher aide hours were being topped up by their school, some parents funded extra teacher aide hours themselves while other children were only attending school for the time their funding covered a teacher aide. The message that was being given by teachers was that for safety reasons, if a child did not have teacher aide time, they could not attend school. When checking out schools to send her son to, one mother reported:

I rang the school and they weren't interested in having him unless he was high, very high needs on their ORRS funding because they needed the money.

Interviewer: Did they say that?

Tom Jones turned around and said, "Is he ORRS funded?" and I said, "Yes." And he said, "The way our financial budget is for the year and you're telling me he needs a teacher aide full time, he'd better be very high needs because we'll need his money to cope with him." I turned around and said, "He is very high, he gets a point two teacher, at the minimum he will get 22.2 hours teacher aide" and he said, "Yes, that's good, we will put him into the school for 22 and a half hours then." I turned around and said, "Right, we don't want you either."

Another Mother noted that while her son was not fully funded, there were others who were a lot worse off:

There's another boy who only goes for the mornings and that's all because that's all their teacher aide time allows for. The parents are Māori, she's a beneficiary, he's got huge behavioural needs so he can only go for the morning. So it means that Mum has him for the afternoon and the mornings are often not enough time to have a sleep or catch up or just to have any time to yourself so that it gets put back on her for the afternoon.

The requirement of having a teacher aide was also enforced in some early childhood centres. A mother who had two children with ASD reported:

They didn't want Leon left alone so if the teacher aide couldn't be there I had to be there but I wasn't allowed to take Ameria with me. I don't know what I was going to do with Ameria, leave her in the car or something! It was horrid.

The ORRS system of funding was not popular amongst a few parents. As previously mentioned it was considered to be Māori-unfriendly. Interestingly, while one mother objected to the negative focus of ORRS, another had problems with the positive focus. She believed that highlighting achievements in an application took attention away from what children couldn't do. It painted a rosier picture than existed in reality and could result in the child missing out on funding.

The administration fee taken from ORRS funding was criticized by one person while a couple challenged the lack of transparency:

There's NO transparency with funding. I don't know how that works but the principal of the school regards that, I suppose, as their business.

They haven't actually given us an estimated amount.

How much is a school given in regards to children with disabilities? They must have a percentage.

Exactly. This is where the school system is shrewd because if there is a high needs child that comes into the school, I believe that their money is put into a pool and therefore unknown to parents. Jamie is covered in regards to his hours at school. We don't know how it's covered ... But I think what they do is share the burden of their teacher aides to cover everybody and with that pool of money they can actually update the special needs room but if it hasn't been updated what else have they done with the money? Apart from people going in there and doing special audits, no one would be able to track where the money has gone. I believe that they try and do what they can with the money... We know that Jamie gets funded, that's about it. [We would like it] broken down so we can see how much the school gets, how much Jamie gets and where is that money going.

The Government's funding system for special education programmes also came under attack. In particular the lack of funding for the on-going provision of promising programmes:

That's the problem, most Government funding comes in a chunk to develop something. When the chunk is finished that is as far as it is developed. It gets buried... [There was a course where] the parents actually went in and they developed a training package and the parents went and held it for groups of teacher aides and some teachers attended around the country. But that has fizzled. They got a huge amount of money from the Government to hold it and then it disappeared off the scene.

One parent believed children with Asperger Syndrome were more disadvantaged in accessing services than children with classic autism:

The Asperger kids in particular don't meet the criteria for ORRS funding and so they never see the money and they never see anything and everyone just struggles, and they fall through the cracks and that is it.

Similarly, a second mother complained because her son was not considered "severe enough" to qualify for ORRS funding. The school was doing its best to meet his needs from their funding and the services available. However, the teachers felt that her son's needs were not being adequately met and they were seeking a review of the ORRS decision.

Another issue raised by three parents was the disparity between the funding supplied by ACC [Accident Compensation Corporation] and that provided by the Ministries of Health and Education. One mother compared the funding her son received with that of a friend's son who was under ACC. Although her son was more financially demanding, his funding was miniscule in comparison!

LACK OF INFORMATION

A major problem reported by parents was the lack of information about services and entitlements. This has been previously discussed in the Early Years - Diagnosis section as it is particularly problematic at that stage. However, parents reported that it was a continuing problem. A couple remarked:

Parents need to know. They don't need to just know this and this, they need to know everything. We feel we are being kept in the dark.

We didn't know about the disability allowance. It feels like you're banging your head against a brick wall every year.

I believe that's how the Government likes it - here are hurdles for people to try and get over to really see if they are committed to looking after their own children. I think, "They're playing their game again."

Another person commented:

But, in terms of what you are entitled to, it took me forever just to get hold of the [organisation for this information] ... We floundered really, we still are floundering along, not really sure where you fit, or who you really see. It is hard work, the amount of times where I have just wanted to say, "Okay, I can't do this anymore."

While a third parent noted:

Without my cousin having been through it I wouldn't have known about respite care, I wouldn't have heard about child allowances for them, so really it is not widely advertised that if you have got a child with a disability, this is what you can get. You know, when you see ads on TV about Family Assistance - you do this and this and this, you can qualify for that, so why not [for children with ASD]... Helpwise ... it is there, it is just hard to find.

This particular mother reached crisis point at one stage. After physically hurting her son she made a number of desperate phone calls to find help. She stated:

Yes, now I know how to deal with it, how to cope with it, I know who to get hold of if it gets to the point where it gets too much, and I have got someone on call 24 hours if I do get to that crunch time. Even Support Services said, "If it gets to the point where you can't cope with him, ring us and we will come and get him, and we will just take him away for the night."

Interviewer: And, that is what you needed to know before you came to that situation?

Yes, that is all I needed - there is help there - why didn't you say that before?

Parents reported incidents of being given incorrect information or minimal information from people who should know. For example, one mother was told that they were not entitled to a child disability allowance because it was means tested. Years later when she discovered it wasn't, she tried to get the allowance back-dated to when she was given the wrong information. She was not successful. Another mother's experience of dealing with the same organisation was:

I was actually quite disgusted at the lack of knowledge, when families ask for help, they get minimal response, or they are not told where they can go for help.

In the end this mother was given information because she "screamed really loudly and they gave it to me to shut me up!... I have just got no shame. I will just go up and ask anybody which is quite handy." However, she was concerned that because information did not come as a matter of course, people who were less assertive, less confident or did not know the right questions to ask, missed out.

One mother whose son was under ACC noted that accessibility to services was easier for her given that funding was available from this organisation. What was difficult however, was finding out what services were appropriate to access. Similarly, another mother complained that because services had not been offered to her, she was forced to find them for herself but she did not know where to start looking.

FINANCIAL STRAIN

A strong theme to emerge from the interviews was the financial strain having a child with ASD placed parents under. This was mentioned by most parents. Various types of financial assistance were available such as the child disability allowance, travel allowances and funding for such things as fencing and home modifications. While these were greatly appreciated many parents stated that they came nowhere near covering the extra cost involved in raising a child with ASD. The extra costs that were mentioned were: special food, shoes and clothes including imported seamless socks; carpet cleaning; repair of damages such as fixing holes in walls, ripped wallpaper and broken furniture, cupboards and equipment; replacing torn school books and wrecked CDs; expensive “ASD-proof” toys, games and puzzles; expensive therapy such as ABA and ISADD; travel costs to doctors, hospital, school, school trips and therapies; equipment for teaching including computer ink cartridges and software, laminating, talking books and puzzles; music lessons; locks; information costs including photocopying, books, meeting and course attendance; medical expenses including doctor, dental and specialist visits and medication; costs of consultation with Tony Attwood; nappies; car seat restraints; relocation costs and bubble bath! While many of these expenses might be considered the natural costs of raising children, it is the amount and frequency involved rather than the item itself that is different. For example, many children wreck their school books but not on such a regular basis as some children with ASD. Similarly, many parents accompany their children on school trips but they travel on the bus with them and are not required to take their own car just in case their child “plays up” or becomes upset.

Parents talked about the expenses they faced:

The financial is mainly the damage ... because when she gets mad she can lie down on her back and she can put a hole through the wall. She's kicked the wall in there but usually if we've had to put her in the room I've had to put the bed in the middle of her room and she lies on the bed and I don't put her by a wall because she'll kick through it on purpose or she'll pull the cupboard off. Those damages are real damages and you're not allowed to get any help for that. They don't recognise that. I know about that sort of thing and I know that when parents want locks, they want locks and they need them now... That's related to the disability, that's related to autism. Repairs are not covered... She was way worse when she was little. There were holes in the wall. I had to get tradesmen in, I had to paper that myself, she would shove things down the toilet and you'd have to get a plumber in, all that sort of thing.

The financial drain is absolutely incredible. To think that I'm not available to go and work, mainly because we don't sleep at night so I catch up in the day time or make myself available for school if he's having a bad day and now he gets taken late, he gets brought home early or he doesn't get taken at all. After he suffered from the separation anxiety at the end of October, we rarely went to school because by 11.30am I would say, “Don't worry I'll just take him home with me” or I'd have to take him there and then try and sneak away which wasn't that great for him in the end and we found it was easier for me to stay than for him not to go. So I would be the worst employee ever. Just for me it's not an option to go to work. So we have a reduced income and as well as that he's so destructive, we're just constantly replacing things and constantly having to fix things. It's little things like my daughter buys a CD and within 20 minutes he's bitten it and it's useless. Him breaking stuff, even with climbing and breaking and pulling the wallpaper off and just constantly wrecking so the financial drain is huge and we do appreciate the \$38 a week. Most of the time it doesn't cover the doctors trips and the

prescription charges ... We've been very lucky in our case that my husband in his business that we're financially well resourced but I can't imagine what it's like for the parents who are on the benefit or Māori with low income. How it must be for them and how they can't just keep replacing and replacing like we do. We went through a stage before we had the kids, we worked hard and we took a lot of pride in what we had and you slowly have to change all your values - "It's only whatever!" I think that's difficult.

Six mothers specifically mentioned either not being able to work or having to take night shift and weekend work when their partners were able to baby sit. A solo mother explained the choices she was faced with:

For example, getting a job, you have to jump through all sorts of hoops to come up with the right formula so that you can get the job and look after your child otherwise you're either going to be not having a job and be as poor as anything or ... have a full time job and then there will be a stress at the end of it. I had to find the middle ground and that middle ground has a cost, that is a lower salary than I could make. I could make twice as much if I worked full time so that puts me in a lower economic bracket only because I've got a daughter with a disability.

One mother questioned why she could not be paid to look after her severely disabled daughter at school. Her daughter had attended a kōhanga reo where the mother was employed but now that she had moved on to school the mother needed to give up her job because of transporting demands. As a consequence of giving up her job, mortgage commitments could not be met and the family house was put on the market.

Another mother talked of "struggling to afford" the music lessons she believed were so beneficial to her son:

Most families are like us, they are single income families, money is a real issue. We are hugely disadvantaged as a community because you have a child who requires so much care and attention that mums aren't able to work.

The cost of taking their children to and from school was a considerable expense for some parents. Although a travel allowance was paid, parents commented that it did not cover the actual costs involved. For example, one father was having to travel 60km a day to take his son to and from school. In fact this father could have utilised a taxi service but he chose not to as a previous driver had "rude magazines" in his cab and so the father was uncomfortable having his son travel alone in taxis. Two other parents chose not to use taxi services because of one child's challenging behaviour and erratic time schedule and another child's sister not being allowed to travel with him.

A number of parents also mentioned that while financial assistance was available, the effort, explaining, "red tape" and length of wait for approval were off-putting and sometimes upsetting.

The other financial thing was going to the specialist at \$160 an hour. I paid for that too.

Interviewer: That should be covered, shouldn't it?

I couldn't find the appropriate help and I didn't want to be stuffed around too much about it. For me it was very traumatic even going there and getting my daughter assessed and me being told what it was so I didn't want to go through the WINZ thing too much so I just found the money myself to pay for it.

Interviewer: When you say traumatic, why was that - because you were having to seek help or because of the nature of the people there?

It's just being constantly reminded that there's something wrong with your child and there's not a damn thing you can do about it.

After waiting for twelve months to get a plastic covering on her wall, one mother described the circumstances that hastened things along:

However we did have the OT [Occupational Therapist] in on Monday because we'd put the plastic lining in the bathroom and I'd phoned them up and asked if through ENABLE whether they would pay to put it into the toilet as well. While waiting for that to happen Reggie had kicked holes in the wall so I asked if we could have it on the two walls in his bedroom and said it's because of the toileting. The builder said, "We haven't done this for anyone else before." I said, "I don't care, he's not toilet trained at nearly eight and if he gets it on his hands he just wipes it on the walls. This is a toilet, we have heaps of people through like the whānau and his sister and I want to be able to just spray it and wipe it rather than it getting ingrained in the wallpaper." He then said, "Okay, give me a minute to measure up" and the occupational therapist and I came out here and Reggie was on the bench top pooing! He was crouched over. I said, "Get down from there and go into the toilet right now" and so he put his poo into his hand and went running past her with the poo in his hand, plonked it in the toilet and wiped his hand on the wall. I thought, "Brilliant!" So we are getting funds.

One mother noted how her son's dribbling caused wear and tear on his clothing while his flat-footed style of running played havoc on his shoes. Replacement shoes were usually dearer because he required footwear without laces. In a similar vein, one child who had tactile sensitivity could not bear to wear socks with seams across the toes so his mother was getting seamless socks sent from the United States until she was able to locate a source here in New Zealand.

The cost of various early intervention therapies, ABA and ISADD were mentioned by five parents. One family was fortunate enough to be given a grant from a charitable Trust to help pay for her son's ISADD therapy. It was recommended that he receive at least 20 hours a week therapy but in order to make the grant money stretch, the child was having 10 hours with the therapists and 10 hours with his mother. His mother remarked that learning how to provide therapy was great but also noted that her son was better behaved for the therapist than for her. Whānau were investigating possible Māori Trust or tribal funding for ISADD sessions but so far none had been identified.

A parent who home-schooled her son noted that ORRS funding did not go anywhere near covering the teaching expenses involved. Equipment such as tactile objects and talking puzzles were paid for from family funds. Her twelve-year old son who was incontinent had only been receiving free nappies for the last four years. Glasses were partially funded by the Foundation for the Blind but the mother commented that it was the "sheer volume" of requirements that resulted in financial strain. "He's cost us in the vicinity of about \$40,000 so far." Another person noted that medical related expenses for his son had cost him his "life savings."

Extra costs were often of an "invisible" nature. For example, one mother explained how she was reluctant to use the toy library because her son was likely to destroy the toys provided and also because he became so "attached" to some toys, returning them caused a problem. Another parent noted how taking her son to the movies could be an ordeal. After paying for him to get in, he could

start screaming and disturbing everyone so she would have to bring him out - but her money would not usually be refunded! Parents were also charged for school “activity” fees for activities their children could not participate in and, ironically, had to pay extra for substitute or additional activities. Five parents mentioned having moved or were planning to move specifically to give their children with ASD better opportunities for education and life. Therefore, the expense of shifting is another cost that is indirectly related to ASD.

ASSESSMENT HASSLES

A variety of problems relating to assessment were mentioned. These included: inadequate time to assess properly; inappropriate assessment tools, procedures and venues; “missing” assessments; inexperienced assessors; the subjectivity of assessments; and “waste of time” assessments.

One parent’s assessment experience illustrates the problems faced. Her son was given two 15 minute consultations spread over two weeks. On the second occasion he had had a major epileptic seizure in the morning and despite the mother’s request to postpone his IQ testing because “He won’t be able to sit still, this is his normal post-seizure behaviour” the assessment proceeded. The outcome was he was diagnosed as having high anxiety levels and ADHD [Attention Deficit Hyperactivity Disorder]. Drugs were prescribed which the mother described as ironical because the original reason for the assessment was behavioural - her son was refusing to take his anticonvulsant medication! “What I was really looking for was some help and some strategies to get him to take his damn pills. We didn’t get any of that instead he got a lecture and Ritalin!”

Another parent had a similar experience. Her request was for assessment at home or in another environment where her son felt “safe.” She explained how he hated hospitals and played up to such an extent in that environment that an inaccurate assessment resulted:

[Home assessment] would make our lives so much easier, because this is the one place that he feels safe. If he is feeling unsafe, which happens quite often, and he gets very uptight and stuff like that, you bring him home, as soon as you get him home he will settle down - he is home, he is safe. If he could be seen in his natural environment as such they would see a different kid, but of course you take him outside of that environment and he is just bloody berserk. And, the last time we saw the paediatrician he was talking about medication for him! For ADHD.

I don’t believe that this child has ADHD, because look at him, he has been sitting on the computer for ages. He will sit down with you now and read for an hour, that is not a child with ADHD, but it is what the other environments do to him, and his only way of dealing with his fears and anxieties is that he acts out and his behaviour just becomes appalling and he cries and he screams and he hits and drops.

The boy’s father added:

Usually I end up putting him into a fireman’s hold and dragging him into the hospital!

The subjective nature of assessment was questioned by one mother. She complained that her son was not entitled to physiotherapy services because he wasn’t deemed to be “bad enough.”

The fact that he couldn’t tie his own shoe laces and the fact that he tripped over everything all the time, but he wasn’t bad enough. He was in that grey area, and that

just annoys me too, because it is really subjective. What's bad is a problem in the kids life, yes, it's bad enough, we will do something about it.

Two parents challenged the amount of assessment that was required for funding purposes. A father remarked that despite early assessments noting the unlikelihood of there being “any significant change” in the future, their daughter was still required to have periodic medical assessments to ensure that her funding continued. While another parent remarked:

It just strikes me that ACC is paying \$300 to have her assess something that we already know from years of experience, to get something that is going to cost \$300 for two terms of one-on-one assistance - 'arrrgghh,' it is really frustrating!!

On the other hand, a parent noted that although her son had a whole range of assessments conducted on him, they never included any testing for his tactile sensitivities. She commented that it would have been really helpful to have known at an early age what her son's sensitivities were and what could be done about them.

ORGANISATIONAL, SYSTEM AND PROCEDURAL HASSLES

Parents reported a variety of organisational barriers such as “red tape,” inflexible rules and timetabling, competition for clients, administrative delays, inappropriate resources, and unhelpful work styles and scheduling.

One mother told of her battle with “red tape”:

Last year I was advised I had cancer and I asked if I could have more respite care just in case I needed it. I had to make this application and that and I had to have papers from down in Wellington and papers from Palmerston and in the end I just said, “Stuff it, it's just too much work!” In the end I never needed it but I just felt, “I can't be bothered, I don't want to talk to you anymore,” it was bad. Fair enough needing one letter but not continual we need this, we need that, we need this.

A couple described their experiences of inflexible rules and unhelpful regulations: Knowing their son Tama would have problems coping with woodwork and metal work, the parents suggested that instead he “double up” with sewing and cooking. This could not be accommodated and so Tama now leaves technocraft early to return to his primary school. The parent's suggestion to solve a transport problem was also not listened to:

Another service that we were working through was the taxi service for Tama. [He qualified for the taxi service but] we'd still have to go to school to take his sister anyway so there didn't seem any point. We even suggested that maybe they take both of them either to school or home from school and we do the other trip... We would have been quite happy to do this but they said they couldn't take special needs kids and non-special needs kids in the same vehicle. I don't know why. There must be some law or rule. So we ended up not using that service.

However, another parental request was granted - eventually.

It has taken a long time for them to realise that he needs to have that time-out space where he can go away from all the other kids. It took a long time for us to convince the school to let him do that because they have a policy that at lunchtime or playtime the kids have to be outside in the playground with all the other kids and for him he used to

hate being around lots of noise, he still does. Environments like the playground can be overbearing for him. He had to search for a quiet place that he could go. He'd often just go into somebody's classroom that was open just so he could be by himself. So we tried to convince the school to let him go into the library because he used to love reading and when it got to situations like that, he'd be quite happy ... just to go into the library and get a book and just sit down and read. So those are the sort of things we've been pushing for at school.

The final example relates to school camp. The BoT at Tama's school refused to pay for the overnight support needed for children with special needs. When the annual camp was close by Tama could go for the day but needed to return home at night. When the camp was further away, the parents reported that one of them must accompany him on camp or Tama would not be allowed to go. His teacher aide was more than happy to sleep over with him but the BoT refused to pay the extra cost involved.

Taxis also presented a problem for another family. Because one mother chose to send her son to a school across town and had to bypass a number of schools enroute, her son's taxi was not funded.

I said, "Legally they [schools] are not allowed to turn my son down, but I'm allowed to turn them down and I don't like their attitude." He ended up taking another month off school to fight all the "red tape" to get it.

One parent battled with her son's school about moving him out of the new entrant class:

They said to me, "Our policy here is that the child is to stay at new entrants for this long and then we'll move him," and I said, "I don't care what your policy is, this is when Jed will move, you have to accommodate him, he doesn't have to accommodate you or fit in with you," and I left and they sat there looking like, "One of those mothers!" They're going to move him soon up to another level but to me he's really intelligent anyway, socially he has to be ready as well otherwise a lot of damage can be done... You can have all the intelligence in the world but if he can't start talking or interacting because he's being pushed up too fast then it will be no good for him... His social skills are more important to me.

Another parent complained about the delay in getting resources. After two years of waiting for a computer for her son, his school received it in the school holidays before he moved on to college. The wait for free nappies was even longer:

Mind you, Tamati was incontinent until he was nine and after arguing and asking and asking, because he was night time incontinent, the incontinent service rang last year and said, "We found your referral," and I said, "but I asked for that 10 years ago!" She said, "Oh, it is a bit out of date, I wondered."

The inappropriateness of resources was another issue:

You go from doing Te Whaariki to primary modules and then those children that are so developmentally delayed, they sit right between the two. So the manipulative play things that they have for the younger ones don't fit Bennie because he knows they're not age-appropriate. The toys that come in at that higher end are too advanced, he can't do them.

Two parents described teaching schedules that involved frequent changes of teacher aides. Their children found this confusing and unsettling: “People would come and go and disappear ... and he wasn’t shown properly where they fit in.”

Although having respite care was really appreciated by one couple, they found the “red tape” involved frustrating. The detailed timesheets that needed to be filled out, signed and submitted every two weeks had to be posted by a certain time or the carer missed out on their money. The family asked if they could email or fax these sheets but this was not permitted:

What makes it harder, a lot of people with special needs, even though it’s the carer that’s meant to be sending out the form, the parents have got to sign them anyway and if it’s a family member it’s left up to me to send the forms and it’s hard for me to get out, to take two kids down to the post office, it would be much easier to fax it.

One parent talked of inter-organisational rivalry:

In fact, to get social stories for us the only place that was doing them was Miro Services, and our then Tui Services person actually snuck, because they weren’t allowed to give work to Miro, they were seen as rivals by the old manager at Tui Services and so she snuck the Miro person in to see us one evening at home, took time out of her own busy schedule to sort that out for us.

In a related vein two parents mentioned the mixed messages that were given out about the ABA programme. This was strongly supported by some organisations and “experts” and criticized by others leaving parents quite confused.

Three parents criticized the consultative model of working as being of little practical use to them:

I found them absolutely useless. All they do is do a consultative model. Nobody came in and actually showed me, “This is actually what you do.” I had to go to books and read up and find out what you do, how do you teach.

They wrote down a lot of notes and they hardly did anything really.

Probably the most frustrating thing for us all the way through the journey has been, this is at the hospital and also the so-called professionals who come in. They come in and they listen to where John is up to and then they just write a report on it and so many times I’m saying, “What are you going to do about it? When do we actually see the therapy? When do we see the real work? When are you going to tell us what to do and how to fix it or how to get to the next stage?” and that just never happened.

Similarly, a couple considered their child’s team to be following a predetermined process that was not actually achieving anything:

This is how I feel about Special Education ... “What are you going to do about it? Why do you come to these meetings because you don’t get anywhere?” Once again they’re doing their tick in the box thing, they come through, they look at the calendar, “Oh yeah, it’s three months, we’ve got an IEP with ...”

There are so many different Special Education people, he’s been through so many I’ve lost track and I don’t even know who his one is at the moment.

Okay people need to grow and they move on, I can't help that but the information that they hold is in that dusty old filing cabinet that they pull out - "Oh it's three months, we have to ..."

One parent criticized the need to have people attend meetings purely for administrative reasons:

We have no choice, we get XY services because they hold the ACC contract to ensure that IEP's are right and everything goes well, and that is a national contract so there is not a lot of choice ... Paul's case manager after the last IEP said we had two people from XY sitting there, we are going to get charged for their services and it was blatantly obvious that the school staff and I and the ACC lady could have done it without them, that there was no real purpose in them being there other than two extra lots of paper work and money.

A LACK OF KNOWLEDGE AMONGST PROFESSIONALS

Parents complained of professionals not appearing to have the necessary expertise and of making incorrect, unwise, unreasonable and sometimes bizarre decisions and statements. The doctor who told parents not to give their son apples or he would grow too tall is a case in point!

An example of an incorrect decision was when a child's previous diagnosis of Asperger Syndrome was changed to ADHD after the post-seizure assessment described earlier. In the mother's opinion the report she received showed the assessor did not fully understand Asperger Syndrome and the drugs described were inappropriate:

I said, "No, he is not going on Ritalin,"... it reacts badly with the anti-convulsants, haven't you read that? We know that they are not a good combination for anybody. I honestly felt like, "You are the experts, why don't you know this, it is all there, it is in your little drug book when you look it up." And there was no way I wanted him to go on the happy pills - the anti-depressants, or anti-psychotics, I said, "He is post-ictal today, if we can get his seizures under control a lot of this behaviour minimizes. The stuff that you are really worried about, it minimizes when the epilepsy is under control. Don't you know anything about epilepsy?" Obviously not, it was really inappropriate. And the report went everywhere because they are really proud of their reports in that service, so it went everywhere. I spent two months mopping up the damage they'd caused and in the end everybody screwed that report up and tossed it.

Parents frequently talked of the lack of knowledge about ASD amongst teachers and teacher aides and of the inappropriate programmes their children were receiving. Setting work at a too difficult level; not preparing children for changes in routine; class trips to inappropriate venues; practices and procedures that did not take ASD traits into consideration; requiring children with limited concentration to work for long periods of time and to do activities that were completely inappropriate were common criticisms. Some examples include:

They put him on a beam. I said, "Don't put him on high things because he can't walk properly." They put him on a beam and they said they had someone on each side and I had a phone call saying, "Jackson is a bit sore, he's fallen over, what shall we do? Shall we take him to the hospital or the doctors or shall we wait until you come to pick him up?" I said, "No, take him straight in." So they took him over and I met them over there and he'd broken his leg. He fell off the beam. The week before that with another boy the same thing happened. I didn't know that until the mother came in and told me.

Jackson couldn't hardly walk properly so it was stupid to have him on the beam. So we got that fixed but then the leg wasn't quite right, it was a bit out of shape to what it normally was so I took him in and they said it was a bit too far out when they set it so we went to see the doctor to take him to the specialist at the hospital to check him out. There were two specialists there checking his leg out and they said they'd take him to orthotics to have braces on his legs. We did all that and he seemed to be walking a lot straighter and then a couple of weeks ago I heard from the physio at the college saying they don't think the braces are very good for him.

They didn't structure his programme around him, he didn't know what was coming and they had things that they wouldn't prepare Jason for, like they were having a morning tea at school. All the school would come but Jason wasn't prepared for that. It would really agitate and upset him... They didn't know what to do and when they used to do news time, it went too long for Jason because their news time would start after karakia time and it would go for about an hour and a half. They would do their news and then go and do it on the computers or whatever they were doing but Jason's got a short attention span, goes from here to there and then you've got to move onto something else. He'd spend half his day yawning because he was tired and bored ... Jason has a vision impediment and they were not taking into account his vision. There was lots of glare in the classroom. There were things being displayed to Jason that he couldn't see ... Because he's got cortical visual impairment he works better with objects than being shown the visuals and none of that was done even though I gave them all the information that I had at my disposal.

The early intervention teacher said, "Children learn through play," and I said, "Yes they might have 20 years ago, but they have found with autistic children that they don't learn through play because they aren't interested in other kids and don't watch the other kids. If you leave them in a sandpit they will just do the same thing again and again. And if you leave him, Bill instead of drawing with crayons would rather line them up, so he's not learning from watching the other kids." She would not accept that and we couldn't get that passed her, and her attitude filtered through to all the other staff... The speech-language therapists had no idea of how to work with him or what to do and the psychologist had no idea what to do with him either. We said to her, "How do we get him to play with us? How do we get him to pay attention? How do we provide the best learning situation for him, so he's not just sitting on the carpet all the time looking at a fleck in the carpet?" She sent us six pages of things about play. I phoned her up and asked her, "Did you not listen to anything we said? Did you not notice anything he did? Nothing in these forms is appropriate." She said, "Yes they are, they are standard [information] about play for a normal child."

[In his first year at school] the teacher expected all her children in the class to be all one, at the same level and she didn't see that Jeremy had a disability. Jeremy was really disruptive but only because he couldn't express himself... His attention span is not that great... She expected Jeremy to do this, this and this ... Jeremy is in his last year at school and it's only just now that another special needs teacher came in and talked to the vice principal and they looked at Jeremy's programme through this year and they broke all his programmes down to 10 and 15 minutes. Now why didn't they do that at the very beginning? This is what I couldn't understand. They expected Jeremy to do something for an hour, and another hour.

Last year, Cain's teacher, I had to go in and talk to her several times about his reaction to things they had done in the classroom, things they had changed. He didn't want to go to school at one point because they had changed the rules about going to the toilet, and somebody was weeing on the floors in the boys toilets, like that ever stops! So from then on they had to go in pairs and of course Cain, no way was he going to go to the toilet while someone else was with him. It is too much for him, he doesn't cope with things like that. So, he actually made himself sick, he wouldn't go to the toilet all day. He came home one day from school and he was in the toilet every five seconds nearly, and he was going to the toilet for an hour, and I was like, "Whoa, what is going on here?" The next day he didn't want to go to school, "Okay, what is going on?" "I don't want a toilet buddy," "What is a toilet buddy?" He told me they had to go to the toilet in pairs. I went to the teacher and said, "You can't do this, you can't put that on him because going to the toilet is hard enough for him anyway." I said to her, "If you are going to make changes like that you are going to have to talk to me so I can walk him through it."

In an effort to upskill this teacher, the mother brought her attention to the Cloud 9 book on Asperger Syndrome that had been donated to every school. The mother was told that she could read it because the teacher would not have time.

Inappropriate discipline methods were also mentioned. One mother explained:

Their idea of handling a kid that has already got on his school records as very violent was he would punch the teacher aide, kick, bite and then they'd take him to the park, buy him an ice cream and let him play. You could not get into their heads, no wonder he's punching, kicking and biting you when they're going to give him an ice cream, take him to the park, don't be so stupid! But that was their way of coping was putting him in the car, "If you stop hitting and kicking me we'll go and get you an ice cream." They bought him a popcorn maker. I said, "No, you tell him to do his work, do it without an argument and then we'll get you some popcorn but otherwise its no and go to time-out and don't argue."

Teachers' lack of knowledge placed an extra burden on parents. One mother explained:

When he first got there, it was terrible, at lunchtimes the kids would have to sit in a particular area while they had their lunch... He used to hate noise and one of the areas was where the school bell was so when the school bell would ring after their lunch eating period, he'd hate being anywhere near that area because of the school bell. So little things like that we'd figure out and then we'd have to tell the school. Because something would be happening and we'd have to look into it and try and figure out what the trigger was. We'd figure it out and then let the school know and come up with a solution or an alternative and then that problem would go away but it's a battle when it's us that has to keep figuring these things out.

Three parents mentioned unreasonable requests from professionals. One related to asking a mother with three young children to instigate a time consuming programme at home. The other two parents talked about an expectation teachers have that parents should deal with problems that arise at school:

At the IEP meeting, because they say that William has been disruptive and hurt the teacher by kicking, what are we going to do about it?

Similarly, a teacher's strategy for handling a child's inappropriate behaviour at PE (Physical Education) was to ask the mother to deal with it at home. She replied:

It's not going to work, school is school, home is home... To me if something is happening at school that's life-threatening to him, if he's threatening the other children, fine, ring me up, I'll go and pick him up from school but pinching another teacher's backside! They wanted me to say that it was inappropriate and to stay by the teacher aide and don't leave her side. So I am sitting there scratching my head thinking, "Fred didn't go to bed at 7.30 last night I want you to ring him up and tell him it's inappropriate." The teacher could not get the point. That's when I said to her, "We had roast chicken last night and Fred ate like a pig and choked cos he scoffed like a pig. Tell him tomorrow when he comes to school- no canteen today cos you ate like a pig last night! She couldn't see my point that it was stupid. They took him away from PE and completely ignored the situation, very old-fashioned, out of sight, out of mind, if we don't mention it, it's going to stop. It will ease off and finish itself. I said to them, "Out of sight, out of mind doesn't work with Fred."

One parent was concerned that teachers who did not understand ASD misinterpreted ritualistic behaviour as misbehaviour and consequently used discipline inappropriately. She believed they needed an understanding of autistic behaviours and an ability to discern the difference between these behaviours and immaturity.

A further observation of three parents was that teachers always blamed the children and never looked at school factors that might contribute to misbehaviour. When one child was threatened with expulsion for his aggressive behaviour, his parents remarked:

Children will tease and will get nasty. Adam doesn't know how to react to that, of course he's going to retaliate but why isn't there anybody out there watching out for him? Why wasn't the teacher aide there when it happened? Why is there no training for other kids to teach them? ...

It's all Adam's fault, they don't see it as their fault as well. It's just one side, one story and it's Adam. I was really angry.

In this case the teachers discussed taking a control and restraint course and sought permission to use the techniques learnt to control Adam. His father objected:

I believe that they shouldn't because I think that if they are good enough teachers they should know what they're doing. The teachers that are there have known Adam since he was five so they know what he's like. Okay, he's a bit bigger now, they can hold him by the hand, because I do. I grab him by the hand and I can lead him and they can lead him to a quiet place and let him relax there. Because by them using a type of control and restraint in front of other children, the other children will get frightened ... They will get worried and then they'll back away from Adam.

Another participant stated:

A lot of denial. No school wants to admit fault that is what I have learnt over the years. They want to rule out everything at home, bad sleeping patterns, bad diet, mum and dad having hassles right down to his teacher saying, "Baby is eight months, it must be teething and keeping the kids awake?" I spun around and said, "She's eight months old, she sleeps seven till seven since she was five weeks old. I told them, "Look in your

own backyard.” Before I said, “I will write in the log book, ‘Had a hell of a night - Sam’s playing up.’ If I don’t get time to write in the log book because of baby I will ring you. Have I rung you this week? No! Have I written in the log book? No! Well it’s not me and when I get sick of him playing up and can’t cope, I will ring you to find out what is going on down there?” “Oh it’s not us.”

While parents were keen for teachers and teacher aides to learn more about ASD, they were also wary about blanket decisions based on book knowledge. As one mother noted:

Every child is so different, the basics are the same but he’s an individual, he’s got his own traits of that characteristic, his own ways of doing it so I don’t want somebody to come in and say, “I know this, this and this”.

Sometimes a little knowledge could be a dangerous thing:

One thing I found with the schools too is that when they had a semi-understanding of Asperger’s that there was the assumption that everything he did was because of the Asperger’s and you have to remind them that sometimes it’s just because he’s naughty. It doesn’t matter what problem you have, they can still be just as naughty as other kids and sometimes that’s all it is, to be aware that sometimes he’s doing something it’s not because of any particular trait, he’s just being hōhā!

In fact, one mother claimed that a lot of knowledge could also be dangerous! She had attended a lecture from an overseas expert and complained that he was training people to lower their expectations for their children. She explained that her autistic son was very affectionate but the expert was saying:

“Autistic children are not affectionate children and don’t expect cuddles.” So it’s drummed into a parent’s head so severely that they’re not cuddling their kids and they’re wondering why their kids have got no speech, they’re wondering why their kids are so violent natured continually.

This mother challenged the expert on three different points:

He spun around and said, “How old was your child when you got him to sleep through the night?” and I said, “Two and a half.” “How old was he when he got toilet trained?” “Three and half out of night naps,” “And he’s got autistic spectrum disorder and he speaks?” and I said, “Yes, typical male, what’s for tea? What’s on TV? I don’t want to watch that channel?” “I’d like to see this child, he sounds very interesting. In over 20 years I have not found a child that well advanced at that young age, what are you doing that’s different?” I was straight up and said, “Not listening to you!” He had some good points, you can actually sit there and say, “Yes, I can agree with that”... but everybody follows his word like a bible. I’m not saying he doesn’t know what he’s talking about but they need to get their noses out of books and realise, like a normal kid these kids are different... Although they are autistic they are just children and every child is different. You have to have normal expectations for your children.

DETRIMENTAL ATTITUDES

Parents reported a variety of detrimental attitudes amongst professionals and the public at large. In respect to professionals, the major complaints were not being listened to, being disbelieved or having their opinions and suggestions undervalued. Many examples of this barrier have been

reported elsewhere under other relevant sections. This illustrates the all-pervading nature of this grievance.

The frustration of being ignored is well illustrated in the following story:

We have been there under general anaesthetic three times now, in three years. Up until then he had had four lots of grommets put in, and he had had his tongue tie fixed, and we'd done all of those through Portland Hospital and I was always there, and he was still breast feed. I said, "Please let me be there, it is very important, if he goes into the general that I'm there when he comes out of it, so I can assure him straight away that it's okay. And also please take the little butterfly thing out of his hand because the first thing that he does when he sees that, is try to rip it out, and it becomes unsafe and more painful." They said, "Okay, that's fine, go and wait in the waiting room." I waited for a very long time and heard him screaming and when I went in, there were four people trying to hold him down and I actually felt like walking out. I also felt like telling them, "I told you, I should have been there." You try and tell these people, I told the anaesthetist, I told the pre-surgery doctor, I told the dentists on the day, I told the anaesthetic guy on the day and I told the nurses, I told them, "Please let me be there it is very important that I'm there," and I wasn't. It was awful for Maurice, for having to go through that. He tried to rip out the little butterfly thing and it was a huge problem. And then they asked me to please take him out of the room, because he was disturbing all of the other patients.

One parent related her experience of going to a course which was specifically designed to help parents understand ASD and cope with their children's behaviour. She withdrew from the course because some of the activities:

put me way out of my comfort zone. I didn't like it at all and I found that I would say how I felt with my children and they'd be saying, "Well, no what's actually happening is ..." and I thought, "I don't need this." It was horrid.

Parents told many stories of having to convince medical and educational personnel that there was actually something wrong with their child. One parent told of providing drawing samples and detailed observational evidence to support her contention that her son was regressing. The doctor did not believe her until the special needs teacher accompanied her to their meetings, "It was as if, when she said it, it must be right."

Even with diagnosis parents still experienced scepticism and disbelief as this story illustrates:

We have to fight, we have to fight for every single little thing... and we are still fighting... Special Services, they don't quite believe that there is anything wrong with these boys - even after diagnosis. Even when I got a diagnosis for Corey the school didn't want to know.

Interviewer: In what way, when you say they didn't want to know?

Well, I went and told them that I had this diagnosis and that I was concerned about how he was socially, and I was concerned about how he is getting on at lunchtimes and playtimes. I'm not worried about him in the classroom, I know he is doing well, but it is what is happening in the lunch time and play times, that is what concerns me, his social development. The headmaster said to me, 'Oh yes, we will get back to you about that one, we will sort out and see if we can get all this funding.' She never, ever came back

to me and we are talking about 12 months on, and I have never heard anything back from the school.

One parent complained that a previous case manager was hell-bent on her son learning life skills such as cooking. The family had other priorities they wished to focus on and felt that they could teach their son to cook and clean. Their wishes were not listened to. The mother commented:

You are absolutely at the mercy of your case manager's particular philosophical bent and that is a real worry. So when you get a good one whose philosophical bent is, "What does this person need, let them tell me," you hold onto them for dear life.

Parents faced disbelief not only amongst professionals but also in the public at large. One parent told of how her insurance claim was challenged:

One of his favourite things was to run away. You'd turn your back and he'd be gone in just a matter of seconds. In one case, he damaged the car. I had to prove that I wasn't liable to my insurance company ... I said, "This is what happened, I turned around to answer someone's question, I turned back and he'd gone," and he'd thrown something out of a two storey building onto a car.

The claim was accepted only when she took her son in to visit the insurance assessors.

Negative attitudes relating to children's behaviour were also frequently reported. Parents talked of their children being stared at, growled, feared, ignored and excluded while they themselves were often subject to insensitive, insulting and sometimes downright rude remarks.

One mother told the story of going to an Intermediate school for a transition visit. She was also employed as a teacher aide at the primary school and the Intermediate teachers were unaware of her dual role.

I didn't let on [that I was his mother] and I got growled at for that, but it was good to hear truthful comments... Well he ran riot. The teachers just spun out, "He can't be here unless he's got one-on-one the whole time. How can we cope with this? We're not used to having this lot here." They didn't see him as a child. I thought, "How are we going to get through this?" It was really interesting and I said, "Some of those teachers up there need to have some information."

Similarly, a couple told of negative attitudes towards their son's behaviour resulting in him being excluded from kindergarten.

They decided they didn't want him there. He had a teacher aide but the kindy thought that he was disruptive to the other children. They said, "It might be best that you look at another one." We said that was okay. We were a bit down but then we went to Paraone.

Another mother told of her son being excluded from primary school:

The school said, "We will find you another school, we don't want him." They're not allowed to do that but it was a matter of that or threatening with suspensions and all that rubbish. All my husband's family said, "Fight it, they can't do it." My attitude was, "Why fight it when they don't want him there? They'll make your life a living hell." It was already going down to the Principal's office twice a week, going to the school every day to see the teacher and find out what was happening this week.

When one parent had a concern about her son's reaction to a long distance day trip, she offered to come along as a parent-help to keep an eye on her son and to assist with the other children. The reaction to this offer of help was:

"Well, maybe he shouldn't go if you think he is going to have trouble," and I said "No, that is not what I'm saying, I'm saying that I would just like to be there just in case he does get nervous and he does get worried," "Well, maybe you should take your own car," and I was like, "I'm not going to segregate him from the rest of the group." I was livid.

One mother described the reaction to her son at Playcentre:

The Lester people look after the Lester children but any outsiders they ignore or look the other way. I have seen them do it. One time I was outside with his little sister and they came out and said, "Benjamin is playing in the toilet," and I said, "Did you get him out?" and she said, "No I thought you would." I've seen them look the other way when he is doing things, they think I can't see... They might be scared to.

A similar experience was recounted by another mother:

Playcentre is run by parents and a lot of parents now are too much into their own children to spare time for special needs children. In saying that, there are exceptions... people who were very good but if you've got mothers up there that are doing Ring a Ring a Rosie and Jodi is running around the outside of the circle because no one has asked her to join in, then that's not acceptable. I'd be doing an observation on another child so I'd actually be watching. I believe in the Play Centre philosophy though... We put up little boards, little phrases or little things to repeat to her. She was still constantly being ignored, like the pet that you'd have. It got really bad in the end. I didn't like it at all.

This mother actually changed her daughter to a kindergarten because she "wanted trained teachers that will work with any child, not a mother that keeps saying, 'I just don't know what to do,' That's not good enough for me."

After having a difficult year with a particular teacher, Brian's mother was upset that her son had again been placed in that teacher's class. She explained:

When I found out she was teaching him I thought, "Not another year of stress"... I knew the conflict would be there. She's a lovely teacher but I know that deep down she is frightened of Brian and once you've got that fear you can't get it out. It doesn't matter how many times I've told her, "Don't let him get his own way, but work around it." But because she has got other children in the class, she doesn't want to have to do that, she doesn't want to think about that. She's got other things to do.

One mother related a reaction to her son while they were out shopping:

We went to the supermarket yesterday. He let out a little scream because we were leaving, It wasn't bad or anything and the lady on the checkout turned around and said, "Have you got a problem?" and so I said, "Yes, he does." She said it quite rudely. I said, "He's autistic," and she went bright red. One time he threw a massive tantrum in Pak 'n Save. He was screaming away and this old guy says, "Oh God, will you just shut up!" So I went up to him and said, "Would you just shut up telling a little kid to shut

up.” And people came up to me and said, “Good on you.” It’s just when you’ve had enough yourself and then someone says something!

Six parents specifically mentioned shopping as an activity they found challenging because of people’s negative attitudes:

I never used to be [assertive]. I’ve never really had to fight for my kids before until you get special needs children, people treat you so differently, it’s quite amazing. If Catherine is screaming like she can do, she gets anxious if we go into certain places, she starts screaming as we’re going there, like walking into a shop. People will all stare and I’m thinking, surely you must have seen a four year old throw a tantrum. You can’t tell me they know they are special needs from that distance. I’ve had people say, “Is she alright?” and I say, “Yes she’s fine.” They don’t realise. My husband gets a bit uptight, a bit nervous. I don’t care, she can scream for twenty minutes around the shop and I know everyone’s looking but I can’t help it I’ve got to do the shopping and I have to take her. She can only get over these things if she gets in her mind a picture that there is nothing to be anxious about.

He was just absolutely horrible to take out anywhere and you would feel it. People look at you and I had this old woman once in Pak ‘n Save look at me and say, “What is wrong with him?!”

Four parents remarked that because their child looked “normal” this could actually be a disadvantage when it came to people’s attitudes. Because they were not obviously “disabled” in any way, people expected them to behave “normally.”

If he was blind, or he was deaf, people deal with that. When we got a hearing aid for him, everybody seemed to deal with that and cope with it just fine. It was kind of like, “I can see this, I can deal with it.” But with the Asperger thing it is harder for people to get their heads around because it is so subtle ... With Ben it is just considered that he is a naughty kid and you know the old school, “Just smack him, just discipline him.”

When they see my son, because he looks normal, you can’t see autism and when he starts flapping his hands, when he gets excited I just don’t worry about it – that is just him. People stare, and sometimes I just want to go and punch them in the nose, but I think, “Hey, that is not going to work.”

Another parent described the “ignorant” people she had come across:

People didn’t know diddly squat and even if they did they just pretended they didn’t know anything. Like the psychologist that didn’t properly diagnose her and the paediatrician that turned his back when I said, “Did this affect her brain?” and the GP that said to me, “Is it money that you’re after?”

PARENTAL STRESS

Having a child with ASD is by its very nature challenging. Parents told stories of having to cope with destructive, unsafe, violent, demanding, self-injurious and frustrating behaviours. However, in addition to coping with the actual behaviours, parents have also had to contend with the many barriers described above. The need to fight for services emerged as a barrier that proved particularly stressful for parents.

As one mother stated:

People say to me, "You have to fight for blah blah," and "You have to fight for..." I spend enough energy getting through the day with this child, please don't tell me I have to fight! But you do, and it is a reality, and there are so many times.

Another mother reported having to fight and push for "everything."

We learn all the time. No one offers you much. You've really got to ask and push and fight for things. You've really got to stand up for your kids, that's for sure.

... You've got to make a fuss to be noticed.

A third mother's story illustrates an occasion when she was forced "to make a fuss." Going to the dentist was a traumatic experience for her son. Consequently he was put under a general anaesthetic on such occasions. When an emergency visit to the oral surgeon was necessary, the mother asked if all her son's teeth could be checked to save a later visit. The surgeon refused. He extracted the offending tooth which was given to the mother. Subsequently, the mother found out that the tooth could have been filled. It did not need to be removed. After that experience and being told by a reliable source that the dental service for special needs children was called, "the mental dental day," the mother stated on her next visit, "I expect his teeth to have the same treatment as the other children. If there is an extraction, I want that tooth kept and I'm going to take it to be analysed to make sure it needed extracting."

While the great majority of parents in this research have had to "fight" for appropriate services for their children at one time or another, a small number have become politically active, contacting media and organizing public meetings to agitate for services for children with ASD in particular and special needs children in general. This has not been an easy battle. One mother told of having to fight organisations to gain access to children's files, of having information altered and of being pressured into remaining quiet:

They phoned me three times to try and put pressure on me to try and gag me. One of the phone calls was, "This is not in the best interest of your son to be going public like this." It was emotional blackmail, "You are humiliating our organisation and you have nothing to gain from it." I said, "If you had provided adequate services and if you'd listened to me when I first complained, I wouldn't have had to do this, so don't talk to me about my son." If I hadn't have been as assertive, they would have tried to squash it... This was four years ago. After that newspaper article came out, the phone rang straight away. I'd hear a parent's story and put the phone down and it would ring again and I'd hear another parent's story, it just went on and on and on... At night my husband said, "Turn that phone off, it has been going all night and we haven't even had tea together." That went full on for three days.

These experiences took their toll on the mother's health. When she was diagnosed with high blood pressure she decided it was time to pull back from the public battles she had been leading. As she explained:

We do worry about my health. We've been told that under the stress that we live under that I need to make a choice, that I need to revise our lifestyle which we can't do in Fraser's condition or I'm not going to be here long term, so you worry about what happens to Fraser long term.

A second parent who has played a very active role in helping others talked of the strain involved:

But the problem is that these people are getting burnt out, like myself, I'm burnt out at the moment. That's why in the last year I've withdrawn from everything... The parents are tired. Because if they find that someone's doing something, invariably everybody comes and asks you, even if you're not on the Autism Committee, they'll still come and find you and ask for your help. I get stopped in the supermarket all the time by people.

Physical stress was also mentioned in relation to sleepless nights and having to be constantly vigilant about dangerous situations. The following story is a poignant illustration of the former:

I went through four months of getting between three and four hours sleep a night and I said that one night I was just so tired I just wanted to put a pillow on his head and make him go to sleep because I was tired. I didn't but soon as it happened I thought, "Oh my God." So I went to my GP the next day and we got our referral to the paediatrician within two days and I rang up my GP and said, "Did you tell him I was mad? No one gets in that quickly!" He put a referral to Awhi Services to come and help with some of the needs and they phoned and said, "We can't come and see you for a month and then we have a three month waiting list so we can't actually take you on our books for another three months after that." So I said to him, "Have we learnt nothing from Aubrey Thompson? Has anything changed?"

Psychological and emotional stress were also issues. One mother chose a residential special school for her daughter because of the expertise of the staff, the holistic programme offered and the 24/7 care. However, the resulting separation from her daughter was described as "being absolutely devastating on my psyche. Just having her apart from us, she's apart from her family. That really hurt me and I think it's hurt her brother too."

Another mother lamented:

If I had a dollar for every tear that I have cried.

Interviewer: A lot of it sounds like it is a result of the ignorance of others?

Yes, and that is for sure, it has been that. I think we have just had to stay bloody minded about it. I know when Terry was first diagnosed ... I had one of those bloody nurses come out and tell me that she didn't think that there was anything wrong with him because she had been here for half an hour and she had seen him, and she had decided he was okay. She basically put it on me that I was an over bearing parent... Also I don't understand the school system, because I come from a parents' perspective and I'm emotionally involved, but at the same time I have to be his advocate – I have to be his teacher, I have to be the one who knows all to get him into the system, you know, and I hate that. I just want to be his mum and I want somebody else to come along and say, "We need to do this, and this needs to happen and this is how the system works."

Many mothers described how their personality had changed as a result of having a child with ASD. They described how they had once been easy-going, reluctant to speak up, "airy fairy" and "wafty" but as a result of having to fight for services they had become more "focused, grounded," assertive and even aggressive on their child's behalf. However, it should be noted that while this research contained many very strong, assertive parents not all were like this. Others were shy and found speaking out quite difficult, in fact one parent noted:

I'm glad I did come here [to this interview] because now I know. That's exactly what I want but I didn't know how to let it out, I would never have told them.

Another cause of stress and concern is the responsibility parents felt to provide consistent, on-going assistance in order for their child to progress. Knowing that their input could make a real difference but not always having the time and energy to provide the level of involvement and challenge needed, left parents feeling anxious and guilty. As a mother explained:

We're always looking at the big picture and sometimes I get a bit down cos I think, "How are we going to get this taught in time?"

One parent talked about existing from day to day in a survival mode and being forced to step out of her safety zone to provide for her son. While another mother described a situation when she became stressed out:

It is such a hard job with Winston... He is terrible with his brothers and sisters, he chokes them, he hits them, they are frightened. It is just a matter of having four eyes – eyes in the back of my head, and watch him and watch the other ones and do what I have got to do too. He has just got a bad frustration inside him where he can't let his anger out... I actually got into a bit of a rough spot with Winston where I wanted to kill him and it was just all that was on my mind. I walked passed the window one day and he was choking Eddie on the trampoline, and it was just a long day, it was hot, and it was the school holidays, and I snapped, and I actually went around there and put my hand around his throat, and it was like I didn't want to let him go, and I actually said to him, "How does it feel?" Because Winston doesn't understand he doesn't take it in. He did stop and get a fright. I gave myself a fright too... I could have even killed him, then what I'm this bad mum who couldn't cope and I would end up in jail for something I regretted doing because it would just happen at the drop of a hat ... I hear about mums who kill their kids all the time and it wasn't until I actually did what I almost did that I actually sat back and thought, maybe some cases are, "It has just happened." It wasn't premeditated and it was I got to the point when I thought, "Oh, I could have killed you instantly, without even thinking about it." Mind you, I even said I would never, ever do that, and I actually did something that I said I would never do...

A concern about what will happen to their children "when they grow up" caused considerable worry to a number of parents – the teenage years, adulthood and when the parents died were particular areas of anxiety:

You have to be even super, dooper aware of him because he internalises everything. And that is my worry, because by the time he gets to a teenager, what on earth is going to be thrown at him? Because he is such a sweet child I'm not sure how he is going to handle being a teen, and all the horribleness that goes with it. So I guess, we are just holding our breath really and taking each day as it comes.

Sometimes at night when we're just lying there or he wakes up in the morning and we give him a cuddle and he comes in and he does all the special things that he does, you think, "Who's going to do all of this? Does he even know that he's loved?" ... Really the people before us have just always sent everyone to Kimberley. Even with the boy who was on TV, there was a boy whose father worked for the social welfare and they had an older autistic boy and they tied him to the chair twice a day or something for a couple of hours, and it came on TV and it was spread all over the place about how terrible it

was and they arranged respite care. My friend was visiting her daughter at [a psychiatric facility] when [the boy on TV] was there and apparently the only way that they could control him was to drug him and he was tied to the table. He was totally out of it. She said that they criticized how the kids were treated at home and yet their alternative was twice as bad. So for me as a parent it doesn't give me a lot of faith in the system and that my son will be well looked after and that he will be well cared for.

The attitudes and actions of the general public can also cause parental stress as illustrated in this story:

Through ignorance and misunderstanding like in public Katera threw a wobbly in Main Street. People were looking at me as if, "Why don't you give her a good hiding, that's what she needs." You could see it in their faces, talking to each other and pretty much formed a circle around us staring. That sort of thing is difficult because it really humiliates you. Everybody is staring and your child is big and you're going like that... it's like, "What's wrong? Can't you control your child? What kind of parent are you?" It's not what they say but it's in their eyes, it's a judgement you feel.

Having a child with ASD can also put stress on marital, family and friendship relationships. One mother specifically stated that if she had known about and used respite care then her marriage might not have broken up. Another person told of how a friend walked away from her when her son became excited and started flapping his hands in public. This mother also mentioned:

You find that people often don't like me taking him to their house and that is quite hurtful, especially when it is family members. Mind you, letting him loose in any house is like letting a bull loose in a china shop – because he would destroy it!

Parents reported a number of ways having a child with ASD placed limitations on their lifestyle. One mother noted that sometimes it was easier not to go out than to handle her son's behaviour elsewhere:

Because when we got to people's places he used to run and throw things around... When people look after him they are knackered! He's into everything. And especially going to people's houses where they don't have kids, it's a nightmare.

Similarly, a father mentioned the difficulty of getting babysitters for his daughter when she was young. However, he added this was overcome by inviting people around to their house rather than going out.

MISCELLANEOUS

A number of other barriers were mentioned by participants. These included safety issues, unsuitable environments, bullying and parent organisation problems. Safety issues were a major concern of parents. Most often this related to school environments. Four parents mentioned that an important criteria for selecting a school for their child was how safe the physical environment was. Schools near busy roads were avoided for three children because they were "runners" As one mother explained:

He has no fear, the whole moving car thing – there is no concept of the fact that it could actually hit him and hurt him ... He is alright with boundaries, I mean physical boundaries. At the kindy there is physical boundaries and there is a child-proof fence all around. He

deals with that, but if you take those fences away it is like he doesn't cope with it. And, if there is no physical boundary, it is like that door, it is a physical boundary, but if you open that door he is off. And, he just doesn't know when to stop... He can't go to Sunrise School because they are right on the main road where trucks and everything drive around and their fences are about this high – not child-proof. What schools are? There aren't schools out there with child-proof fencing. They have all got open gates.

This mother finally chose a school that is “in a back street and it is surrounded by houses, so it has got a physical boundary which is what we needed for him.” Another important factor in her decision was “cultural safety.” She felt that her son would feel more at home in this school with its high proportion of Māori children than in his local school which was predominantly Pākehā. She noted how ironic it was that she and her husband had worked hard to enable them to buy a house in a nice neighbourhood and they ended up sending their son across town to a school in a less desirable area!

Noisy, busy and over-stimulating environments were also a cause of concern to parents:

[At school] they placed him in a place where a lot of children came in and out of. He's got quite a big personal space and there were too many people in his space

Four instances of bullying were reported by parents. The two cases in mainstream environments were relatively minor and dealt with reasonably quickly. However, the two cases in segregated settings were of a more serious nature and involved physical injury caused by other children with special needs.

Another issue that was raised by three parents who had been involved in parent organisations was the way these organisations functioned. Independently, these three parents became disillusioned and decreased their involvement because of hassles within the organisations. The first complaint was that meetings became unpleasant because of individuals “hijacking” the floor and because of disparities between parents of children with severe autism and those whose children had high functioning autism or Asperger Syndrome. One parent explained:

They've folded. It became a problem with some of the people on the committee where their children were highly autistic like my son is and then there'd be a lot of people who'd come in who would be very proactive with Asperger children and they would talk about problems that we would think, “I'd love my son to be able to talk.” To us it seemed relatively minor... and they didn't like it when we started telling our stories. They would just be disgusted and think it was horrible. I very rarely said things in the support group meetings but when they did, I would think, “Yeah, yeah, yeah” and the person next door would say, “Oh yuck, I wish they wouldn't go on like that.” It was like apples versus pears. And so there was a great deal of intolerance from both sides really where the people who had the autistic children as opposed to Asperger's, we're like, “Oh, big deal, is that all?!” It's all relative, isn't it? For them it was a big issue. I think that caused problems as well.

The second issue that impinged on the effectiveness of these groups was a workload issue. As one mother explained, her group was meant to be a “support” group but this function had been buried by other demands. She explained:

We started out as a support group and if we'd stuck to a support group we would have been cool but we couldn't because there was too much need from the parents wanting information and wanting advocates to go and do things. It got too spread out but we didn't have the resources or the knowledge to actually do those things and when we

changed committees I said, “Look, the people who are happy to do those things weren’t on the committee, we need to come back to the very essence of what we started with which was a support group.” That’s where a paid person for any disabilities could go and do those things or be the person to contact and say, “Where do we go for this?” and take it away from the support group and leave the support to be a straight support group and then there would be no problems. All the members have their other jobs to do and their own families to raise. We need somebody who could be dedicated from 8.00am-5.00pm. The whole day could be dedicated to dealing with issues to do with the Association as opposed to somebody’s Mum who can fit it in but not today because of a meeting at the school. I think that would be really good for any new families that are diagnosed, to have a person to go to who is unbiased and is a wealth of information. A lot of people that are new to the district would turn up at the meetings and they would stay for the meeting but you wouldn’t see them again because it just wasn’t a very inviting environment. Within our Association, they’re all just parents, they’re all exhausted and Parent-to-Parent, they have a paid coordinator but there needs to be somebody who’s a paid person who can do it professionally who is able to do that as a full time job. So the paediatricians or the SES or whoever is the first point of call, they can say, “Would you like me to pass your name on to this coordinator?” and then that person will come and tell you everything. Not just autism, Asperger’s, any disability... If there’s a paid coordinator for your area then that person is the key person and if they had come to me this week and two months time they might go to someone else and they will know that it is the same situation and then talk to both of us. “Here’s someone you might want to contact at some stage.” Then it takes it away from the parents, it takes it away from the bickering.

One mother mentioned that the Associations in the large cities did have paid regional field workers who fulfilled the function mentioned above but in smaller areas parents tried to do everything, they burnt out and often the branch folded.

A POST SCRIPT

Although this chapter is on barriers it would not seem right to conclude this section without mentioning that parents also spoke of the many joys their children brought them. The content of this chapter may lead people to believe that having a child with ASD is a totally negative experience. While it is evident that a multitude of challenges exist, there are also positives. Suffice to conclude with a quote from one father:

She has enriched our lives more than anything.

Chapter Six: Social Development

SOCIAL DEVELOPMENT

Children with ASD typically have difficulty developing social relationships and appropriate social skills. This was true for the children in this study. Many parents reported that difficulties in socializing were evident from an early age especially when comparisons were made with the social development of siblings. With one exception, children were reported as not having “good friends.” Social difficulties described by parents included:

He lacks the language to keep a conversation going. He can ask a question or answer a question but he needs the language to keep a conversation going or be prompted. You're never going to change this with Murray, the need to want to talk to someone. It doesn't really worry him.

He wanders off, he is miles away sometimes. He likes to be on his own, he doesn't like anyone in his space. He will play with the kids for a little bit and then that's it. To him it is, “No, go away, I have had enough.”

He doesn't like kids all over him, he doesn't like them in his space. He will tolerate them for a while in his space but then he starts getting agitated. He has got to be pulled away, so he can have his space to himself...

Interviewer: And, has he got a special friend?

No, I don't think he even knows what one is.

At kōhanga they encouraged her and tried to include her in everything but she preferred to be by herself. She has always had difficulty making eye contact with other people and other kids and that sort of thing, so she just basically played by herself, and that was about it really. [Approximately 16 years later] ... She has made progress in terms of her ability to socialize with other kids, she was able to not get upset if a kid came in the area that she considered her space and she handled that better. She still now, at almost 20, doesn't really like looking people directly in the eye, but she sort of was able to be spoken to without getting too upset about it.

One parent noted that her two sons did have friends who frequently came to play, however the level of social interaction left a lot to be desired. She elaborated:

Larry and that come over and he has got his wee mates, but he is sort of a bit indifferent to them. Raniera is the same, like Raniera is probably over there right now not actually playing with Abel, but sitting on his Play Station, because that is kind of what they do. They get their friends over and inevitably what happens is the friends entertain themselves while they play on the computer, or they will play something individually, so yes, they are a little bit different about friends even though they love it. They love having other people around and stuff like that but they end up doing their own thing ... We have had to teach Raniera what is socially acceptable and what is not – it is not okay to have your friends over here and ignore them.

A further difficulty Raniera experienced was his social “naivety.” His mother explained:

Yes, he [got bullied] a while there in his first year at school, because if you hit him and say sorry it is okay, so what the kids at school were doing was hitting him and saying,

“Sorry,” and then kicking him and saying, “Sorry,” and he was accepting that that was okay because they had said, “Sorry.”

This naivety, together with a tendency to go along with whatever his “mates” said and to internalize problems rather than speak out were major concerns for his parents.

A mother of a child with Asperger Syndrome noted that the pedantic nature of his speech could be off-putting. She mentioned that although her son did have a best friend throughout his school years, and although the staff at his kura were really inclusive and supportive, he was miserable at times because he “never really fitted in.” Difficulties with his peers were caused because “he didn’t understand, he couldn’t read the signs when people were just teasing for fun, or when they were being mean.”

One parent reported that her son’s lack of social skills could be embarrassing while another remarked on the additional stress placed on her because her son was always at home. He never went off to play with friends as other children his age commonly did. However, the most frequently mentioned cause of distress was the pain parents felt seeing their children socially excluded:

Socialising- it was pretty hard for me just watching him at kindy just looking at everybody playing, not getting involved or anything.

I don’t go to the school if I can help it. I stay away from the school because I know he will always be on his own, sitting on his own, playing on his own, or playing watching the other kids. And, it breaks your heart to watch him playing on his own and I even told the school, “Don’t ring me unless I really have to,” because I don’t like to see him sitting on his own and playing by himself... It is hard going for him. I feel sorry for him, and the school is very wary that if they ring me up, “Can you come to the school?” and I ask them first, “What’s he doing?” and if he is in class, “Yes, I’ll come.”

BARRIERS TO SOCIAL INTERACTION AND DEVELOPMENT

A number of circumstances and activities that hindered social development were mentioned by parents. For example, two parents mentioned that having to select schools on the basis of their special needs facilities and the safety of their environment meant that their children were not able to move on to the same school as the children with whom they had received their early childhood or primary education. Any budding or established friendships were consequently severed. Additionally, having to attend schools outside of their own neighbourhood lessened their opportunities for social interaction out of school hours.

While the benefits of computers have been previously outlined, three parents also mentioned they had drawbacks socially. As one parent explained:

When he first started school he seemed to be on the computer quite a lot and I told them to cut that down because social skills on the computer are nothing. Just looking at a screen, looking at favourite stories that you like all day. They’ve cut that out a lot which is good.

Two other parents noted a similar situation at home. As one stated, “We have to watch him on the computer because he’d just live on it.”

One father complained that nothing was being done to teach other children how to interact with his son. He believed this would be a helpful strategy. On the other hand, a socially unhelpful strategy was reported by another parent. She complained that the use of “time out” for her son’s misbehaviour further isolated him from his peers.

A mother described the dilemma she faced in raising her children according to certain standards but potentially adding to their socialization problems by doing so. She explained:

Yes, I mean even like the wee boy whose house he just went to, he is a year younger than Te Ra, but I think that there are certain things that he does that are more mature than Te Ra, just because of Te Ra and who he is. And I guess we don’t help that either because we are very strict on what the kids watch, we are very strict on what the children are exposed to. Whereas I think a lot of the kids these days are exposed to a hell of a lot, way more than we feel children should be, and I guess in a way they are not exposed to – like a lot of these movies and things on TV and stuff a lot of his friends are watching. There is no reason for him to know about all of that stuff yet. So I guess in a way we kind of add to the naivety because we are not keeping him up with the play with all his friends, because he doesn’t watch blood and guts and horrible movies and stuff like that. We don’t allow him to play games that kill.

An added challenge was:

He is still very much the kid who loves his soft toys and he has a name for his soft toys... He wanted to take a little dog that he had to school and I kind of steered him away from it, even though I think it is wonderful, and we encourage it here, but outside of here that is setting him up.

FOSTERING SOCIAL DEVELOPMENT

At Schools and Early Childhood Centres

A mother whose child attended a kōhanga reo believed that the formal, structured way language was taught there was of great benefit to her son. She also believed that the support he received from the teachers and most of the children at the kura kaupapa Māori he moved on to was pivotal in helping him to cope with his social challenges:

It was the philosophy, it was absolutely the tikanga thing, the whanaungatanga, manaakitanga absolutely, and it made a hell of a difference, and the teachers’ attitudes too.

Similarly, the interaction with other Māori children in bilingual classes, whānau classes and kapa haka groups was seen as having socializing benefits both in and out of the school. For example, a mother explained how her son’s involvement in kapa haka and visits to the bilingual class helped other children realise, “He’s not really scary, he does some funny things, he’s not bad.” Then it spread within the whānau classes. While her husband added:

Where we used to live in Strathveld you’d see it down the street where him and his sister would go to play. All the other Māori kids would be walking home from school together... I think [it is a Māori thing] because I think that’s just the way Māori kids are brought up. They’re brought up with their whānau where you don’t have to be blood cousins to be cousins, everybody is your cousin, everybody who’s older. When I

go to the school all the Māori kids call me Papa Pete. They might call the other parents John or Mr Smith or whatever but I'm always Papa Pete and so when I walk into their classes, "Kia ora Papa Pete" and down the street. And so with the Māori kids, because they attach that whānau thing to other Māori I think that's what's happened with my son because he's been with them...

He'd be walking to school and he would see this cat door and he'd be playing with his toys in this cat door. Just thinking of Rasmussen street, we used to walk up there where all the Māori kids live. Up there it wouldn't have been a problem if he'd gone in a cat door. They'd just say, "Oh Rawiri, get off to school." They all kind of know him now which is really good. The other kids were good but they don't have the same acceptance ... And that was the lower socio economic part of our area and our kids used to love walking that way to school cos you could go two different ways. They used to like going that way cos that is where all their mates lived.

Interestingly, one mother whose son's social naivety made him a potential target for bullying chose not to send him to a predominantly Māori school with his brother because of her fear that the children there might give him a hard time.

Two parents mentioned getting children "out into the community" as a useful strategy not only to develop children's life skills and social skills but also to raise community awareness and acceptance. As one mother explained:

Stanley goes out into the community and they might go and do the mail or they'll go and get morning tea and he and Jane will go in the car. That's just to get him out into the community and to get other people to accept that this child has got a disability, just get other people aware.

One problem that was mentioned was children's inability to initiate any social interaction. While parents reported that some children were not interested in socializing with their peers, others were described as wanting to join in but lacking the social skills to do so. A variety of school strategies to help children become socially involved were outlined:

He won't go in there and say, "Can I play?" If they're playing sport, he'll go and stand around. His teacher aide has rearranged her programme with Joel, she is more or less out with him at lunch time too ... She told me the other day that the senior boys were playing basketball and he was standing in there, arms folded and they were saying to her, "Why is Joel standing by us?" She said, "Maybe you should throw the ball to him and involve him." Last week he was outside playing basketball with the boys. It was exciting.

They encourage one-on-one games or turn-taking activities and games where you've got to pass on to the next person, say it to the next person... With Luke it takes a lot for him, even though he's intelligent, to actually focus on the teacher and he can get very tired.

No, he hasn't got any [friends]. That is what we are working on at school. He plays alongside kids, he watches from the outside. He wants to get in, but he won't. He has always got to have prompts, all day, from his teachers... They gave him a tennis ball and started bouncing it to him and it attracted a lot of kids and it got to about 20 kids and he backed off because he didn't want to be in a crowd of too many and they are learning that. They put him in a group of three and start building it up... We have got

him on a buddy system. It is the older kids learning to look after the younger kids. They have got ten year olds taking Henry, "Come on Henry, let's go play," mingling him in... He has got different children every week taking him out on the field, "Lets go play tag." We tried it yesterday and he was okay, he was a bit sceptical and he was wondering, "What's going on? You don't normally come and play with me."

This mother specifically requested that Henry's brother not be called on to assist him. She explained why:

The school wanted to use his brother, Kevin, when he gets there to mingle with Henry but I said, "No." I told them, "No, I know what it is like to grow up with a child like Henry ... I want Kevin to enjoy his life, enjoy his school, and just learn." I said, "Henry is a different story, we'll deal with Henry separately." And they saw my point of view. I told them, "You need to step into my shoes. I grew up with his mum, and I know exactly what Kevin would be in for all through college, everything, and I don't want him to be like that. I don't want him to have to look back and say, "I spent 30 years of my life carting you around and sticking up for you," because that was what my life was like with his mum, right up until we left Bridgebank and she was a good 32 then. So yes, I spent 32 years having her with me constantly all the time, because she couldn't do things for herself and she couldn't add money properly so I had to do it. She was in all my classes, every year ... and I sit back and think about it, I actually babysat her my whole life and I don't want that for Kevin and I want Henry to have his independence too.

Two parents remarked that their ideal way of teaching social skills would involve specially prepared life skill scenarios. They explained:

Like those programmes on Telly where you set someone up, everyone knows what is going on except for one person. Set up situations in the real world ... with him being the only special needs person there and having a group of people knowing what they have to do and for him to go in and - Like going into a shop, everybody knows their role and everybody knows that he's going to be difficult and knows who he is and for him to go through and to help him out.

[Activities] to teach him how to respond to every day things. For instance, going to school and kids would walk past and say, "Hello Riki," and Riki wouldn't answer them back. Responding is something that Asperger kids have to be taught what to do. They can't just learn it by watching other kids, somebody actually has to show it to them over and over again. Then they learn to respond because it's a learned response. Little things like that, teaching him to say, "Hello" and he'll say, "Hello" because we've told him to. And do it often enough that when someone says, "Hello Riki," it becomes automatic for him. It would be nice to have scenarios which are every day type of scenarios, people role playing and demonstrating just simple responses for him to learn from.

Another vital ingredient for promoting social interaction was a supportive, encouraging teacher. A good example was provided by a teacher at a school camp:

One of the boys was complaining and the teacher said, "Listen you lot, he's in a room by himself, he's part of the class, he wants to be part of you guys. He hasn't got a room with other children in it. If he's not doing any harm, leave him, let him be involved." It was so neat and when it was shower time it was, "You can't be in there now, they're all

getting changed, it's the girls' room." She was really really good with him. Whereas others would go, if they're moaning then kick him out.

Involving other children in a child's therapy was another strategy that was mentioned:

Carlos couldn't walk properly then so the kids in the mornings would pick him up and walk him around the school every day. He couldn't walk at all. He was just floppy. They'd grab his arms and take him around. Every morning the girls would come and pick him up and take him.

However, one mother mentioned that while classmates might be very well intentioned in their efforts to "help," on occasions her daughter objected to the "awhi" she received because it invaded her personal space.

In the Home

The most frequently mentioned strategy to encourage socialization at home was having friends and relatives around to play or visiting friends and relatives. Parents explained:

We've got family with kids the same age.

His cousins are out there and they're all running around and he loves them.

Once they'd go off and play and he'd be doing his own thing but now he's with them and even Sonya will join them sometimes.

I just took him around to my friends' places and got him interacting with other kids around there.

Her sister's friends come around all the time and friends of ours come around with their children and she is fine. She will come out and sit and talk to them and say, "Hello," and she will start conversations now, "How was last night?" and "How was work Belinda?" No, she is fine. And, all our friends know her really well, and our kids know her really well. She is part of the furniture really, it is old hat now. She still has her room which she withdraws to and we only go into her room when we are taking stuff to her or when she asks us to come in and we don't let the other kids go in unless she asks them to.

Another strategy was to include the child with ASD in their older siblings' recreational activities. This was not always accepted with enthusiasm by the siblings as evidenced in an earlier quote about the school disco.

At age five one child was assessed by psychologists at a university Psychology Department. The mother was told that because her son was not picking up social skills "naturally" from interaction with other children and adults in his environment, it would be wise to teach social skills formally. She explained what she did:

At home in English I taught him really formal old fashioned manners and really formal socialisation skills. We started teaching that way and by high school it was starting to pay off, so it is not a quick fix. And one of the things, especially when he first started high school, that kept coming through from all the staff was how polite he was. He is very, very polite, but we have taught him how to say, "Pleased to meet you," "How are

you?” “It’s nice to see you,” to shake hands, not to interrupt other people’s speaking – and that was major.

Fostering children’s interest and involvement in various sports was another strategy a few parents mentioned although this was not always successful as the following stories illustrate:

Zane has never really been a physically active person sports wise. He’s played soccer one year when he was five – standing in the middle of the field with his train! “Here’s the ball, go kick it” and he’d be running after the other boys trying to show them his train – I thought, “Oh God!”

I tried to get her into Lollipop Gymnastics when she was little, but the only kids that would dance with her were the ones that were special needs teachers’ children! None of the other children would come near her. They just kept away from her. Another time while we were with the Lollipop Gymnastics, she ran up on the stage and started sniffing the instructor because the instructor was sweating and she could probably smell it and she was saying, “Get off me.” So we couldn’t go back after that because it was a bit embarrassing. Another time we went back again and they were doing aerobics and she was trying her hardest to keep up and then they changed the routine and she had just had enough and threw a big wobbly. She tried really hard with it, ribbons all over the place, dancing two by two and then they went and formed a circle and it threw her right out. We were sort of excluded from that because of the nature of the activity. You can’t tell them to have a special one for her, for one person. At the same time this is what happens all over the place.

Activities such as gym class and social skills programmes are provided especially for children with ASD but one parent’s experience of these was not successful:

Oh dear, what a disaster! I worked it out later, there were ten kids and five of them were about the same age and if one was hyped up for the day, the others fed off it. All these kids running around doing stupid things and I’d just get Mahaki settled and one of the kids would come running across with a ball and do something stupid and he thought, “This is fun” ... running around and doing it as well! He might have been good one day and someone else would start but he seemed to feed the most off other kids. You could settle the others down, you couldn’t settle him. I didn’t think it was a great thing at all in the end... Once he spun out. He’d been working so well and I said to a mum, “Just keep a close eye on him, he’s nearly out of his limit,” but the mum wanted him to do something and he didn’t. I think it was a bit of a reaction but she was right there. They asked us to leave ... These are parents that are used to Asperger’s children and ours has still driven them up the wall! We left that day ... we had a sort of debrief and they all said, “It was wonderful to see him on the last trip.” I found that social thing quite hard with other children. He’d find it easier to socialise with normal children.

Interviewer: Because of them not setting each other off?

Definitely. And with the other kids you can tell them to stop doing something and they will. If you keep winding him up you know that he is going to dong someone soon. Other kids can understand, some think, “Oh sure, let’s see what happens,” and then, “I told you not to do that!”

A more successful strategy sportswise was when parents initiated and became involved in the game – throwing a rugby ball outside with the family, beach games and rock climbing were all mentioned. Another strategy was to involve children in supporting sport such as going to watch rugby on Saturday. However, the mother who mentioned this said her son lost interest, “He spent the second half sitting in the car, but that’s okay. We can expand from there.”

One mother explained how involving her son with his siblings and friends in video games was a successful strategy. Another was to include a younger sibling in the visual strategy activities and learning games she played with him at home.

Involvement in out of school cultural activities proved a successful socialization strategy for one family. The father explained:

I teach [kapa haka at night school] on Monday nights and so the kids every Monday they can take one of their mates from their class home, bring them out to [the venue], take them out to the pool to have a swim and then go and have dinner with me and then come back and I’d stay there and take a class. So that’s something that Petera looks forward to, picking a different person in his class each time... So that’s the social thing when we go out to [the venue] we say, “You’re the host – you have to teach children where to go and what the rules are and what they are allowed to do.” He does it quite well.

One parent mentioned that she specifically sent her son to school for the socialization benefits but found this was not happening. She now home schools her son and feels socially he is better off because of the opportunities he is being provided with and the strategies she employs:

He does socialize, he has got lots of cousins he socialises with, with his brother. He goes out in the environment. He sees probably more of the environment than other children and I’ve seen other children and socially Joshua is more adapted than they will ever be. I can take Joshua out in the middle of a crowd and he will not panic. He knows where he’s going, he’s got his objects, he’s got his visuals, he’s got his talking book, mum’s there, he’s fine.

Respite care provided another opportunity for socialization for one child. The family that provided his respite care contained a child in his class. This situation allowed an in-school acquaintance to be developed into an out-of-school friendship.

One couple mentioned how their son adopted his older brother’s friends:

All his older brother’s friends treat Cody really nicely but Lionel has always had nice friends anyway. Lionel’s friend Hohepa comes around and Cody can’t wait for Hohepa to come around, “That’s my mate too, that’s my buddy.”

The environment also had an influence on the opportunities children had to socialize. One father explained how they had moved to a house in the country and while this had benefits for his son and the family, it also had drawbacks:

They don’t have the other kids down the street readily available to go and play with after school like they used to when we were in town. It was nice to look out of the window when we were in town and see him sitting out by the mail box with the other kids riding their bikes or on their skateboards and he’d just be sitting there and they’re playing with him or talking to him.

To summarise, the children in this study experienced difficulty in initiating and maintaining social interactions and in developing friendships. This situation is typical of children with ASD. However, it was exacerbated by circumstances such as having to travel out of the neighbourhood to attend schools which had appropriate special education programmes and an ASD-friendly environment. A variety of strategies to foster social development were being utilised at early childhood centres, schools and in the home. Although the success rate of these strategies varied, it was encouraging to learn from parents that some approaches were proving beneficial to their children.

Chapter Seven: Past, Present and Future Wishes and Dreams

PAST WISHES

Reflecting on what would have been helpful in the past, parents mentioned a variety of services and support strategies they would have welcomed in earlier years. Most of their “wishes” have been incorporated into previous chapters. However, broadly speaking, parental requests fell into two categories.

Firstly, the provision of more information and personal support at diagnosis.

As two parents explained:

Somebody to sit down and explain to you what's happening and help you plan, do some sort of life plan, give you some sort of idea about what's happening... and what to expect [in the future]. There was none of that. It was very much that I was floundering around trying to get information and trying to get support.

In my ideal world when Lester was diagnosed somebody somewhere would have given me a list of things that would make my life easier, or our lives easier ...

What are the things that are going to help with this? Where can you go to get them? ... These are the services that are available [Both nationally and locally]

... Also somebody to help you with routines because it is really easy to say you have got to have a routine at home and you have got to stick to your routine – what does that mean? How do you make that happen? So, it would have been lovely if somebody had come in and looked at what we do as a family and said, “Hey, if we do it like this it will make it easier on you.”

Secondly, the provision of on-going support, information, services and equipment to meet their child’s changing needs and circumstances. For example: behavioural support and an emergency phone contact in times of crisis; car restraints; locks; nappies; home help; a “safe room”; information about appropriate schools; respite care; access to appropriate programmes; speech therapy; and financial assistance were all mentioned as provisions that were needed but unavailable in the past.

PRESENT WISHES

Parents discussed their present “wish list” for their children. Requests centred around services and equipment they felt their child needed but were not currently receiving or not receiving to the extent needed. Examples include: speech language therapy; communication devices; computers; more one-on-one, hands-on assistance; more social skills and living skills; a male teacher aide; a Māori key worker; the TIPS programme delivered locally; and music therapy.

A father explained his “wish list”:

Speech therapy. A specialist in speech therapy said that Robert's motor skills were good and that he would talk. She gave him a programme, pictures, he could pick up pictures and make a sentence and know exactly what he's saying. She said he should carry one around with him so he can communicate with people. So I got the letter and I was very excited about it but it didn't happen... I think what could be helpful would be

a computer, something he could relate to like it was his right hand, he could communicate... I know he's screaming inside, "Let me out, let me out!"

Parents also had a "wish list" for themselves which included: information, resources and services being widely available and easily accessed; increased financial assistance; more respite care; a paid local co-ordinator for parent associations; some say in selecting their child's support workers and teacher aides; more practical help; and local parent support groups. These last two requests were explained by one mother:

Parents are in survival mode as it is tough with these kids and they are hard yacka. Give them ideas on what they can do with these kids ... make games with them, make things with them. Make a support group where they are in a safe environment, where they can let these kids run riot and they can sit back and breathe, knowing these kids aren't going to hurt themselves and they are not going to be able to escape... The practical help is getting the support groups and classes set up in the towns – not the big cities, in the towns, the smaller towns, for people with autistic children because then the parents can give each other ideas. Because not every one has got a car, not everyone can make it to the next city.

DREAMS FOR THE FUTURE

Invariably parents' dreams for their children's future were for them to be happy and as independent as possible. Typical responses were:

I would like her to be able to have supported independent living, her lifestyle supported. I'd like her to be in a house where she can get appropriate care, have some activities outside of the home but pretty much a supported independent life.

I've had to revise my dreams. I was planning that he'd be a rocket scientist! However, at this stage I guess that our dream is to be as happy as he can be. We worked very hard initially. We paid a huge amount of money for ABA but he lost most of the stuff that he'd learnt. We wanted to give him the best start in life that we could and now we're to the stage where we think even at school now that his well being and his happiness comes before whether he can write his name and if he doesn't learn to write his name out backwards and forwards and in three languages it doesn't matter.

Independence, basics, confidence ... Just to be happy. To take advantage of what's out there, what life has to offer him.

To be independent. Have his own bach, have his job, do his own shopping and that sort of thing. Those are the dreams, the things that I want for him. They could happen.

I'd like him to have friends, have a job and be able to do things for himself and that's what I want to try and work towards for him. Same things that I want for my other kids ... to be normal and to be liked and to be happy and know that mummy is always going to be here – except when I'm six feet under!

For him, to be the best he can be. I mean I haven't got outrageous expectations for him. I want him to do the best he can, and I am proud of that... For him to be able to go out into society and function without the criticisms and get the support and understanding that he will need... I would love to see Darren be able to function in society but I don't know if that will happen. [Society needs] ... to accept ASD and be more understanding

and patient of it, because it is frightening to think what could happen to him out there. I mean, I shudder to think.

Happiness and love. I just want a world for them where they are safe in it and that I want to be able to give them enough of a foundation through their growing up to give them the best education that they can possibly get, to get them all the support they can possibly get, and to just get them through really. And, at the end of the day, as long as they are happy, and to be strong. I just want them to be strong and to know who they are. I just want to give them everything they possibly can to ensure that they get the very best start that they can, because in 15 years time it is not going to be mine anymore. I am just the caretaker for the next few years and I have to do the best I can and hope like hell that they get enough of a good foundation to stand strong and to be the good young men that I know – the fine young men that I know they are going to be. What do I want for them? – the very best!

Parents' perceptions of independence and the means of obtaining it varied - usually according to the severity of their child's ASD. For example, while one mother talked of her son having independence in these terms:

I want him to have a job and get into relationships and have a social life and I don't want him to always rely on mum and dad for the rest of his life. I want him to be able to do things for himself ... I just want him to be happy and if he chooses to go to work, do something he wants to be doing. Just being able to live on your own, or have a partner and have his own family one day.

Another mother's dreams for independence were quite different:

To be as independent as he possibly can. Because he's got such a severe developmental delay to be able to toilet himself. When he's done a bowel motion he can actually let me know beforehand and he'll do it in the toilet and that's only just happened in the last month which has been a real breakthrough for him. A great release for the family. He still wets himself but to be able to do that would be huge and to be able to dress himself. He's trying to help and he's trying to do things now. But it's trying to come through the developmental stage he's got to get through. I always see him living within the family.

For one parent, dreams were a luxury she did not indulge in. She explained:

I don't have dreams and that's putting it plainly. He wakes up the next day in a good mood, I'm happy. I've got no hopes, dreams. I'm quite happy to plod. I'd like to see a lot of the "red tape" removed... It's not that I don't want him to be independent, I'm at the stage that if he's still with me when he's 32, he's still with me. If he's not, I'll go out and get a life. I don't hold the dreams that I want him to be independent, I want him to do this, I want him to do that because it's just too stressful when they don't happen and you do get quite stressed out, whereas I just go from day to day.

Similarly, a couple explained that they did not set goals for their children and are happy to support them in whatever eventuates:

I don't really have [a dream for them]. I'd like to see if we can get more family support and more acceptance but I don't have any dreams left in me for them. Just to be happy and accepted for what they are really. If Laura can be independent with help and Harry can develop a friendship that might lead to a marriage and children that would be

really fantastic. You never know with these children. Wherever their comfort level is and whatever they can achieve is fine. I'm fine with whatever.

Parents also discussed potential barriers to gaining future independence. For example, one mother remarked:

There are houses that people start-Trusts. Rich parents have these houses for their children and they get in flatmates ... I would like to think that in the future my daughter can have that as well as others and I don't want them to say, "No, it's only for mildly intellectually impaired people, we don't want behavioural problems here." I don't want them to say that that's going to be a barrier. I want them to say, "Yes we have trained staff who understand about this sort of thing, yes we can provide that."

One mother noted that her fears for the future were much greater than their hopes. She explained that she found it difficult now to get her seven-year old son to do things he did not want to:

In the last six months I've been out in public three times where I've had to phone my husband and say, "You need to come and help me," and he carries him out of the shop. What happens in five years when he's even too big for my husband? So we do worry ... If [an accident happens] is there a process set up especially for our kids where they don't understand, they're not going to cooperate, won't even have a little butterfly clip for the IV? How would they do anything? How would any of the procedures happen? Up until now it hasn't been much of an issue because we've been more powerful than him but he's much stronger than us now so what do we do? When we tried to put the probes in his head and there ended up three of us holding him down and that was when he was three or four and that was relatively easy but what happens now? I haven't spoken to any of the other parents because they all just joke about how tough it would be but I'd like to see something in place or even thought about, some sort of process thought through before we have to go through it rather than having to pave the way or try and fix it up afterwards... The hopes would be that somewhere along the way that there would be systems in place to support him regardless of how he ends up and that it be done so that there's still dignity and caring and support for him as a person.

... If I had to ask that anything be put in place, that there is a place that is suitable. And it's not a one class to fix all injuries issue, that it be looked at as the best things for Tony's needs would be to put in place, that there be the choices there, the correct choices and that there be adequate support. I guess the fear for us is what happens when he gets bigger? Who do we go to? Who do we ask about who is there to support?

Two other parents' fears for the future were related to their son's inability to communicate and control himself:

I think that is my biggest fear for when he is older, if we can't get him to control himself and get him to work things out ...

Or to explain so that he can say what he wants to do even if it is not an acceptable thing, at least they will know what he is trying to do.

Conclusion

This report has provided a glimpse into the lives of 19 Māori children with ASD, their parents and whānau. As parents' quotes have shown, raising these children is a challenging and often exhausting undertaking. While they have received some really helpful services and support from a number of outstanding individuals, they have also had to face a myriad of barriers along the way. As a caring community we have a responsibility to remove these barriers, to assist parents in the challenges they face and to ensure both Māori and non-Māori children with ASD are given every opportunity to develop their abilities and to lead a happy and fulfilled life.

These aims can be achieved by taking onboard the messages parents have given. There is a pressing need to increase relevant services to ensure that a diagnosis is obtained as early as possible. Assessment needs to be in an environment where children feel safe and secure – where possible this should be in the home. Where this is not possible, systems and environments need to be ASD-friendly in order to put the child at ease and to gain an accurate assessment. Most importantly, parents need to be listened to and their concerns taken seriously, after all, nobody knows a child as well as their parents.

At diagnosis parents should be given helpful information and personal support. They should not have to seek this out for themselves but rather it should be provided as a matter of course. As parents pointed out, they did not want to be given a number to ring or a multitude of information to wade through. What they did want however, was for someone to sit down with them to explain exactly what ASD meant; how they could assist their child; what were future implications; what services, equipment and entitlements existed; and not only to explain how these could be obtained, but also to assist them in the process.

Parents need to have on-going support to help them meet the growing and changing needs of their child. In particular, information and support is critical when children reach milestones such as going to primary and secondary school and leaving school. Parents should be assisted to make appropriate educational choices, they should be included in decisions relating to their child and funding should be transparent.

The research revealed a need for more culturally appropriate programmes and services for children with ASD. This can be achieved by providing more Māori-centred services, by upskilling the personnel in existing Māori services and by increasing the bicultural and bilingual expertise of personnel in mainstream services. Teachers also need to improve their knowledge of ASD and Māoritanga. Increased knowledge will, hopefully, bring with it more accurate assessments, more appropriate programmes, more ASD-friendly, safe environments and more informed decisions regarding children with ASD. In addition, increased knowledge is likely to lead to much-needed attitudinal changes and greater understanding and tolerance of children with ASD. This attitudinal change needs to happen not just amongst teachers and professionals but also amongst society in general. This may necessitate media programmes to facilitate awareness and understanding of ASD. Parents should be able to take their children to their local shops without being stared and glared at and made to feel they and their children are unwelcome.

There is also a pressing need for an increase in the number of professionals and services that help children with ASD, their parents and whānau. For example, insufficient or non-existent speech-language therapy and long waiting lists for behavioural support services are simply not acceptable.

Parents should not have to “fight” for services, nor should children have to go without the professional assistance that could improve their ability to communicate, to learn and to interact with others. Parents can also be significantly helped by reducing the “red tape” involved in accessing services while increasing the amount of financial assistance they receive to enable them to care for their children. ASD-related expenses need to be recognised and provided for. Finally, services need to be put in place to alleviate parental fears for their children’s future. May the mother who asked for future systems and services to support her son with caring and dignity be granted her wish.

Engari, he manako te kouri i kore ai

However, wishful thinking will not catch a crayfish

(action is needed!)

Glossary Of Māori Words

The meanings of Māori words provided in this glossary relate specifically to their use in this report.

Aroha	Love in its broadest sense
Awhi	Provide help and support
E tū	Stand up
Haere mai	Come here
Hapū	Sub tribe
Hei aha	Never mind
Hōhā	Troublesome
Homai	School for Visually Impaired Children
Hui	A gathering following Māori meeting protocols
Ika	Fish
Kai	Food
Kaiako	Teacher
Kaitiakitanga	Guardianship
Kapa haka	Māori culture, performing arts group
Karakia	Prayer, ritual chant
Kaumātua	Respected elder (both men and women)
Kaupapa	Purpose
Kawa	Protocol, procedure
Kia ora	Hello
Kei te pai	That is good
Kōhanga reo	Māori-medium early childhood centre
Kōrero	Speak, talk, conversation, discussion
Kuia	Respected female elder
Kura	School
Kura kaupapa Māori	Māori-medium primary school
Manaakitanga	The showing of respect, kindness, hospitality
Manu Kōrero	Talking Bird – Māori Speech Competition
Māoritanga	Māori culture, Māori perspective
Marae	Cultural meeting ground/place
Mokopuna/moko	Grandchild
Noho marae	Overnight stay at a marae
Paepae	Orators' bench
Pākehā	New Zealander of Caucasian descent
Reo	Language
Rongoā	Medicine
Roto	In
Rūmaki	Immersion
Rūnanga	Council
Taha Māori	Māori dimension
Taiaha	Wooden weapon, long club
Tamariki	Children
Tangi/Tangihanga	Funeral
Tapu	Sacred, forbidden
Tātou, tātou	All of us
Tautoko	Support, help
Tauīwi	Non-Māori person/people
Te reo Māori	The Māori language
Te Whaariki	The Early Childhood Curriculum
Tikanga	Customs, protocol, rules, principles
Waiata	Song

Wairua	Spirit
Wairuatanga	Spirituality
Wānanga	Discussion, learning
Whakamā	Shy, embarrassed
Whakapapa	Genealogy
Whakawhanaungatanga	Establishing kinship relationships
Whānau	Extended family
Whanaungatanga	Kinship, relationship
Whāngai	Adopted/cared for child
Whare	Meeting and sleeping house

Glossary of Acronyms and Abbreviations

A.B.A.	Applied Behaviour Analysis (Therapy)
A.C.C.	Accident Compensation Corporation
A.D.H.D	Attention Deficit Hyperactivity Disorder
A.S.D.	Autistic Spectrum Disorders
C.P.R.	Cardio Pulmonary Resuscitation
G.S.E.	Group Special Education
I.E.P.	Individual Education Plan/Programme
I.S.A.D.D.	Intervention Services, Autism and Development Delay
I.V.	Intra venous
M.A.P.S.	Map Action Planning System
O.R.R.S.	Ongoing, Reviewable Resourcing Scheme
O.T.	Occupational Therapist
P.E.	Physical Education
R.T.L.B.	Resource Teacher: Learning and Behaviour
S.E.S.	Specialist Education Services
T.I.P.S	Tailored Individual Profiles – a professional development programme for people who support children with ASD
W.I.N.Z.	Work and Income New Zealand
W.I.S.C.	Wechsler Intelligence Scale for Children – [Intelligence test]

Appendix A

MĀORI PERSPECTIVES OF AUTISTIC SPECTRUM DISORDERS (ASD) INFORMATION SHEET

Kia ora

Ngā mihi nui ki a koutou. Ko te tūmanako kei te ora koutou katoa.

My name is Jill Bevan-Brown. On my mother's side I am of Irish extraction while on my father's side I have iwi and hapū connections to Ngāti Raukawa, Ngāti Wehiwehi, Ngāti Awa and Ngai te Rangi. I am actually a Bevan from Otaki. My husband is Rawhiti Winston Brown (Ngāti Porou) hence the combined name of Bevan-Brown. I work in the Department of Learning and Teaching at Massey University College of Education and am a kaiawhina at te Wānganga-o-Raukawa where my husband and two of my children work.

I can be contacted at Massey University, Private Bag 11222, Palmerston North. My e-mail address is J.M.Bevan-Brown@massey.ac.nz. I can also be contacted by phone at work (06 356 9099 ext 8764) or at home (06 354 9597).

What is the purpose of the study?

I have a long-standing interest and involvement in Special Education for Māori children. Because of my 30 plus years of service in this area I have been asked by the Ministry of Education to speak with whānau of Māori children who have been diagnosed with ASD. The Ministry would like to provide culturally appropriate education for these children. However, information about what Māori whānau members and the children themselves would like is scarce. Similarly, little is known about the barriers to gaining an effective education that may be faced by these children and their parents and whānau. I would like to talk about these things with you so that I can pass this information on to the Ministry of Education to help them improve education for Māori children with ASD.

Who is involved?

In this study I will be interviewing 15 different whānau of Māori children with ASD who live in Wellington, Kapiti Coast, Horowhenua, Wairarapa, Hawkes Bay and Manawatu. The Ministry of Education and the Paediatric Society provided me with a list of all Māori children with ASD in these areas. I simply chose every Xth child on the list and have invited their whānau to participate in these interviews.² While the invitation is extended to whānau members in general I have left the decision about who should be interviewed up to the parent/s or caregiver/s of each child. This includes whether the child should be interviewed or not. I would like to talk with many more people right throughout Aotearoa/New Zealand but, unfortunately, the timeframe available means that I can meet with only 15 whānau.

What is involved?

The interviews will probably take between one and two hours. During this time you will be asked to share your experiences of having a family member with ASD - any barriers you may have faced, services and strategies you have found helpful and suggestions for improving education for Māori

² This was the intention of the research. However, as the number of prospective participants provided by the MoE and Paediatric Society was less than expected, no selection process was needed. Also the study was extended to include 17 whānau.

children with ASD. With your agreement the interview will be audiotaped. This is to help me as I find it difficult to concentrate on what you say and write it down at the same time! After information from the tapes has been transcribed, the tapes will be locked away and, after 10 years, they will be destroyed. (This is the usual procedure that is followed with research information.) All information given in interviews is confidential and it will be reported in such a way that people providing information remain anonymous. I will send each whānau a copy of information from the tape. At this stage you will have the opportunity of adding, deleting or changing any information you have provided before it is analysed and incorporated into the report to the Ministry of Education. I will also send each whānau a summary of the report. If you wish to read the whole report it can be obtained, free of charge, from the Ministry of Education.³

What are my rights if I participate in this study?

First of all, it is up to you whether you participate in the interview or not but if you do choose to be interviewed you can:

- decline to answer any particular question;
- withdraw yourself and the information you have contributed at any time up until the report is written;
- ask any questions about the study at any time during participation;
- provide information on the understanding that your name will not be used unless you give permission to the researcher;
- be given access to a summary of the project findings when it is concluded;
- ask for the audio tape to be turned off at any time during the interview;
- receive counselling support, if you feel disturbed as a result of your participation in this study.

Who do I contact if I have questions or concerns about the study?

If you have any questions about the study please do not hesitate to contact me.

This project has been reviewed and approved by the Massey University Human Ethics Committee, PN Protocol 03/136. If you have any concerns about the conduct of this research, please contact Professor Sylvia V Rumball, Chair, Massey University Campus Human Ethics Committee: Palmerston North, telephone 06 350 5249, email humanethicspn@massey.ac.nz

Arohanui

Jill Bevan-Brown

³ As well as a brief outline of the major research findings each whanau was sent a copy of the full report.

Appendix B

Researcher: Today I would like you to tell me all about raising (insert child's name) right from the time you first learnt or suspected he/she had some difficulties up until the present time. What have been the joys and challenges you have experienced?

Research Themes

(Tick off when covered, provide prompt if not covered)

- ☐ - Understanding of Autism/Asperger Syndrome in relation to their child
- ☐ - Barriers faced
- ☐ - Barriers overcome
- ☐ - Helpful/successful services
- ☐ - Helpful/successful teaching/learning/socialisation strategies
- ☐ - Accessibility issues
- ☐ - Cultural issues arising in assessment & diagnosis
- ☐ - Cultural issues arising in service provision
- ☐ - Cultural issues arising in education & evaluation
- ☐ - What would have been helpful in the past?
- ☐ - What would be helpful in the future?
- ☐ - Future dreams for their child