

# ***AUTISM NEWS***

Newsletter of Autism Tasmania Inc.

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## **In this issue**

Autism Tasmania News

A Tasmanian Family's Experience of  
Auditory Training

Asperger syndrome

What is the Disability Support Pension?

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### ***From the Editor***

First of all my apologies for the delay in getting this issue of Autism News to print. Our deadline is the end of April and here we are, approaching the end of May! The last few months have been extremely hectic particularly with our involvement in Giant Steps and on a personal level.

On the Giant Steps front, nearly three years of hard work is coming to fruition as the centre is due to open in June. While this is an exciting time for many, Autism Tasmania will continue to work towards improving services for all children and adults with autism. Not all families wish to access the centre for a variety of reasons, but if you are interested in what Giant Steps has to offer, please contact Autism Tasmania.

Back in February, I attended the National Autism Conference which was extremely interesting although by day three I felt overloaded. An interesting feature was the trend to refer to autism as "Autism Spectrum Disorder" and a great deal of information on Asperger syndrome was presented. This included a presentation from Mark Page who was in Tasmania recently at our invitation to share his experiences with parents.

Ros Ward - Secretary

### ***New Committee Members***

We are pleased to welcome to the committee Rachel Evans. Rachel is a speech pathologist from Burnie who expressed an interest in filling the vacancy created by Susan Bortignon's resignation. We welcome our first "professional" to the committee and look forward to Rachel's participation. Rachel has a keen interest in autism and has followed the progress of Autism Tasmania, attending many events over the last two years.

We have also co-opted Paula Barnes and her husband Ron, from Launceston, who also expressed an interest in the vacant position. Paula and Ron have a particular interest in the development of services for adolescents and adults as they have a twenty three year old son Michael. Paula has contributed articles for this newsletter which I'm sure you'll find interesting reading. They have also offered to take over organising parent support activities in the north. (Thanks - Ed!)

We were disappointed at the lack of response from the south - we are a statewide organisation and need even representation from throughout the state if we are to develop as such.

#### **APOLOGIES.....AND.....THANK YOU**

We apologise that the April issue of Autism news is not reaching you until late May - thank you for being patient. A special thank you to those members who have contributed to this issue and to Paula Barnes who did a great deal of typing - your efforts are appreciated by the editor!

# AUTISM TASMANIA NEWS

## *Coming Up!!!*

### **Wednesday May 24th - Launceston**

What: Discussion Evening  
Discipline - What, Where and When?"  
Is it appropriate?  
Where: Paula and Ron's  
16 Vaux Street  
West Launceston

Time: 7.45pm - All welcome.

### **Tuesday 30th May - Devonport**

What: Coffee Morning  
  
Where: Liz Marshall's  
60 William Street

Time: 9.30am onwards  
All welcome

### **Thursday June 22nd - Hobart**

What: Discussion Evening

Where: Melanie and David Rowe's  
4 Bellevue Parade  
New Town

Time: 7.45pm - All welcome

### **Sunday July 16th - Launceston**

What: Family Afternoon - Ten Pin Bowling

Where: Kings Meadows Bowling Alley  
Innocent Street

Time: 2pm

Mark Page informed us that the Alpha group (a social group for adolescents and adults with autism in South Australia) enjoy ten pin bowling and that he often has to drag his club members out of the bowling alley. We look forward to an enjoyable afternoon!

## *Happenings*

### **FAMILY SUPPORT**

Family support activities are again occurring throughout the state and we invite you to be part of these.

Sharyn Sturzaker from the north west writes about a late summer picnic held.... "The weather was great to us at our family gathering held at the Dinosaur park in Ulverstone. We all had a picnic lunch and the children played. Some children joined in the cricket, in which the parents showed how a "shield match" should be played!! Others went exploring and found it was great sliding down the dusty slopes on their bottoms, while the play equipment was also an attraction. It was pleasing that some new faces joined us for a great day."

North west parents are also enjoying an occasional night out for dinner and Liz has begun having regular coffee morning in Devonport on Tuesday mornings. Contact Lis or Rose for more information about parent support on the coast.

At the parent workshop held in Hobart a brief discussion was held about the type of support parents want or need. As a result a discussion evening was held on Thursday 18th May but unfortunately the newsletter wasn't out in time to inform everyone. Another evening has been planned for *June 22nd* at the home of David and Melanie Rowe and we look forward to seeing you there! Contact Elizabeth Rutledge for more information.

Family activities in the north are also being well supported. Paula and Ron Barnes have kindly offered to take over the organisation of these activities and their experiences will be invaluable to the group. Yvonne Hawkins has suggested we take the children ten pin bowling (apparently Gerry loves it!) and we are looking forward to this. Contact Paula for more information

# **AUTISM APPOINTMENT**

In the January issue of Autism News we stated that the Department of Education and the Arts was planning to employ Mr Anthony Warren as a statewide consultant on autism. Unfortunately Anthony was unable to take up this position but the department has appointed Mrs Jenny Vince to the position.

The specific role of this position is that of Autism Consultant/Support Person. It is a full time position and Jenny is based at Timsbury Road School in Hobart. She will be offering support to DEA staff in regular and special settings in the assessment, educational programming and management of students with Autism/Pervasive Developmental Disorder in government schools.

Jenny has a keen interest in autism and is looking forward to the challenges of this position.

# **PARENT WORKSHOPS**

Many parents attended our parent workshops held at the end of April and funded under the Commonwealth Respite for Carers Program. On Saturday 29th April approximately 25 parents attended a workshop at Talire School. There were many new faces among the parents: its great to see people being referred on to us by schools, doctors and other professionals or simply looking us up in the telephone book!

Our guests for the day were Vicki Bitsika, a clinical psychologist from Melbourne, Verity Botroff, a lecturer in special education from Adelaide and Mark Page, an adult with Asperger syndrome, also from Adelaide.

We began the day with introductions and general discussion. Many parents were fascinated by Mark Page's experiences and comments, which he seemed only too willing to share. To hear Mark speak can only help us understand our children even more and try to get "inside" their world.

Before and after lunch we divided into two groups - with Vicki leading a discussion on younger children and their needs (and the needs of the family), and Verity and Mark talking with parents of older children and those with Asperger syndrome. During these sessions, advice was sought from the professionals on how to cope with challenging behaviours.

A general discussion finished the day in Hobart. We hope that those parents who attended the day found it informative and beneficial. A similar day was held in Burnie the next day with a large group of parents.

We have received a few evaluation sheets from those who attended - we welcome your input and take on board any criticisms you have. We hope you valued being able to meet with other parents and have your children cared for at the same time. Carers will receive their payment at about the time Autism News go to print.

Editors Note - I attended the day in Hobart and from feedback received from both sessions believe there is a need for parents to get together on a regular basis to share experiences, talk, laugh and cry with other parents. You are welcome at any Autism Tasmania function.

# **FUNDRAISING**

Thank you to those members who assisted with selling chocolates - this is always a good fundraiser. We still have some funds outstanding so if you took chocolates to sell could you please pass the money or the chocolates back to a committee member as soon as possible.



# **SOCKS....SOCKS....SOCKS....SOCKS....SOCK S!!**

With winter fast approaching, we are again offering you the opportunity to purchase socks. When we

offered the socks prior to Christmas many people commented that we should run a sock drive again closer to winter. Please take the opportunity to purchase socks from the enclosed order form - they are good quality and made in Australia. Return your order with payment to Liz Marshall, 60 William Street, Devonport, 7310 by June 20th.

## ***National Autism Conference***

Autism Tasmania purchased a series of audio cassettes at the National Autism Conference covering most presentations. Please contact us if you would like to borrow these. A handbook of the presentations was also received by all delegates. I am not aware of further copies being available for purchase but if you would like copies of any papers we would be happy to assist for a small cost. The presentations included:

Professor Christopher Gillberg  
*Autism and its spectrum disorders: epidemiology and neurobiology*

Professor Elizabeth Newson  
*Evaluating interventions in Autism: problems and results*  
*Enabling flexibility and social empathy in able Autistic children*

Dr Tony Attwood  
*The Australian Scale of Asperger syndrome*  
*Why do repetitive actions occur?*  
*A diagnostic and treatment clinic for children with Asperger syndrome*

Dr Lawrie Bartak  
*Whats an autistic spectrum disorder and what's in a name?*

Dr Sue Bettison  
*Abnormal responses to sound and the long term effects of a new treatment program*

Verity Botroff, Pam Langford, Mark Page  
*Social cognitive skills and implications for social skills training in adolescents with Autism.*

Dr Allen Briggs  
*Medications and their usefulness*

Barbara Hayward

*Siblings of children with Autism*  
*Parenting a child with Autism*

Louise Ulliana & Leonie Kershaw  
*Putting parents in the picture: Running communication workshops for parents*

The keynote speakers at the conference were Professor Christopher Gillberg from Sweden and Professor Elizabeth Newson from the United Kingdom.

Professor Gillberg gave an excellent presentation on the recent developments in autism and its spectrum disorders. He reviewed the prevalence of autism where the various syndromes comprised in the "autistic continuum" need to be taken into account. In a recent Swedish study, Asperger syndrome was present in at least 36 and possibly 71 of 10,000 children born. These findings suggest that Asperger syndrome is at least about 5 times more common than autistic disorder.

The diagnosis of autism regardless of the diagnostic manual used rests on a set of behavioural criteria, invariably comprising communication, social interaction and behavioural deficits. Slightly different subcriteria for each class of symptoms are emphasised by the different manuals, but all agree that there must be severe problems in (1) relating reciprocally to other people, (2) verbal and/or non-verbal communication, and (3) adjusting the behavioural repertoire in a flexible way to the changing demands of new social situations.

Professor Gillberg proceeded to discuss autism and cognition, sex ratios, autism and epilepsy, hearing deficits, speech and language impairments, ophthalmological problems and associated medical disorders.

He discussed the outcomes for both autism and Asperger syndrome - the outcome for autism generally being poor as regards social functioning in adult life. The outcome of Asperger syndrome is not well known but the evidence suggests that it is very much better than in classic autism and that many people with this syndrome lead so called normal lives in adulthood. However, it is equally clear that many have a poor psychosocial prognosis. Bizarre crime, atypical depression, suicide and

overall social ineptness are all quite common types of outcome in Asperger syndrome.

*Please contact us if you would like a full copy of Professor Gillberg's paper.*

## **AUTISM INFORMATION**

### **DIAGNOSING AUTISM - AT 18 MONTHS?**

Early diagnosis is crucial to obtaining specialist early intervention for the child with autism. It is also critical to family adjustment and in coming to understand child needs. Simon Baron-Cohen, Jane Allen and Christopher Gillberg have researched and produced the CHAT, a Checklist which will help to identify infants at risk.

An exciting new report suggests that accurate diagnosis of autism in children as young as 18 months may be possible, using a simply 14-question test.

Simon Baron-Cohen, Jane Allen and Christopher Gillberg developed the CHAT (Checklist for Autism in Toddlers), which asks questions pertaining to social play, social interest, pretend play, joint-attention skills, communicative pointing, and imitation.

Parents answer nine questions (e.g. "Does your child take an interest in other children?") and physicians answer five (e.g. "During the appointment has the child made eye contact with you?")

The researchers had the test administered to 50 randomly selected 18 month olds and to 41 "high risk" 18 month olds with autistic siblings. (About 2% of autistic children have autistic siblings.)

None of the control subjects (those without autistic siblings) failed on more than one item pertaining to pretend play, social pointing, joint attention (attempts to direct another person's attention) social interest, or social play. In the "high risk" group, four children failed on two or more of these items. Each child was re-examined at 30 months of age. The 87 children (both control and high-risk) who had passed four or more of the key developmental areas tested at 18 months had developed normally. In contrast, the researchers say, "The four toddlers who had failed on two or more of these key types of behaviour at 18 months received a diagnosis of autism by 30 months". In other words, "the CHAT detected four cases of autism in a total sample of 91 18 month olds.

The CHAT takes only a few minutes to conduct, which researchers say means that the early diagnosis of autism is both possible and economic. They note that the CHAT includes several items that autistic children pass but most retarded children fail, thus making the test more specific for autism.

A large-scale follow-up study is being conducted.

*Reprinted from Autism Queensland Vol.3 No 1 Feb 1995. First printed in Autism Research Review International, Vol 7, No 1. 1993. "Can autism be detected at 18 months? The needle, the haystack and the CHAT", British Journal of Psychiatry. 1992, 161, pp839-843*

# **ASPERGER SYNDROME**

*The following article is reprinted with permission from Communication Volume 28 Issue 2 (December 1994).*

## **What is Asperger syndrome?**

Asperger syndrome is best understood as one part of the spectrum of autistic disorders. However, what distinguishes people with Asperger syndrome from those with the more 'classic' autism is their greater ability with language, the fact that they are less likely to have an accompanying learning disability and their clumsiness.

People with Asperger syndrome and people with autism share the same core problems: difficulty in communicating feelings and reaction to others; and a failure to understand the non-verbal clues that are used constantly to ascertain other peoples' feelings, social status or even age. However, these problems are often less severe in people with Asperger syndrome and, therefore, more difficult to identify.

## **Learning by observation**

Evidence suggests that people with Asperger syndrome have problems learning by observation and co-operating with others in tasks that involve joint attention. This lack of shared 'attentional structure' can be very apparent in the unusual interests, original and creative thought patterns and odd responses that are so characteristic of so many people with Asperger syndrome.

These unusual interests, such as learning maps, records or lists of names, often involve a classification activity requiring considerable feats of memory. These activities may indicate a wish to make sense of a world which, because of the lack of shared attentional structure, must often seem senseless or unpredictable.

Another source of unpredictability lies in the difficulty that people with Asperger syndrome seem to have in understanding how others think or feel - a lack of "theory of mind" as the current jargon has it.

## **Diagnosis**

The relatively good language skills of those with Asperger syndrome compared to those with autism can often result in late diagnosis because parents and professional may be reluctant to recognise a developmental problem unless it is associated with a marked language difficulty. Many of those affected are not diagnosed until their teens or even adulthood.

The number of people with Asperger syndrome is also very difficult to estimate. For every child diagnosed there may be several in the normal educational system who have not been diagnosed.

The fact that many people with Asperger syndrome attend mainstream school has its advantages and disadvantages. On the one hand they are given the opportunity to learn as other children do whilst on the other their particular social and emotional problems are often not recognised. Even more importantly they may be the target for bullying and teasing by other children who find their differences offensive or upsetting. This in turn can lead to emotional and behavioural problems.

Paradoxically, the fact that people with Asperger syndrome are more able means that they may also be aware of, and therefore more distressed by, their differences than a person who is more severely autistic. This sensitivity is often worse in adolescence, a particularly difficult time for people with Asperger syndrome and their parents.

## **Psychiatric disorders**

Psychiatric disorders such as anxiety or depression may occur and some people with Asperger syndrome can exhibit anti-social behaviour which may involve threats or violence to others.

People with Asperger syndrome are not completely disabled by their handicap, however. Many are able to acquire social skills given the appropriate environment. This, coupled with the greater tolerance of eccentricity in older people in our society, means that once the storms of adolescence and early adulthood have been weathered, many people with Asperger syndrome can look forward to some sort of safe harbour even if it is one that is somewhat unfashionable and out of the way.

# **GIANT STEPS UPDATE**

## **References**

Taken from 'Asperger Syndrome' by Professor Digby Tantam in a collection of papers from a study weekend on Asperger syndrome: Adolescents and Adults with Asperger Syndrome (1991).

After the announcement by the Minister for Education and the Arts, last November of funding for \$15,000 per child, up to a maximum of 15 children, much work has taken place to establish a Giant Steps Centre in Deloraine.

As required by the Minister, a Public Company limited by guarantee has been formed under the corporations law. The company is controlled by a Board of Directors, five of whom are nominated. Two directors are nominated by Autism Tasmania, one by the Meander Valley Council and one each by the Lions and Rotary Clubs. The remaining seven directors on the Board are elected by the members of the company. Initially the Board consists of 15 directors which will reduce to a regular number of 12 directors over two years. The new company is a licensed Public Benevolent Institution.

A property in Deloraine has been purchased and is currently being refurbished ready for commencement of the program in June. Equipment is also being purchased.

All parents who are members of Autism Tasmania or were members of Giant Step Tasmania Inc. and have children between 3 and 13 years of age were canvassed and invited to submit an application for enrolment into the program. Eighteen applications were received and these are currently being processed. Selection depends upon approval by Giant Steps Montreal and meeting criteria set by the Tasmanian Department of Education. A full complement of 15 children is being aimed for.

All Tasmanian parents who expressed an interest in their child attending Giant Steps were invited to a parent information day several weeks ago. Parents were able to hear three of the recruited staff speak and receive an update on the establishment of the centre.

## **PURVIS EUREKA CAR**

It was an opportunity for parents to ask questions of both the staff and the board members present.

The centre is being operated as a non-government special school. Of major concern to many parents is the financial contribution required from parents in order to see the centre established. In 1995, parents are being asked to contribute a sum of \$4,000.00. The Board of Directors recognises this is a substantial amount of money and is supportive of parents seeking outside assistance with this cost.

The Board of Directors have so far made interim appointments of five key staff members who visited Montreal in April for an initial training course. Further appointments will be made over the next month until the entire team is recruited.

It is anticipated that the program will commence mid June, by which time a training team from Canada, including Darlene Berringer will be in Tasmania.

With the generous assistance of substantial grants from service clubs in Deloraine an operating budget has been formulated. Long term viability is still very dependant upon continued sponsorship from the private sector, general fundraising and submissions for federal and state funding. A major raffle is currently being conducted with a Purvis Eureka car valued at \$15,000 as first prize. This car has been chosen for its novelty value. Tickets are \$2.00 and if you can assist by buying or selling tickets, please contact Penny Cromarty on (003) 34 1119.

You can join the company as a member for an annual subscription fee of \$20.00. In the event that the company is ever wound up with insufficient assets to cover its debts, (not one of the aims of the Board!) your own personal liability is limited to \$100.00. If you have any questions regarding company membership please contact the secretary of Giant Steps, Tricia Bourke on (003) 31 6168.



# FROM OUR MEMBERS

## OUR EXPERIENCE WITH AUDITORY INTEGRATION TRAINING

### Michael Rutledge

Ryan was seven when we first learnt of Auditory Integration Training (AIT). It was May 1992 and we were caravanning to Queensland when we watched a program of "Beyond 2,000". Presented, was the idea that some people with autism have hearing disorders, such as heightened sensitivity to certain sounds and diminished sensitivity to other sounds. Not only had this been recognised but a treatment had been developed by Guy Berard and used with some outstanding successes by Edelson in the United States.

We wondered....we had, after all, had Ryan's hearing tested when he was two years old. Was it possible to test an active autistic toddler? The results had indicated that he seemed okay.

We cast our minds back over the years; there was something not quite right. Ryan seemed to hear certain sounds very well, indeed the belting out of Happy Birthday from the extended family around the dining table is now only just tolerated, as is the Public Address System at the K Mart, but also there were times when he acted as if he were deaf, not responding to the barrage of directions, questions and comments that filled his environment.

Later that year at the National Autism Conference, Elizabeth learnt more about AIT and how the world must sound to a person with autism with a hearing disorder, from a presentation given by Dr Sue Bettison. We became more convinced that this was part of Ryan's problems and decided to follow closely the study that Dr Bettison was embarking upon, to assess the success rates, benefits, side effects and adverse reactions to AIT.

Towards the end of 1994 we learnt of a therapist, Mike McCarthy, who visited Australia from the USA to conduct AIT sessions and would be returning early in 1995. We heard of some success stories and read, also that Dr Bettison's study had

shown there to be little, if any, adverse effects and a surprisingly high success rate. I was still somewhat sceptical, but on learning about the latest equipment used by Mike which allowed him to test and measure the patients auditory response without the need for patient feedback, we considered it to be an opportunity worth taking.

There wasn't much time for planning and ten days straight of therapy with Ryan in Newcastle, required a bit of organising and forethought. We decided to drive, enabling us to take plenty of familiar gear and providing us with convenient mobility and a safe haven or refuge in a strange place, if things got bad.

The day before the treatment was to start was reserved for testing. Our appointment was 1.00pm and the time couldn't go fast enough for either Ryan or I. Mike explained the procedure: Ryan was to sit still with little or no head movement fitted with an ear-plug for a few minutes, per ear, while making a minimum of noise.... Difficult? Well, it was completed rather easily. I think Ryan was pleased to finally be "fixing my ears".

Results of the Audiogram were immediately available and clearly showed an abnormal hearing response. There was a deficit in a broad section of mid range frequencies (normal speech sound range) and also a left/right imbalance, with the left side having greater deficit. With such a wide deficit range and apparently no frequencies where a super sensitivity exists, the treatment strategy employed was to initially hit all frequencies with the modified music to bring the level of response up generally. A second Audiogram would be made at the midpoint of the course of treatment to reassess the situation and make any adjustments for the remainder of the program.

Treatment consists of two half hour sessions per day for ten days without a break. The person wears a

set of earphones and listens to specially selected tracks of music which are altered by the McCarthy's Audiokinotron machine. This is normally done while sitting at a table and the person can be engaged in some activity, such as drawing, playing with a toy or looking at a book but nothing noisy or distracting to the extent of taking concentration away from listening.

All went smoothly for our first three sessions then after a delay in our start time, Ryan was restless. Fifteen minutes in and he was becoming increasingly upset, throwing himself around and wanting to stretch and tie knots in the earphone cord. Marcy McCarthy and I held him till the end and he calmed down quickly after but leaving us in no doubt he wanted to do something to the machine.

Ryan told me later that the cord was too long and tomorrow he wanted to use the other machine and though identical, this seemed to work. During the afternoon session, however, he lifted the headphones often and also said that it hurt his eyes; this did not surprise Mike McCarthy and in fact pointed to progress being made in sensory pickup or management ..... encouraging.

The tests at the halfway point of the program showed a definite improvement in all frequencies so it was decided to target certain frequency areas for the rest of the treatment to enhance the response in the midrange which was still below normal levels.

Although there were ups and downs, the rest of the sessions went without significant incident but outside there were odd cases of new and appropriate words and phrases which have continued to come slowly.

The final Audiogram indicated further improvement giving Ryan a near normal hearing response profile, and although there can be some regression, Ryan is generally calmer and more able to tolerate a number of sounds that had upset him previously. These sounds included things like his brother's noisy breathing in bed which would drive Ryan out to the couch, people coughing or tongue clicking and canned laughter on television. We have had instances where Ryan has told us of improvement in his hearing and he is taking great delight in listening

to some of these "new" sounds, such as the whoosh of a car going past our car, with window wound right down, of course. We imagine that to Ryan it must seem like having to learn a new language with all the different mixes of sounds that he can now access.

Yes, it has been worth the effort and more importantly continues to grow in worth.

*If you would like more information, feel free to contact the Rutledges on (002) 49 2422*

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## **AUDITORY TRAINING and STRUCTURED LISTENING with Dr Sue Bettison**

Dr Sue Bettison is a clinical psychologist who is now in private practice in Sydney. Dr Bettison was formerly the director of the Autism research Institute in New South Wales where she was conducting research into sound sensitivity. She hopes to continue the research in her practise but will also be offering treatment for sound sensitivity as one of the services available.

If you would like more information on auditory training and the costs involved please contact Autism Tasmania to obtain an information sheet, or contact Dr Bettison on (02) 428 3206. If there is enough demand Dr Bettison would also be happy to travel to Tasmania. Treatment is available to any child or adult with sound sensitivity, including those with developmental disabilities, learning disorders and autism.

## **DISABILITY SUPPORT PENSION**

*Many of our members have young children and receive the child disability allowance. But what happens when they turn 16 years of age? In the following article Paula Barnes gives us some insight into the Disability Support Pension.*

I can recall feeling totally overwhelmed at the prospect of applying for Disability Support Pension (DSP) on behalf of my son, Michael. What actually was DSP? Was he entitled to help? Was I? I envisaged a bureaucratic nightmare with copious forms to fill, telephone calls, interviews, followed by the inevitable wait as the slow wheels of government departments assessed, digested and processed the contents before finally making a decision.

Already mentally exhausted because this was a particularly harrowing period in our lives when our son, seeing only a bleak future for himself was contemplating suicide, I determined to ask for help. For some of us, asking for help is an alien concept, due in part, I guess, to our socialisation. I have learned since, that this is both foolish and selfish. In latter years it has given more meaning to the proverb, "He that asks a question is a fool for five minutes. He that doesn't ask remains a fool forever."

You may believe that your child who is approaching 16 years or an older son or daughter recently diagnosed, is eligible for D.S.P. What do you do?

With the help of the Department of Social Security in Launceston I have compiled a brief and basic guide which may assist you when considering DSP. It wasn't the nightmare I'd envisaged but preparation is always helpful and remember to start procedures at least three months before eligibility.

### **WHAT IS DISABILITY SUPPORT PENSION?**

If you cannot work because of long term health problems or disability you may be eligible for DSP.

### **WHO IS ELIGIBLE?**

Upon application you must be:

- \*a man aged between 16-64; or
- \*a woman aged between 16-59;
- \*an Australian citizen or permanent resident unable to work because of long term or permanent disability.

You can claim DSP whilst still at school.

### **WHAT CAN I DO IN PREPARATION?**

You will need to provide identification and will be asked for at least three original documents (not photocopies), as proof. Here are some things you could show:

- \*Australian Passport or current overseas passport stamped for entry to Australia.
- \*Certificate of Australian Citizenship.
- \*Birth certificate.
- \*Letter from a government department bearing same address as your claim.
- \*Bank, credit union or building society book more than 12 months old.
- \*Legal documents eg: family court arrangements, custody papers.

### **WHAT ELSE CAN I DO BEFORE APPLYING?**

DSP can only be paid into a bank account so open one in the name of your disabled child. Ask the bank for a form exempting them from government duties, FID etc. Remember to take ID.

Apply for a Tax File Number. Forms are available at local Tax Department and Post Offices. Remember to take ID.

### **HOW DO I APPLY?**

*Pension Claim* forms are available from your local Department of Social Security. You may also require a *Request to Appoint Nominee* form if the pension recipient wishes you to act on their

## **DISABILITY SUPPORT PENSION (cont)**

behalf. There may be other allowances to which you may be entitled so ask about *Rent Allowance*. You will need proof of payments paid for rent board/lodging either in the form of a letter or rent book from you or the person receiving the payment.

You may also be entitled to *Mobility Allowance*. Remember to ask the DSS about eligibility and a claim form.

As a parent or carer you may qualify for a *Carer Pension*. You will need another *Pension Claim* form from DSS.

If your young person needs nursing care contact; Commonwealth Department of Health, Housing and Community Services on (002) 21 2427 for details of *Domiciliary Nursing Care Benefits*.

### **WHAT IF MY CHILD IS AT SCHOOL OR COLLEGE?**

You can still claim DSP. They may also be eligible for *AUSTUDY* because if DSP is approved, they are considered to be independent and family income is not considered in the application. Ask at your local CES.

### **ONCE APPROVED, WILL DSP CONTINUE INDEFINITELY?**

Disability Support Pensions are sometimes reviewed. This can happen if the recipient starts work, or if there is a chance that the current inability to work may improve.

### **SO, HERE'S YOUR CHECKLIST:**

- \*\*start 3 months before eligibility
- \*\*gather at least 3 pieces of identification
- \*\*open bank account - exemption from govt duties form
- \*\*tax file number
- \*\*DSS forms
  - pension application
  - request to appoint nominee
  - rent allowance or rent book/letter
  - mobility allowance
  - carer pension claim
- \*\*domiciliary nursing benefit
- \*\*CES re: school/college austudy

Most people will be required to attend an interview with the DSS to get further information about themselves and their income. The claimant or carer will be required to give medical information and the claimant will probably be asked to sign a form giving their doctor/s authority to release medical information about them. This helps DSS to quickly assess your claim. The report from your doctor is usually all the information needed but sometimes a Commonwealth Medical Officer may request examination. If you have been receiving Child Disability Allowance it is quite likely your claim will be processed quickly.

Remember, you may not be eligible for everything outlined above, but you will never know unless you ask.

# *WE PROGRESS TOGETHER*

## A MOTHER'S PERSPECTIVE

**Paula Barnes**

His entry into the world should have told me something! From day one it was not his intention to be social. A reluctant bottom with it's unseeing eye made a tentative move toward myriad ghost like figures, clad in white, peering above flimsy paper masks. He was rushed to "special care" whilst I was told baby had had a bit of a shock. I waited, legs akimbo to be sutured, feeling more like an accident victim than a woman delivered of child.

Almost two weeks later we were home. His incessant crying seemed in contrast somehow to his beauty. Long dark eyelashes curled above dreamy blue green eyes, his flawless face crowned with thick brown hair in which the slightest hint of auburn glinted in winter sunlight. "You'll break a few hearts when you're older," I cautioned teasingly. I little knew as we set out upon this journey together that the heart to break would be mine. After weeks of crying he finally settled into a routine. His apparent reluctance to be held I dismissed as colic; indeed I had answers for most things in those early years. He was well into his third year before he spoke, he was lazy. He wasn't interested in playing with other children - well, he was an only child and unused to sharing. We lived in the country and visits by others were not as frequent as perhaps those in town - he'd be exposed to more children when I enrolled him at kindergarten.

The years which followed have been written in various ways by different field workers. We can pick up most of the current texts and take a soupcon from this and a generous helping from that....but more plentiful than the texts were the adjectives applied to my son by the misinformed and the ignorant of those earlier years. He was deaf, defiant, inattentive, antisocial, dreamer, loner, looney....the list was endless and I believed them and those directed towards me, conveniently packaged under the heading "Poor Parenting".

I determined to go into battle....not with the accusers but with the accused. With Dickensian firmness I pushed him harder and harder to achieve. He learned, if not altogether understanding concepts entirely, certainly by rote. When I pushed him too hard he would "disappear" from me and the rituals and obsessive behaviour would increase.

Our family became the increasingly unfamiliar "extended family" - my mother came to stay and stayed. Whilst I celebrated my triumphs as her grandson made

monumental strides - she saw only his deficits and mine as a parent but our feuds were few and her judgments borne of ignorance, initially shared by my husband.

His vocabulary increased and he was able to read (though his comprehension was often in doubt) I was too busily applauding every minor scholastic achievement to focus upon his lack of social skills. In retrospect, I think it was easier to ignore them. Whilst other parents complained of their youngsters mixing with undesirables, my son never had friends - it was never a problem. I little knew of the taunting, teasing and at times bullying he was subjected to as an outsider.

The angelic face changed over the years to become handsome but the dreamy look was little altered. It had now become difficult to ignore his loneliness and concerted efforts were made to "socialise" this aloof young man. We dressed him up in scout uniform - he stared admiringly at his reflection in the mirror, for what seemed hours, before finally agreeing to go to the first meeting. He went twice....or was it three times before begging us not to insist he go again. We tried the sea-scouts....the uniform was far more appealing. I think he went to several meetings before saying he did not want to go any more. All those uniforms...so many things we tried. It was his insistence that he look the same as others which found us constantly burrowing deeper into our wallets.

Cricket was more successful although he was not blessed with marvellous co-ordination. On one occasion his team had won their match but they decided to play out the time and give the less able youngsters a chance to bowl the tailenders. The kids preceding had bowled with a determination and speed which would have had most adults running for cover. Nervously our son took hold of the ball. It was like a slow action replay, the batsman hesitated a second before attempting a hook shot which was proudly caught mid-field. Surrounded by players shouting "well done" his smiling face turned to one of sheer horror as the kids jumped on him, tousling his hair, acknowledging his wicket. Instead of congratulating his fielder he stood rigid, terrified in the middle of the pitch. He didn't play again.

High School was a difficult time both scholastically and emotionally. It was a time of remedial classes, guidance officers and educational psychologists. He had made so

much progress in his primary years and suddenly it appeared to stop. He became more and more introverted.

At fifteen he left school to go to Art College. Beautiful drawings adorn our home but his drawing forte was unsupported academically and he left college after only one year. Attempts were made to find some sort of employment and pardon me if I use that prohibited F word....but we failed.

He sank into a dark abyss and we were unable to reach him for a long, long time. He began to gain insight and acknowledge that he was different....but to be so different was too hard to endure. The deterioration was heart breaking as he began to contemplate suicide.

Followed two years of the darkest despair for us all during which Psychiatric Services were at times supportive, at others frustratingly uncooperative. My diary was to read like that of a depressive. My son became increasingly withdrawn and when agitated his rituals would increase.

It wasn't a sunny day indeed it was most unremarkable but I suddenly discovered a new energy and resolve to do battle once again, this time with government agencies. My efforts and those of our son's social worker, Wayne and the manager of what we formerly called Self-help or Sheltered working environments, were rewarded when he was offered a place. His confidence increased and very slowly he began to recover from this nightmare.

Today, some years later at the age of twenty three, he is a handsome young man coming to grips with his differentness. He does some casual work occasionally for a company whose directors and staff have strong moral values and are sensitive to his special needs. He is a conscientious worker but needs constant supervision and reassurance. Employees see him as rather an odd character who appears at time to be a bit of a contradiction.

For most of the time he appears aloof, sits alone but occasionally mimics the voices or characteristics of fellow workers. He is trying to control some of his stereotypic behaviours but when stressed seeks reassurance from these. His father is concerned for his future. His son's naivete makes him a vulnerable target for the unscrupulous. Although he has learned some social niceties he does not have the skills to develop friendships.

Sadly, he finds it difficult to initiate conversation with friends and extended family members so he is always on the periphery of such gatherings. To visitors he seems indifferent but I ponder often on the indifference exhibited by visitors to my son's difficulties.

We have come a long way together but the road never ends and it will be one, eventually, he must travel alone. Today he went to visit some retired friends of ours....the afternoon light became dim and they were tiring. Periods of silence were broken occasionally by their yawns and sighs....but they went unheeded. "It's been nice seeing you" they said; to which he politely replied "yes, you too". Finally, my friend had an inspiration. She led him into the garden asking him to help her pick flowers....filled his arms to overflowing and asked him to take them home to his Mum...before, bless them...they died!

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*AUTISM TASMANIA ANNUAL GENERAL MEETING*

*will be held on*

*SATURDAY 19TH AUGUST 1995*

*in*

*HOBART*

*We are planning to have a guest speaker - please keep this day free.*

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*Autism Tasmania  
Christmas Get Together*