

AUTISM NEWS

Newsletter of Autism Tasmania Inc.

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FROM THE EDITOR

Having recovered from National Autism Week, I am now able to concentrate on the newsletter. Autism Week was an extremely busy time and you will find reports of events that occurred during the week in this issue. I hope you again find Autism News informative - my computer skills are gradually improving but I am still trying to come to terms with a newly acquired program.

One of the advantages of being a committee member is spending time with and getting to know the professionals who visit Tasmania. Dr Lawrie Bartak and Amanda Golding were in Tasmania for the Annual General Meeting of the National Autistic Association and kindly agreed to stay over for our parent workshop. I always find it very interesting talking with professionals who have a major interest in autism. There is so much to learn. I hope those parents who attended the workshop at the conclusion of Autism Week benefited from this day. It was great to see so many parents there, and in particular a lot of new faces.

Ros Ward

ANNUAL GENERAL MEETING

At the Annual General Meeting, held in August, most of the committee was re-elected along with some new faces. The size of the committee has been expanded to enable more people to participate in the running of the association and to share an ever increasing workload.

Welcome to Elizabeth Rutledge (who has been co-opted to organise events in Hobart in the past), Liz Marshall from Devonport, Michael Freeman from Wynyard and Susan Bortignon from Hobart. Liz and Michael are the parents of young newly diagnosed children, Rhys and Kelsey, while Susan is the parent of a teenage son, Joshua.

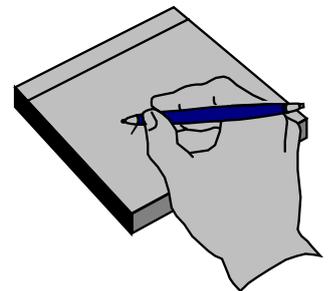
The AGM was attended by approximately twenty people from around the state. As well as the election of office bearers, the Annual Report was presented including the Treasurers report. Your copy of the report is included in this mailing if you did not attend the AGM.

THANK YOU.....

On behalf of the present committee of Autism Tasmania we would like to thank Jenny Mitterbauer for her participation over the last twelve months. Jenny did not seek re-election this year due to family commitments and we thank her for the time and effort she gave to Autism Tasmania.

Have You Paid Your Membership for 94/95?

Many members have already renewed their membership for the next financial year and we thank you for your support. If you wish to continue receiving a copy of Autism News, a reminder slip has been included in this edition. We ask that you forward your subscription as soon as possible. Please note that we are now offering a concession of \$10.00 per year to those families holding a concession card (eg sole parents, unemployed parents, etc.)



Committee

President Mark Ward

(003) 43 2308

Vice President Rose Clark

(004) 42 3594

Elizabeth Rutledge

(002) 49 2422

Secretary Ros Ward

(003) 43 2308

Treasurer Michael Rutledge

(002) 49 2422

Committee Elizabeth Marshall

Members (004) 24 3686

Michael Freeman

(004) 42 2039

Susan Bortignon

(002) 49 5809

FROM AUTISM TASMANIA

Professional Workshops Assessment and Diagnosis and Management of Children with Autism



Assessment and diagnosis workshops will be held in the first week of November throughout the state. Dr Lawrence Bartak (clinical psychologist) will be returning to the state along with Dr Philip Graves (Paediatrician) and possibly Ms Viv Williams (speech pathologist). These professionals work in the developmental assessment clinic at the Monash Medical Centre. They have particular experience of and interest in children with autism.

One day workshops will be held at the assessment centres in Hobart, Launceston and Burnie for those professionals particularly involved in the diagnostic process. In Launceston for example, this includes assessment centre staff, local paediatricians, staff from St. Giles and Walker House Family Health Centre; areas particularly concerned with children's development.

In addition two half day seminars are being held for teachers and Department of Education and the Arts Staff. These seminars are open to teachers and other professionals who are currently working with children with autism or to teachers and professionals who will be working with a child with autism in 1995.

The seminars will be led by Dr Bartak and Dr Graves

and will have a strong practical focus. Participants are requested to bring to the seminar a program of work they have developed for a student with autism.

The proposed seminar outline includes - diagnosis, assessment, relating assessment to developing programs, on going assessment and program review etc.

The seminars are as follows;

North

Date: November 2nd 1994

**Location: Launceston Teachers Centre
Launceston**

Time: 10.00am - 1.30pm

South

Date: November



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**Location: Philip Smith Centre
Hobart**

Time: 9.00am - 12.30pm

If you wish to attend either of these seminars please contact Doug Bridge on (002) 337415 by Monday 24th October.

THANK YOU

Thank you very much to the Apex Club of Frederick Henry Bay in Hobart for their generous donation of \$652.55. This money was raised by Apex members at their last annual bike race against the Lauderdale Fire Brigade. The Fire Brigade contributed to this total with a \$100.00 donation. Our thanks to these groups for their support.

Thank you also to the doctors at the Smithton Surgery for an equally generous donation of \$100.00.

Fundraising

Now that membership is growing it is hoped that fundraising activities can be organised, either on a statewide basis or at a regional level. This is an area in which we have been very quiet, but we would like to change that!!!! We aim to develop fundraising groups in each region or a statewide group with representation from each region. Liz Marshall is happy to co-ordinate activities and has lots of ideas, so if you can help make these a reality please give her a call on (004) 24 3686



Upcoming Social Events

North West:

Date:October 22nd
Time:7.30pm
At:Bass and Flinders Hotel Ulverstone
For:Dinner -
3 Course Meal \$15.00
Rsvp:To Rose Clark or Liz Marshall ASAP

North

Date:November 16th
Time:7pm
At:Calabrisella Restaurant
Wellington Street, Launceston
Rsvp:Ros or Mark Ward by November 10th if you are able to attend.
For:Social evening-Foods great and reasonably priced.

South:

At present there is no date fixed for the next get together but as response to the last two events has been encouraging, Elizabeth will be in touch with members

shortly. She is looking forward to establishing regular get togethers depending upon peoples needs.

Task Force Update

As this newsletter is being produced, we are waiting upon an announcement from the minister regarding service provision for children with autism in Tasmania. You may recall that in the last newsletter, we invited you to attend a series of regional meetings following the task force meeting on July 25th.

Several members in each region took the opportunity to discuss task force proceedings with Mark (Autism Tasmania's representative on the task force) and other task force members, Doug Bridge, Kerry Channel and Dr Alfhild Larson who each attended two of the regional meetings.

The final two task force meetings were chaired by Ms Ruth Radford and an interim report has been produced by the task force and forwarded to the minister. The report initially requests a commitment for funding for a centre based and outreach service and recommends a non-profit organisation contracting services from Health and Education Departments. If this commitment is obtained, the report recommends that further discussions be held with Ms Darlene Berringer of Giant Steps.

The Triffitt family have returned home and brought with them two Giant Steps trained staff to continue Corom's program as much as possible. It has been interesting to look at the reaction that the Triffitts story as shown on A Current Affair generated around the country. Responses have been mixed from both parents and professionals, but as a result there is now a move to also establish a Giant Steps centre in Sydney.

National Autism Week

Publicity

Did you see the community announcements on television throughout Autism Week? Tas Tv were

very kind to us and Ray Martin's head appeared frequently throughout the week, including during prime time!!! The Tas Tv announcement was not dated and continued to be shown after Autism Week had finished.

We were pleased with both announcements and many people in the community have commented on them. We received many calls from throughout the state as a result, both from parents of young children and interested people just wanting to know more.

It was exciting to have the services of Ray Martin, unfortunately we were not able to use his face on Southern Cross as they draw their programs from Channels seven and ten on the mainland. Both stations charged a fee to make the announcements, but they were shown free of charge and I'm sure you'll agree were great publicity in helping to make people autism aware.

Media coverage was reasonably extensive throughout the state. Radio interviews were done on 7ZR and 7NT; newspapers featured personal stories on the Marshall, Freeman, Fehr, Rowe, Minucci, and Ollington families in the Advocate, Mercury and Southern Star while the Examiner and Southern Cross television covered the parent workshop and did interviews with Lawrie Bartak and Amanda Golding.

Parent Activities

Parent activities were held in the South and the North culminating in the parent workshop "Living with Autism and Aspergers Syndrome" in Launceston at the conclusion of Autism week.

Autism week began with a family barbecue at Tolosa Park in Glenorchy. Those who attended were blessed with a lovely sunny day and this helped to make the barbecue a very enjoyable outing.

About half a dozen families attended, including one family who travelled from Maydena, with several others offering apologies. This made a good-sized gathering; the adults were able to



get to know each other while keeping an eye on the children. All the children had a great time with some new friendships being made.

A fundraising concert and supper was held at the Devonport Baptist Church on Monday 12th September. The concert was a great nights entertainment with items from the Hellyer Community Choir, Take Note and The Renae Singers as well as solos from several talented North West Coast performers. (I personally enjoyed a wonderful rendition of "O Holy Night" from the children - Ed.)

The evening not only raised valuable funds for our association, but was a wonderful public relations exercise as well. Congratulations to Liz Marshall for organising a very pleasant and relaxing evening and for exposing autism to the wider Devonport community.

During Autism Week a wine and cheese evening was held for parents in the North, at the home of Mark and Ros Ward. The get together was well attended and began with a general discussion that included Deidre and Kim Triffitt sharing their experiences of their year in Canada.

Such occasions are a very valuable source of support and are an important part of Autism Tasmania. We look forward to many more - see the upcoming social events.

Parent Workshop - Living with Autism and Aspergers Syndrome

A group of over forty parents attended the above workshop with Dr Lawrie Bartak and Ms Amanda Golding in Launceston on Sunday 18th September. Lawrie is a clinical psychologist at Monash University and has vast experience in the field of autism. Amanda is the executive officer of the Victorian Autistic Association and the parent of a thirteen year old son with autism.

After a whole group introduction, we divided into smaller discussion groups. This allowed more parents to ask specific questions of Lawrie and Amanda. Lawrie answered questions on Asperger's syndrome and the difference between the disorder and high functioning autism, amongst other aspects.

Parents had many experiences they were keen to talk about including coping with perseverative behaviour and Lawrie provided some interesting strategies to try. Many parents have had negative experiences and it was reassuring to hear him say that we should try to put the past behind us and concentrate on the present. Hindsight is a wonderful thing, but as parents we all do what we believe is right at the time given the information available.

Amanda led a very participative session which concentrated on eating difficulties and managing difficult behaviours. As well as hearing of Amanda's own experiences with her son, it was a great opportunity for the large group of parents to exchange stories and strategies and learn from each other. Amanda gave specific help on distinguishing a limited (but still healthy) diet from one where the child may have underlying allergies or physiological problems. Amanda also gave a brief outline of services available in Victoria.

Dr Lawrie Bartak

Photo courtesy of the Examiner

A range of child care options was available for the day although most parents chose to bring their children with them and have them cared for at the venue. This worked quite well and one parent commented on the relief of having someone else care for his son, which allowed him to relax. The aim of the day was to provide respite for parents while they had the opportunity to meet and talk with other parents.

Our thanks to Ruth Armstrong from Pilgrim Services in Launceston, who assisted in finding qualified child carers for the day. Although most of the carers had

only limited or no experience with autism, they all coped really well and after a rocky start (to be expected!), most of the children settled down quite quickly. Our thanks also to Brett Mullins and Stephanie Best who travelled from Burnie to work as carers, particularly as they have recent experience in working with an autistic child.

A special thank you also to St Georges School for allowing us to use part of the school as the venue for this workshop.

National Autistic Association - Annual General Meeting

The AGM of the National Association was held in Launceston on the 16th and 17th September with delegates attending from all states and the A.C.T. Mark Ward and Rose Clark represented Autism Tasmania on both days.

The meeting covered many points, including the future role of the National Association. In recent times the NAA has met in a different city each year, however the group is aiming to become more political and more empowered and will now meet annually in Canberra with a view to seeking federal funding.

Apart from Tasmania, all states and the ACT are service providers for children with autism. The National Association is generally concerned about the level of funding currently being allocated to children with autism and the trend in some states for governments to move away from autism specific services. The Association is also looking to develop a National publicity campaign for Autism Week.

AUTISM CARDS

These are now available from Autism Tasmania at a cost of 10 for \$2.00. The business size cards carry information on autism and Autism Tasmania and are available with the following message stamped on the alternate side "Please excuse my child's behaviour, he/she has autism." A sample card has been included with this issue of Autism News.

Amanda Golding had a useful suggestion for the use of the cards. As well as giving to strangers to explain our children's behaviours in difficult situations,

Amanda's son carries the cards when he is out alone. On the unstamped side, Amanda writes a message to the effect of "My name is and I have autism. Please contact my mother on ph..... if I am in difficulty."

Attention

Parents of Adults and Adolescents with Autism and Asperger's Syndrome

At the recent parent workshop it became evident that there is a growing group of adolescent and adult children with autism and Asperger's syndrome within Autism Tasmania whose parents are seeking social outlets for their children. One suggestion in the short term was that we could possibly tap into camps etc that are being held for autistic adults and adolescents in Melbourne.

Following the workshop however, one of our newest members Paula Barnes, has expressed a desire to establish a social network and activities for older children. If you have any ideas on what you would



like to see happen or if you would like your child to participate, please contact Paula on (003) 43 1293 during the day or any committee members. Paula is the mother of a high functioning son, Michael, who is 21. She is waiting to hear from you!!!!

Change of Address

Please note that Autism Tasmania has a new postal address. All correspondence can be mailed to this address or faxed to the number below.

**P.O. Box 1552 Fax (003) 43 2308
Launceston
Tasmania 7250**

Ethics

This is a subject which has been written about before - but here we go again. Many of our parent members have had negative experiences both with health and education professionals in the past and I realise parents need to discuss these situations. However, in order to gain credibility with these professions, it is important that we too are seen as professional. I believe that it is in the best interests of our association not to mention names of doctors, teachers, hospitals, psychologists etc when discussing experiences at Autism Tasmania get-togethers.

1995 National Autism Conference 24 -26 February 1995 Brisbane Queensland

The National Conference will be held at the Sheraton Brisbane Hotel and Towers next February. It will provide realistic and practical information to understand and deal with challenging behaviours in day to day life. Delegates will include parents, teachers, and representatives of all professions involved with autism/Aspergers syndrome.

International keynote speakers will include:
Professor Elizabeth Newson
Child Research Development Unit
University of Nottingham, United Kingdom

Professor Christopher Gillberg
Department of Paediatrics and Child Psychiatry
University of Goteberg, Sweden

To date we have not received further information regarding registrations for the conference. However, Autism Tasmania has put in a submission to the National Equity Program for Schools (NEPS) 1995 for a number of people to attend the conference. More about this later if the submission is succesful.

Have you been to Windmill?

Windmill Educational Supplies are located at 95a Hobart Road, Kings Meadows, Launceston and are valued supporters of Autism Tasmania. The large shop is well stocked with physio equipment (balls, barrels etc), toys, puzzles, books, play equipment

(swings, slides) and is a delight to visit. If you would like a catalogue, give Dennis or Jo a call on (003) 433 700 and they will be happy to forward one to you or contact Autism Tasmania and we will arrange for one to be sent.

Aspergers Syndrome

What is it?

Only when the community acknowledges, understands and appropriately addresses this disability can people with Asperger's syndrome minimise the effects of misunderstanding and reach and maximise their full potential.

Asperger's Syndrome is a pervasive developmental disorder which falls within the Autism Spectrum. The main features of this disorder become obvious during early childhood and remain constant throughout life, although adaptation and degree of actual disability vary. It is very rarely recognised before the age of three and is more common in boys than girls.

Some Common features of Asperger's Syndrome Children:

These children have excellent rote memory and absorb facts easily.

They generally perform well at maths and science.

They are generally anxious children who are unable to cope with any form of criticism or imperfection.

They can be the victims of teasing in a school environment, which may cause them to withdraw into isolated activities.

They find it difficult to generalise learned skills and appear to need to re-learn the procedure for each situation.

They are often seen as being odd and/or eccentric.

Language often appears good but may have limited content and poor social understanding.

Most attend normal primary and secondary schools.

While Asperger's Syndrome children have many of the features of the syndrome in common, they

may vary enormously in other ways especially in the areas of intelligence and temperament.

Difficulties are observed in the following areas.....

Communication

Usually speaks at the age expected. A full command of grammar is usually acquired. Content of speech may be abnormal, tending to be pedantic and often centering on one or two favourite topics. Sometimes a word or phrase is repeated over and over in stereotyped fashion. Usually there is a comprehension deficit despite apparent superior verbal skills. Non-verbal communication, both expressive and receptive is often impaired.

Social Interaction

There tends to be impairment in two way social interaction due in the most part to an inability to understand the rules governing social behaviour. A lack of empathy with others and little or no eye contact may be evident. Appears to be stuck at the egocentric stage of development and therefore these people perceive the world almost exclusively from their own point of view.

Social Behaviour

Social Behaviour is often naive and peculiar. They tend to become intensely attached to particular possessions. They engage in repetitive activities and are resistant to change, coping best when life is

predictable. They are rigid and prefer structure and may concentrate exclusively on matters in which they are interested. May appear non-compliant as they have difficulty taking direction and coping with negative feedback.

PROFILE

The typical person with Aspergers is a "loner" who never quite fits in because of eccentric behaviour, peculiar ways of speaking and a lack of social skills.

He or she may be interested in social relationships but lacks the ability to understand and use the rules governing social behaviour. He or she may try to make contact inappropriately, for example ignoring contextual cues or expressing inadequacy aggressively.

People with Asperger's Syndrome may graduate from regular schools and hold down jobs, but they are often disadvantaged by their odd behaviour and resistance to change.

They have difficulty establishing relationships and children often refuse to return to their homes to play with them.

Older children may over time withdraw from the uncomfortable interactions which characterised their early years and retreat into the safety of their family or even isolate themselves from their family. They may feel rejected but do not understand how their behavioural response contributed to their isolation.

The preceding material was taken from the recently launched brochure produced by the Asperger's Syndrome Support Network in Victoria. Reprinted with permission from the VACAA's "Autism News" - September 1994.

News and Views

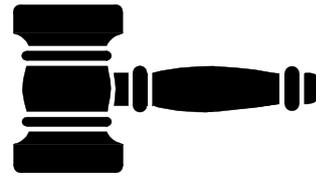
ADDSUP CAMP

ADDSUP (Tas) is planning to hold a camp for children on Sept 10th-16th 1995 at Camp Clayton in Ulverstone. Addsup principally offers support to parents and children with ADD (Attention Deficit

Disorder). However, if you are interested in this event write to Jan Clark P.O. Box 514, Ulverstone, Tas 7315.

Autism and Youth Parliament

brought to the attention of the Tasmanian youth of today the



On the 6th September 1994, a bill for an act to establish an Autism Therapeutic and Education Centre was presented by a Collegiate school team, in the Tasmanian Youth Parliament for 1994. It was sponsored by Taia Rowe.

A gathering of approximately 50 students from high schools, colleges and the United Nations Youth Association from all over the state met for two days in Parliament House to discuss and bring forth bills on matters that they felt needed review. Among bills for the drainage of Lake Peddar, decriminalisation of Indian Hemp, Shop Trading Hours and Aboriginal Self Government was the Autism Therapeutic and Education Centre Bill.

It would seem that such a worthy bill for the disadvantaged members of the community would receive general support. But the youth of Tasmania were not only concerned with the well being of autism sufferers, but there were mixed feelings as to economic costs and benefits. Why should this particular group be granted funding and special treatment while others receive none? Others did not really understand what autism was and based their claims on previous known stereotypes, such as Rainman. Supposedly justifying that these people were never going to change, where would the benefits be?

This was a subject on which almost everyone had a point of view. For the passing of a bill, Youth Parliament works on a conscience vote, unhindered by obligations to government or opposition. A division had to be called, the numbers differing only by one. The Youth Parliament passed the bill for an Autism Therapeutic and Education Centre with very few amendments.

Congratulations Taia for your participation in this event and for your contribution to Autism News. You have

needs of autistic people and their plight in our state at present. We are informed that the results of the Youth Parliament are forwarded to the Tasmanian Government. Well Done!!!

Autism and Respite Care

Also held during Autism Week was the National Respite Conference at the Launceston Casino. The conference attracted delegates from all over Australia, made up of service providers, carers and parents.

The keynote speaker from the United States, Ms Nancy Rosenau urged service providers to look closely at the care they provided. Many papers and workshops were presented over the five day conference including Dr Tony Attwood who presented two sessions titled, "Dealing with Autism in Respite Situations" and "A Closer Look at Autism". For those who have heard Tony speak, he was again extremely entertaining and held his audiences spellbound, providing much needed information to service providers.

The thrust of Tony's talk was about the nature of care required for children with autism and the range of respite options which need to be available to parents. Tony outlined a variety of respite options -

IN HOME CARE - This is the desirable option for the young autistic child who perhaps has a greater affinity with a building than for people who live in it. The home is constant and is a refuge to the young autistic child.

OUT OF HOME CARE - With this care, consistency in caregivers is important whether it is in a residential facility or if the child is being cared for by another family. People are unpredictable and it takes a while for both parties to understand each

other. It is essential for caregivers to understand autism and to recognise that the bizarre behaviour often exhibited by autistic people is a way of coping with the stresses in their lives.

It is important that the autistic person in care has space and privacy to be alone on occasions. Tony used the example of a residential facility where other people are perhaps intrusive. This is not relaxing to an autistic person. Routine and structure are important and also need to be allowed and catered for.

If another family is going to care for the autistic child, Tony outlined that the introduction needs to occur gradually over a long period of time. Whether families caring for autistic children care for the child in the child's home, or their home, depends upon many factors. However it highlights the fact that a range of care options need to be available for parents to choose from depending upon their circumstances. Bear in mind too that these change as the child grows older.

Are you receiving respite care in any shape or form? At the Autism Forum held last March, we were informed that only

The following article is reprinted from the latest edition of the Victorian Association's Autism News. The article is written by Lindsay Weeks who was guest speaker at the VACAA's Annual General Meeting and Lindsay kindly allowed the VACAA to include his presentation in their newsletter. We have been given permission to reprint it and I'm sure you will find it interesting reading. Lindsay Weeks is autistic.

One of the strangest things to happen to me in recent years occurred not long after I set foot in Irabina Early Intervention Program for the first time. I felt as though I belonged there, among people, albeit very small, who were like me.

I had no expectation that this would happen; if I had any expectation at all it was that I would be given a standard tour of the establishment, taking perhaps an hour and that would be it. I was there -at the EIP and then at the school- for 4 1/2 hours and left in a state very close to shock.

Perhaps in my circumstances, so would you. The feeling of separation from others which so many autistic people have, has been variously described as like being a foreigner in a strange land, or as an extra-terrestrial needing a guidebook to planet earth, or of seeing the world through a glass wall. All these

three families with autistic children in the South were using Family Based Care. Presumably in the North and North West the figures would not have been much greater. Family Based Care (located in each region and listed in the telephone book) provide occasional respite care to children in the home, or care with host families outside the home. They will assign carers to you (known as support workers) or you may nominate someone that you wish to be your carer. Some families in the North also use St Giles which provides respite care in a residential situation. Look closely at the respite options available to you and if you are told there is a waiting list, keep trying. This creates a need for a greater service. (We have used family based respite care for the past three years and it is a wonderful support to us. We don't have family close by and find it difficult to use casual baby sitters. Although we have had to educate new carers it has been worth it - Ed)

Rose Clark was invited to co-present a workshop at the conference on Thursday 15th September. Rose led two sessions on Family Dynamics which involved presenting information on respite in a home situation involving a child with autism. Congratulations Rose!!!

descriptions are valid, and to suddenly have this feeling of strangeness removed was an unexpected, even startling thing.

So almost from the moment I set foot in Irabina I was off balance and by the time I left I had absorbed so much data that my brain was refusing to process much more and I was at the start of the process that I call "shutting down".

What this means is that my vision becomes very distant, like seeing the world through the wrong end of a pair of binoculars and unless I back off, that is, physically remove myself from the source of input, then my vision fragments. At the same time, my hearing loses its selective focus and I become acutely aware of every noise occurring within my range of hearing; bird noises, bus noises, speech, footsteps, chainsaws, the wind rattling two palm fronds together;

the list is endless.

In addition, I also become hypersensitive to touch: at this point, all touch is unpleasant, whether anticipated or not. It is not a repellent touch, or a slimy one, more a subtle source of awareness of

the nerve endings in whatever part of me is touching the person or object. Whether you call this a heightened sense of touch or a deadened sense of pain, this experience is unpleasant.

I've found that the best way of dealing with this is to reduce to a minimum all sensory input; to darken the room, tune the TV to an unused channel so that the white noise will drown out all other noise, and go to bed.

These days, this process of shutting down happens very rarely because I have learned not to expose myself to continuous sensory bombardment at a high level of awareness. That first visit to Irabina caught me out.

When I was a child, however, this process happened more often, but usually at the first sign of a distancing of vision I would panic and start screaming. Often the screaming saved me, firstly, by providing a form of white noise and secondly because the process of screaming in itself would usually mean that I was swiftly removed from the source of overload. That is, I would be allowed to lie down for a while, while my puzzled parents or teacher wondered what had set me off this time.

Additionally I also reacted badly to dogs, vacuum cleaners, sudden events and quite a few other things. When I was about five or six, I used to go often to a house a few doors away where the middle aged couple there had an old wind up gramophone which entranced me. Although they had a large collection of old 78 records, only one interested me and I liked to play it again and again, sometimes letting the gramophone wind down so that the sound would slow and I would have to wind it up to make the sound fast again.

Although these were tolerant, obliging people, they naturally had their limits and when these were reached all they had to do was produce their vacuum cleaner and I would flee screaming back home. Until next time.

Not only was the sound of the vacuum cleaner unpleasant, in the end just the sight of it scared me off. Does any of this sound familiar? I could also be set off by not knowing what was happening, or not knowing why I was at a given place at a given time, or not knowing what was expected of me on a particular occasion or not knowing how long that occasion would last.

My second visit to Irabina EIP was much less dramatic for me because I knew what to expect. It lasted all day as have my subsequent visits. I have always been questioned intensively by the staff and I don't say that as a criticism. I regard such questioning as only natural, given their interest in and commitment to the subject of autism. But, as the questioning has begun to slow down I'm consequently able to spend more time with the kids and that's fun. Last February, a couple of the higher functioning kids and I had a really terrific game of ball and we all enjoyed ourselves and were grinning from ear to ear. I have photos of this which I have with me.

On the visit before that, a boy had mislaid one of his five plastic dinosaurs. For him, everything came to a halt until the missing toy could be found. I've experienced this myself. I knew that for him the rest of the world was peripheral to the problem of the missing toy. It occupied 100% of his attention and he would not be able to resume his daily routine until the toy was found. The staff at Irabina were determined that he would pursue his daily routine come what may, and it was nearly time to get changed for the pool. At the changing room door, his teacher decided to try reasoning with him one last time but to no avail. Then I leaned against the wall in a slouched way and gave him a very solid stare in his face (not his eyes). He walked away, back towards his classroom, and motioned for me to follow. We searched quite a few places for that toy and eventually the office manager found it in the photocopying room where some other child had placed it. At that, he consented to go swimming without further ado. Why did he select me to go with him? Body language. He sensed that I understood his problem perfectly.

And these kids are like me. They may be small but they are all like me and consequently Irabina is one place where I do not feel like a stranger, or an extra-terrestrial. There is no glass wall and it was the unexpected absence of it that threw me off balance

the first time.

One of the first questions Val Spence asked me was whether or not I saw any benefit in providing the kids with structure. My answer was an emphatic yes, as autism at its worst is sensory chaos and the enemy of chaos is structure, order, routine.

As a child, I got up at 6.30 every day, always. Not 6.29 or 6.31 but exactly 6.30. I followed the same routine and ate the same breakfast every day for years. My whole day was structured in stages and I had them counted. On Wednesdays, walking from school to the station to catch a train into town was stage 15. Going to bed was stage 24. Following the stages precisely was essential. If something had caused me to miss a stage, I would have become stuck at that point just like the boy with the missing dinosaur. So not only was my day structured, but my week, month, and even year. Always the same food at Christmas.

As well, of course my room had to remain the same: everything had its place and was removed only to be replaced in the same spot. Today, traces of this structure still remain, but I am far more flexible and I attribute the changes simply to growing up and becoming more self confident in my ability to interpret the world around me.

During my adult years I have met quite a few people similar to me, although I have to say that most of them don't function as well as I do. Most of them seemed to have more trouble making sense of the world and some of them seemed frankly a little retarded. I have met only three other adults who functioned on the same level as I do, although about 12 months ago I became aware of a group of autistic people in the States who function at a very high level indeed. I'm referring to Autism Network International, which is a self-help and support network run by and for autistic people. This organisation does not exist solely for high functioning autistics, of course. Anyone can join. But in the nature of things high-functioning people make up a majority of membership. And I can assure you that it is a new and wonderful thing to be able to communicate with other autistic people and to know that other extra-terrestrials are out there.

Donna Williams, or Donna Venables as she is now, wrote to me saying that she was also forming a network of autistic people...not, she says in opposition to the ANI. But she has not so far told

me why she is doing this. I suspect that the people she is gathering together will be more the type she describes as "able", that is, mentally able even if physically handicapped in some way. Time will tell. The important thing is that more and more autistic people are coming together, pooling their knowledge and experience, and realising how very few things, if any, we can't do.

I would now like to discuss an issue that I am asked about quite often: Do I regard myself as person with autism or as an autistic person? Jim Sinclair, the convenor of ANI, has made the point that autism is not an appendage. It is impossible to separate the autism from the person because autism is pervasive. It affects all sensory input. There's no getting away from it.

For me to describe myself as a "person with autism" additionally carries the implication that people need to be reminded that I am a person. I take for granted that others take that fact for granted also.

I don't deny that people who use the terms "person with autism" or "having autism" mean well. But I relate to the world as autistic and I'm not going to have my identity reduced to the status of an appendage. Being autistic is very much being different. Sooner or later all autistic people wake up to this, or at least those with normal or above IQ's, then they ask the question: "why am I different?" The answer is "because I'm autistic". Viewed this way, no other phrasing is appropriate. Over the years I have also met quite a few spastics. Does my use of this word jar? Should I have said "persons with cerebral palsy"? Not according to the ones I have spoken to. They reject that phrasing for precisely the same reasons as blacks reject being called persons of colour. Or for the same reasons that I reject "person with autism".

Definition of Autism

Autism is a severely incapacitating life long developmental disability that typically appears in the first three years of life. The results of a neurological disorder that affects functioning of the brain, Autism and its behavioural symptoms occur in approximately fifteen out of every 10,000 births. Autism is four times more common in boys than girls. It has been found throughout the world in families of all racial,

ethnic, and social backgrounds. No known factors in the psychological environment of a child have been shown to cause autism.

Some behavioural symptoms of autism include:

1. Disturbances in the rate of physical, social and language skills.
2. Abnormal responses to sensations. Any one or a combination of senses or responses are affected: sight, hearing, touch, balance, smell, taste, reaction to pain, and the way a child holds his or her body.
3. Speech and language are absent or delayed while specific thinking capabilities may be present.
4. Abnormal ways of relating to people, objects and events.

Autism occurs by itself or in association with other disorders which affect the function of the brain such as viral infections, metabolic disturbances and epilepsy. It is important to distinguish autism from retardation or mental disorders since diagnostic confusion may result in referral to inappropriate and ineffective treatment techniques. The severe form of the syndrome may include extreme self injurious, repetitive, highly unusual and aggressive behaviour. Special educational programs using behavioural methods have proved to be the most helpful treatment of persons with autism.

AUTISM IS TREATABLE. Early diagnosis and intervention are vital to the future development of the child.

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