



AUTISM NEWS

Newsletter of Autism Tasmania Inc.

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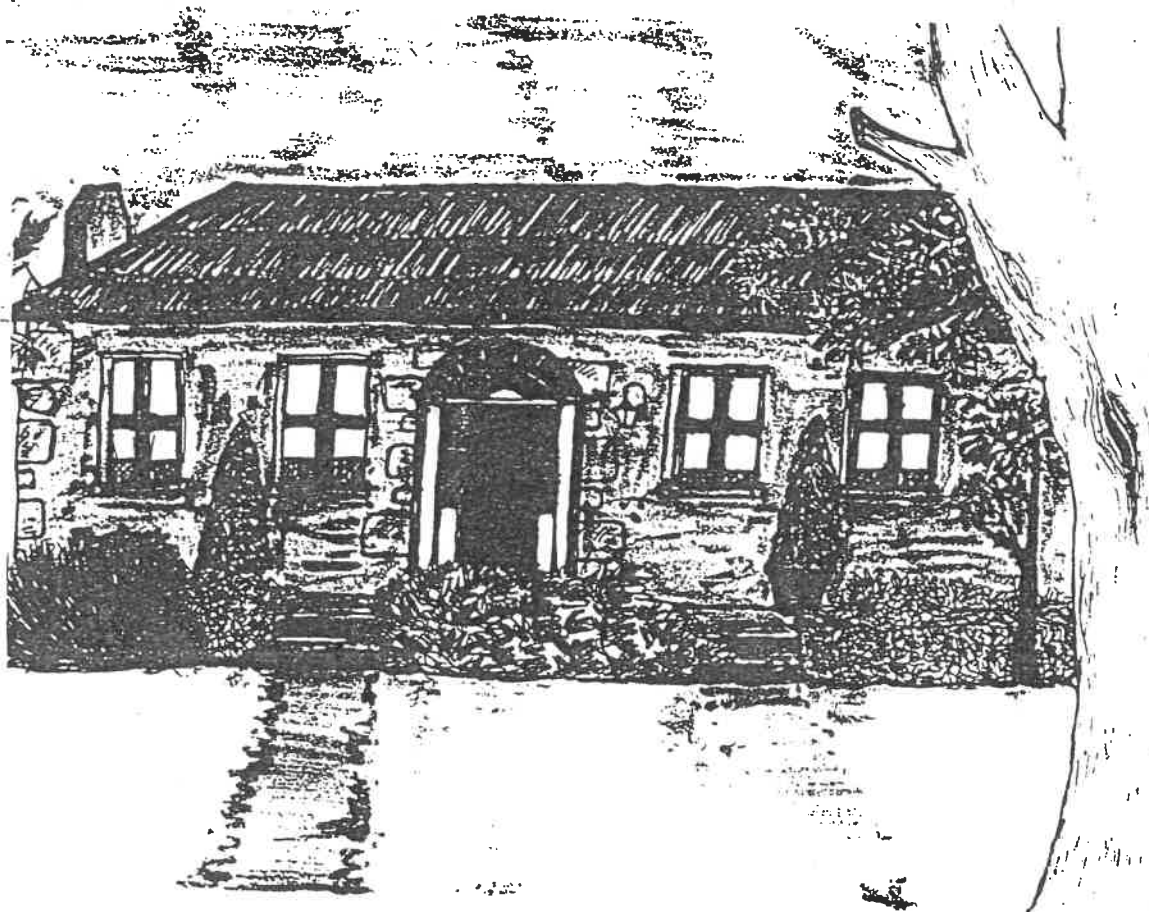
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By Michael Baxter-Barnes aged 25
(Michael has Autism and is high functioning)

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Treasurer	Rosanne Lay	6244 2540
Committee Members	Lisa Minchin	6223 2317
	Liz Maddern	6435 2021 (work)
	Julie Fyfe	6362 3189

From the President

Welcome to this newsletter. A lot has happened since our last posting. Autism Tasmania held it's 5th Annual General Meeting in Hobart on 16th August and a pleasing number of members came along to the proceedings, then stayed for lunch and a chat.

As you can see from the list above, the committee has changed very little. We have to say a big thankyou to out-going committee member, Julie Chamberlain, who worked diligently during her year on the committee. Thank you also to Ron Barnes, our step-in Treasurer. We appreciate the help that you have given us.

We welcome 2 new committee members - Liz Maddern from Burnie and Julie Fyfe from Deloraine - and look forward to working with both of them.

In July, we were very fortunate to have a quick visit from Wendy Lawson. Wendy has been a guest speaker at Autism Tasmania seminars in the past and was very enthusiastic about returning to Tasmania. Wendy, who has a diagnosis of Asperger Disorder, is a very honest and open speaker who shares experiences from the heart. The many people she spoke with found her knowledge and insight very valuable.

Autism Tasmania has a growing membership, which is great to see. It is especially good to see increasing numbers of people who are members of extended families, as they play such a significant role in the family life of those with Autism Spectrum Disorder.

I recently attended the National Association's Annual General Meeting in Tanunda, South Australia. People at that meeting were very impressed with the poster competition winner from last year's National Autism Awareness Week. Several states requested a copy. Our new parent handbook was also well received. It's rewarding to see our state receiving such positive recognition.

The Autism Tasmania library continues to grow and we will publish a list of items available to borrow, in our next newsletter. We are currently awaiting the arrival of a new order.

Both Jenny Vince and I will be attending the New Zealand Autism Conference in late October. Dr Temple Grandin is one of the keynote speakers, a person that I have great respect for and have wanted to hear speak for some time. We will report on this conference in the next issue.

Rose Clark

About This Newsletter

This newsletter has as its focus an educational theme; we have included articles about education and inclusion from a variety of sources. We hope you find them interesting, informative and thought provoking.

You will probably realise that this newsletter is late, and it is!! We appreciate any articles, thoughts, or ideas that you may have - it's your newsletter after all. Producing the newsletter is a time consuming but important function of Autism Tasmania and to make this process more effective we have recently formed an editorial committee (Paula Barnes, Rose Clark, Julie Fyfe and Ros Ward) who will collate, type, format and print each edition. Our next issue will focus on Asperger Disorder and be in your letterboxes in December.

If you have an article for the December edition, the deadline date is Friday 4th November, 1997. Please contact any of the committee members if you have a contribution. Thank you to those people who have taken the time to write articles for this edition of "Autism News".

Committee Report

The committee has had a couple of meetings since our

last newsletter. We have moved around the state quite a lot this past year - alternating between Launceston and Hobart.

Our meetings in the south have involved Penny Archer from Conference Design, who have been advising us on all aspects of planning and running the 1999 National Autism Conference. Although August 1999 seems a long way off, there is a lot to be done; we are currently setting up a critical path and a budget.

Several of our meetings have had assessment and diagnosis on the agenda. This is an area that remains a real issue for us. The proposed adoption of Victoria's guidelines, by the National Association (as mentioned in our report on the recent national meeting) will definitely be helpful to us and a step in the right direction.

The Parent Information Handbook is complete and being printed. Information sharing and distribution has been a concern to us in the past, because of the nature of our state.

We are currently discussing National Autism Awareness Week for 1998 and will ensure that all regions have display packs by the beginning of May 1998.

Our next Committee meeting, on 18th October, will be in Launceston and be attended by our 2 new Committee members - Julie Fyfe and Liz Maddern.

The National Association for Autism Australia

Delegates from each state met for the Annual General Meeting in South Australia on Friday and Saturday, 12th & 13th September.

The National Association is to become an incorporated body and consequently adopt new articles of association. These were discussed at length and some further legal advice is being sought on some of the wording detail. As they stand, they are not specific enough in relation to Autism Spectrum Disorder. The new status of national incorporation will open the way for the National Association to be registered as a peak body for the disability. Currently, Autism Spectrum Disorder is not represented in this way.

The meeting also considered the adoption of a national logo. The preferred options concerning the "jigsaw piece" are,

* turn the hand outward, to avoid the appearance of crying.

* turn all sides of the jigsaw piece outward to eliminate the hole in the head.

* approach a designer to revamp the jigsaw idea so that it does not have a cartoon appearance.

These steps will go ahead, with complete changeover of stationery, etc. taking about 2 years.

Each state association presented a report. It was interesting to hear the different services that they provide; some have substantial budgets to work with.

Following the reports a paper on lobbying was discussed. This was presented as a submission from the National Association to the National Disability Advisory Council and outlined what Autism Spectrum Disorder is, the incidence and the key issues facing each state. In the context of this submission, the need for a national peak body is clear.

Assessment guidelines and protocols for the identification of Autism Spectrum Disorders were also discussed. Autism Victoria presented an excellent document which they have been using for some time and revised. It is likely to be adopted by other states. More information as it becomes available.

There is also a push for the development of a national profile to support fundraising opportunities. The NSW Association has been working very hard towards this and for some time has engaged a full-time fundraising coordinator who has some very innovative ideas. There will be further talks between the states to work towards national activities.

In accordance with the current constitution, the following new office bearers were elected.

President - Imelda Dodds (NSW)

Vice Presidents - Sherry McArdle-English (ACT)

- Bruce Fay (Qld)

Secretary - Jacqui Roberts (NSW)

Treasurer - Paul Power (NSW)

National Autism Week was discussed and set to start on Monday, 18th May 1998. The two days of meetings were very productive and we agreed to meet at the same venue in 1998.

Rose Clark

North West Tasmania Support Team

Please note that the phone number to contact the North West Integration support team is (03) 6430 5786.

FEATURE ARTICLES

BOWEL PROBLEMS IN AUTISM - Dr Sue Bettison

Dr Sue Bettison (B.A) (Hons), Dip Ed, PhD has worked with autistic children and adults since 1967 as a clinician, researcher, lecturer and administrator. She has published widely in Australia and overseas about both autism and intellectual disability and is currently completing a second study of Auditory Integration Training as a treatment for the sound processing problems common in autism and, to some extent, other developmental disabilities. Sue is currently working as a clinical psychologist and is an Honorary Consultant at the Royal Alexandra Hospital for Children. She can be contacted by writing to PO Box 108 Lane Cove, NSW 2066. Reprinted from Autism News, Newsletter of Autism Victoria, March 1997.

Like too many other characteristics commonly found in association with autism, bowel problems are rarely mentioned. There is very little in the research literature other than a few case studies. Yet, over the years, I have come across many more instances of bowel problems in autistic children than would be found among non-disabled children, or children with other disorders. Not only has this been apparent in my clinical work, which you would expect, since I provide toilet training advice and programs for parents, but also in my senior positions as clinical psychologist and administrator in both specialist and developmental disability services in two Australian states.

Problems in bowel control often exist alongside full self control of bladder, although some autistic children also have difficulty learning bladder control as well. As in so many other aspects of autism, bowel problems differ markedly from one autistic child to another. However, there are two abnormalities in bowel control which are common in autistic children.

One seems to be a problem in the digestive process itself. Stools may be very loose some or all of the time, or they may be formed, but of a consistency that provides no pressure against the bowel wall. It is very difficult for any individual either to pick up the sensations just prior to a bowel motion or to control stools of this consistency. This is because the sensations prior to a bowel motion come from pressure on the bowel wall, resulting when there is enough firm bulk to exert this pressure. Firm stools with bulk are also necessary to prevent them from slopping out through the bowel opening as a result of reflex contractions in the gut. A child with this kind of digestive problem cannot physically prevent soiling or get to the toilet in time to catch bowel motions. The solution requires adjusting the digestive system, something which few practitioners of any kind are either aware of or offer as a service. The few practitioners whom I have been told do tackle digestive problems are either medical practitioners interested in holistic medicine or naturopaths. There may be others who can help.

I am not qualified to deal directly with the digestive system. However, when it has not been possible or advisable to adjust the child's digestion, I have found that psyllium husks in powdered form will often provide enough bulk to enable bowel motions to be controlled. Psyllium husks are a food consisting fibre which swells up as it absorbs water. One to three teaspoons full will be enough to provide adequate bulk for most children. The amount can be adjusted according to the consistency of the stools. Powdered psyllium husks in tasteless form are available at most health food shops or, in orange or vanilla flavour, at pharmacies. The greatest difficulty can be persuading the child to accept the powder. Parents have used many different strategies; sprinkled in milkshakes (it does go to jelly in liquids), in stews, on sandwiches, in several foods throughout the day, or with a reward for eating the powder in any form. Often psyllium husks alone have resulted in full self control of bowel motions, consistent toilet use and no more soiled pants.

The second problem commonly found in autistic children is real anger and distress at passing stools. I have interpreted this as part of their fear of any event which they cannot either understand or control. Children with these problems often hid when passing stools and some will hold back a bowel motion for days or weeks despite experiencing extreme discomfort to pain. Then, of course the chronic constipation and additional pain from tears in the bowel opening may add to the problem. Many children also insist in only passing stools while wearing a nappy. Some will even ask for a nappy to be put on and will then go into another room, have a bowel motion, then ask for the nappy to be removed.

The same kind of help to overcome any aversion to change is useful here. However, specific intensive teaching strategies may be necessary to bring the child to understand what should be done and how to do it.

Behaviour Support, Social Support and Inclusion

At the National Autism Conference in Leura earlier this year, Dr Pat Mirenda (University of British Columbia, Vancouver) gave a powerful Keynote Address which was both moving and challenging. The following article was prepared by Amanda Golding, Executive Officer, Autism Victoria and is reprinted with permission from Autism News, Newsletter of Autism Victoria, June 1997.

Experience with inclusion has highlighted three major concerns often expressed by those working in the school environment -

1. Learning and behaviour concerns for other students.
2. Social concerns.
3. Learning concerns for the student with autism.

1. Learning and behaviour concerns for other students.

Teachers and the school community worry about the disruptive behaviour of the autistic student, that it will affect the learning of the other students. Further they worry that the autistic student will take up too much of the teacher's time. In some classes they worry that the other students may get hurt.

The usual response is to implement a range of Behaviour Management strategies. Dr Mirenda suggests that we should shift our focus and develop strategies of Behaviour Support.

What is the difference between behaviour management and behaviour support?

Dr Mirenda believes that teachers who rely on behaviour management rather than behaviour support do so because:

- * they are not aware of a more holistic way of viewing challenging behaviour;
- * they lack information and training in the design of multi level behaviour support plans; and
- * they lack the skills to implement an effective behaviour support plan.

In BEHAVIOUR MANAGEMENT the focus is on:	In BEHAVIOUR SUPPORT the focus is on:
the behaviour	supporting the person
measuring behaviours	understanding behaviours
consequences (reactivity)-after the behaviour	antecedents (proactivity) - what happened before the behaviour
modifying a behaviour	preventing a behaviour
behaviour reduction - measuring decrease in incidence of the challenging behaviour	enhancing the quality of life - is the person calm, are they happy?, - and by the way has their challenging behaviour reduced?

The student with challenging behaviours is generally regarded as not ready for inclusion - why? Dr Mirenda believes it is because he does not receive effective behaviour support, NOT because he has challenging behaviours. A student should not have to earn their place in a regular class.

CASE STUDY: Matt is 22 years old and has been in an inclusive adult setting for three years. He is echolalic and has a severe intellectual disability. He had in the past been aggressive toward others. An analysis of his behaviour revealed that the episodes of aggression related to him wanting or not wanting something. That is, he needed to make a choice, but did not have the communication skills to make his choice. The outbursts also related to his need for predictability - he needed a whole day, big picture plan. His behaviour messages appeared to be "I want" and "I don't want".

The intervention plan made everything as predictable as possible for Matt, and he was given a choice as often as possible. A picture communication system was developed using a board and a range of meaningful pictures. Any items that did not have a choice option were marked with a red dot - ie. these are things that will happen. Matt's whole day was mapped out on his picture

board. He was able to make choices for recreational activities, food, clothing to be worn and so on. Over a period of time, many picture schedules were developed.

Matt went from having major aggressive outbursts almost daily to having a few if any outbursts. Matt's carers learnt to support him by providing him with a means of making choices and scheduling his day. The strategies did not address the actual behaviour (reaction), they proactively addressed the antecedents, or causes of the behaviour. The strategies were also applied in a holistic way - covering many activities, choices and environments.

By supporting Matt's behaviour, he was able to be included into a regular program. It is important to note that this support must be ongoing. After a period of calm - Matt was happy and relaxed, the aggressive outbursts returned. Careful analysis of Matt's environment revealed an almost complete turnover of staff in his home - he was not always allowed his usual choices and the new staff did not respect his daily schedule. Staff training rectified this problem and Matt's aggressive behaviours disappeared.

Dr Mirenda's bottom line is that whilst a schools' concerns about the effects of the behaviour of the autistic student on other students are real, the answer lies with effective behaviour support.

2. Social Concerns

Our social concerns for autistic children in a regular school range from the inherent meanness of children, the presence of bullying, the tendency for children to be 'freaked out' by anything not 'normal' and the likelihood of the autistic child remaining friendless.

A school environment can nurture strong social supports by providing effective role models and a positive attitude - you don't need extensive resources to provide the following:

- * children learn how to tolerate from respected adults and peer models;
- * children need to see attitudes of respect and positive regard for the student with autism;
- * children need to see that adults are not 'freaked out';
- * school students need (and want) information and

explanations - about autism, about communication techniques and about the connection between behaviour and communication.

- * students need to be taught proactive, generic strategies to use to respond when any other students are bothering them - including the student with autism.

- * students need to see the autistic student as an active participant in learning - that he is learning too, and that they can actively share their learning.

- * students need to be shown that the autistic child is a valued classmate by having regular opportunities to interact with him.

For the autistic student, the aide has a critical role: with autism:

- * they should be a "social bridge builder" not a "container" of the students behaviour. The containment attitude inhibits social contact between students.

- * the aide needs to understand that there are many different types of friends and that each has value. Just being with a group is a big step - high level interaction is not the only 'successful' interaction.

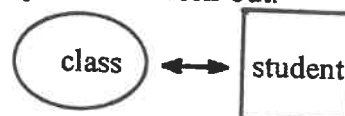
- * the aide should ensure that there are regular opportunities for positive social interaction and that the autistic student needs to feel safe and able to set their own pace for social interaction.

Dr Mirenda then showed a video, called "He Can Still be Your Friend", where the children were able to "talk for themselves". It showed two examples of inclusion which incorporated all of the above points. Those who saw the video commented that it showed us that inclusion is more about attitude than anything else. The involvement of the classmates was extensive and spontaneous, and several scenes showed the mutual benefits to be gained. One socially marginalised child spoke of his happiness because the autistic child "likes me".

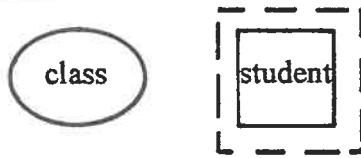
3. Learning concerns for the student with autism.

What and how the autistic child learns depends on how inclusion is defined by others. There are a number of options:

a. "Place and Hope" - find a place, assign a 1:1 aide and hope it will work out.

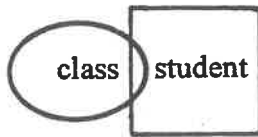


- a good aide will facilitate interaction



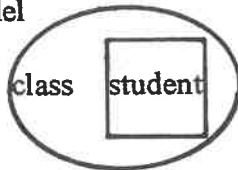
- a poor aide will build up a containment model and prevent meaningful interaction.

b.



In this model, the student is placed, an aide is assigned, a consultant provides regular support to the teacher, and some overlap starts to occur. The autistic student is starting to fit in and learning will occur. "This is about as good as it gets for most included students."

c. - ideal model



If we really want to include a student with autism, it is a school reform issue. This is not a special education issue, it is about transforming schools into educational settings that welcome all students." School transformation encompasses:

- * an appreciation and celebration of adversity;
- * the provision of a variety of instructional strategies;
- * a willingness to adapt and modify;
- * a variety of learning goals.

When we make a classroom inclusive for the student with autism, we make it more inclusive for other kids as well. An inclusive classroom will provide more opportunities to learn skills in natural environments, environments which encourage the development of generalisation of skills learnt. Inclusion doesn't exist independent of the people who are involved in it. People are the key!"

The Inclusion Debate

Jenny Vince (B.Ed, M.Ed.)

Jenny completed her Bachelor of Education degree at the University of Tasmania in 1983. As an early childhood teacher she taught at several southern schools before beginning her Master of Education degree in 1991, focusing on Special Education.

While completing her Masters, Jenny worked with adults with intellectual disability, adults with poor literacy skills and some workplace education courses. Jenny returned to the Education Department in 1993 as a support teacher, supporting teachers of students with special needs in regular schools. In 1994 Jenny was promoted to AST 2 and the following year, Jenny was appointed to the new position of Autism Consultant. She has been working in this capacity since then supporting teachers of students with autism spectrum disorder in both regular and special schools on a statewide basis. She has also been an active member of the Autism Tasmania committee since 1995.

"It is not unusual to hear professionals discuss inclusion in terms of inclusive students, inclusive classrooms, or inclusive schools. Unfortunately, these terms lend to the confusion surrounding inclusion. Inclusion is not a student, a classroom or a school. Rather, inclusion is a belief that ALL students, regardless of labels, should be members of the general community. As members of the general education community, students with and without disabilities should have access to the full range of curriculum options. This means, for example, that students without disabilities should be able to utilise resource rooms without receiving a label first. It also means that students with disabilities should have access to typical home rooms, general education classrooms and courses, and school clubs. The philosophy of inclusion encourages the elimination of the dual special and general education systems, and the creation of a merged system that is responsive to the realities of the student population."

"Today, the controversy over the appropriateness of inclusion for students with autism continues. Unfortunately, the debate about the benefits of inclusion versus segregation misses one critical point. Neither general education nor special education settings are inherently good. Placement in a general education setting does not mean that a student is learning valuable information. And segregation does not equal quality programming. The failure of students with autism in general education settings can be attributed to strategies and classroom structures that make learning difficult for all students. It is clearly time to get past the arguments surrounding inclusion and focus our

efforts on teaching students what they need to know and in a manner that is effective. For schools to successfully support students with diverse learning needs, special education reform must be viewed within the broader context of school restructuring. Schools which are focused on improving student outcomes and on preparing students without disabilities for meaningful and productive lives are in a better position to address the needs of students with disabilities. In other words, good schools are good schools for all. And good teachers are good teachers for any student. It is within the context of global school restructuring activities that educators can better focus their efforts on supporting students with autism in gaining maximum educational benefit from the general education setting."

Throughout Tasmania there are approximately 120 students with autism spectrum disorder who attend their regular neighbourhood school. This figure represents the full spectrum, including students with a diagnosis of Pervasive Developmental Disorder - Not Otherwise Specified (PDDNOS); those with Asperger's Disorder; including the full range of cognitive functioning, ranging from children as young as two (who attend Early Special Education) to eighteen year old college students. These students are being well catered for within the regular education system, with teachers adopting "innovative and flexible instructional strategies to ensure that educational objectives are met and that students are supported across a diverse array of educational settings." To further facilitate their inclusion some students receive funding for some teacher assistant support. The amount of teacher assistant time that each student receives varies greatly depending on the students level of functioning. Some students are funded centrally (category A), a resource which is allocated for those students with the most severe disabilities. This group comprises one to two per cent of the entire population and funding allocations are moderated across the state. Those students with less severe disabilities are funded at a district level (category B). This whole area of funding causes much controversy, with receiving schools and parents dissatisfied with the amount of funding they are allocated. It is true that for some situations more funding would be preferable but unfortunately resources are limited and must be distributed as equitably as possible for all students. It is also true

that for some situations added teacher assistant time would not be in the student's best interests, as the student can become dependent upon the adult. Obviously the goal for students with autism spectrum disorder is to make them as independent as possible.

Many people continue to voice a concern about whether inclusion can work. Success stories from around the state provide testimony that students with autism can learn in general education settings if students' time is wisely used, support is provided, and proven methods of instruction are used.

(All references taken from Pratt, Cathy: **There is No Place Called *Inclusion*** in *Reporter* Volume 2, Number 3, Spring 1997.)

INCLUSION - A Perspective

Maurice Hogan (B.Ed., G. Dip Sp. Ed., M. Ed. St.)

Maurice Hogan received his Bachelor of Education degree in 1977. He continued to pursue his studies with vigour obtaining two Graduate Diplomas in Special Education in 1980 and 1987 respectively and gaining his Master of Educational Studies in 1993. Mr Hogan has had over 20 years teaching experience in a range of settings within regular schools and special education settings. He held a position as officer responsible for students with disabilities in ordinary schools. Mr Hogan is currently the AST 3 at Elphin Rise Special School. Amongst his many responsibilities he is a resource teacher in a city primary school. He has developed several accredited TCE courses for grade 9-10 students including 'Skills and Strategies for Learning' and a series of A courses called 'Out of the Ordinary,' to teach senior students about disabilities and people with disabilities.

Integration/normalisation/inclusion* is already occurring in Australia, and is a generally held philosophy of our education departments. Normalisation, as an educational concept is most commendable and if adequately practised it benefits our children with special needs and indeed our whole society. However, it should only be practised by those with a complete understanding of it, and by those who are personally and professionally committed to its proper implementation. If practised by such people, rather

than forced upon us all as in the American scene, there will be very few problems.

Integration or inclusion must be understood as a practical educational policy before it is adopted by any educators anywhere. Integration, normalisation and inclusion* have become emotive catchcrys in Special Education. For many people a strict and revolutionary implementation of physical integration is seen as the major priority that must be commenced now. However, while most would agree with the philosophy of it, informed opinions appear to be rare motives for many espousing such philosophy.

Integration or inclusion is meant to provide children, currently only children with special needs, with the least restrictive environment, and concomitantly give the child the best situation (including physical environment, teaching materials, methods, social contacts etc.) for attaining his/her full potential. This admirable philosophy however, has become tangled with the rights of man to freedom, and many have focussed upon this superficial idealistic concept alone as the motive for integration/inclusion. Some of these people would enforce immediate physical integration, thereby fulfilling their freedom argument. However, in reality less freedom may well accrue to the children for they may become more isolated socially and less capable academically than may have been the case in a segregated setting. 'Research on inclusion shows that the results for many kids are disappointing. It is possible for kids to do worse, both academically and socially in inclusive settings than in alternative placements.' (O'Neil, 1994/95, p.9; see also Fuchs & Fuchs, 1995, p. 25.) Enforced 'integration' to placate the 'freedom fighters', when it is not fully understood or supported, will be at the children's expense. 'Systematic data on the academic and social progress of students in inclusive settings (as well as in all settings) is essential. Research questions must go beyond which model is best and consider the condition and setting that contribute to learning for each student.' (Vaughn & Schumm, 1995, p. 270)

Whatever changes are advocated for our special children, their desirability must always be measured against what real benefits will accrue to the

children. Teacher inconvenience, departmental finances and researchers convenience must not become the major forces for change. Unfortunately inclusion appears to be convenient, in its most superficial sense, to many who influence policy, but who do not necessarily wish to put in the extreme hard work required to make it work adequately for the children it is meant to benefit. 'Having a restrictive philosophy is also - let's be honest - just plain easy. One has to make no individual case to parents ; one merely recites a bundle of philosophical postulates... We are reminded of the famous quote attributed to Henry Ford when he introduced the 'new' Model T : "You can have any colour you want , as long as its black." We need to remind inclusionists that schools are very different from Ford's assembly line.' (Smelter, Rasch & Yudewitz, 1994, p. 38) Very firm guidelines, checks and support systems are essential prerequisites for proper inclusion if it is not to become just another educational fad which ends up being most detrimental to those it was meant to assist.

Unfortunately some integration/inclusion advocates have naively assumed the issue is black and white. Some would physically integrate all special children and desecrate any segregated settings. This would be a catastrophic backward step for education. Rather, be it less conceptually easy, integration/inclusion* should be viewed as a continuum of varying degrees of changes that increasingly 'normalise' the child's whole educational setting in accordance with that child's needs and abilities. This philosophy does mean change, especially for the host of special education settings that make no effort to educate or lead children towards attaining their full potential. It does refute the inane labelling system based on IQ results, and programs that do not move children towards greater normalisation; either by teaching them basic skills and/or educating them in social skills etc..

Integration, normalisation and inclusion can be as evident and successful in *segregated* settings as in 'all in one class systems'. A physically segregated setting may be the most appropriate form of integration/inclusion or normalisation for certain children. In that system the child may learn more academically and socially than in a 'physically'

integrated system. Children can reach their full potential, their greatest degree of personal freedom, by being taught in settings other than the ordinary, unfortunately labelled, normal, classroom. To deny children the benefits of a segregated setting may be to deny them their best chance of attaining normalisation!

'A century ago overenthusiasm for the institution as the sole placement option for people with disabilities resulted in great injustices and the needless exclusion of many individuals from regular schools and communities. Perhaps overenthusiasm for the regular school and the regular classroom as the sole replacement options for students with disabilities has the potential for creating an equal tyranny.' (Kauffman, Lloyd, Baker & Riedel 1995, p.546)

Many argue that segregated settings achieve no more than ordinary classroom placement. We are told for example, that 'remedial reading' classes achieve nothing worthwhile for the children in the long run, and that classes for the emotionally disturbed are of no benefit. These points are made to argue for mandatory physical integration now. N. E. Silberberg and M. C. Silberberg (1969) mention studies by Balow (1965), Collins (1961), Rasmussen and Dienne (1962) and Heckerl and Sansbury (1968) and conclude that remedial reading classes are only of value to children while they are in the program. 'However, this improvement quickly "washes out" and the children sink to a level commensurate with their preremedial experience.' (Silberberg & Silberberg, 1969, p. 211) N.A. Vacc's article states that 'the results indicate that emotionally disturbed children receiving special class intervention received no more positive or negative selection scores than the emotionally disturbed children who remained in the regular class.' (Vacc, N.A., p.180) He concludes that 'special classes do not result in long term changes for emotionally disturbed children as compared to emotionally disturbed children placed in regular classes.' (Vacc, p.182) Be such data so convenient however for the inclusionist argument, they are flawed and in fact the result of a naive and lazy consideration of the real situation.

Some do accept such findings at face value and argue for the physical integration of all children in similar programs. However, I would argue that despite the inconvenience to all concerned, a more worthwhile and just approach would be to look below the superficial findings. One needs to know

why these particular studies were chosen and what it is that makes them representative of other programs! We should also know the entry and exit reading levels of the 'reading' students, the tests used, the amount of time given to the programs, the teaching methods and materials involved both during and after treatment. If the children did not reach an independent level of reading accuracy; for argument's sake a reading accuracy age of eleven years using the Neale Analysis of Reading Ability, then they may not have attained a sufficient development of skills to maintain them. One cannot teach a 'reading disabled' child half the skills and then expect him/her to keep learning the skills without more teaching. Lack of teaching is the very reason for many reading disability cases in the first place. (e.g. see Haring, Lovitt, Eaton & Hansen, 1978; Oakhill & Garnham, 1988) Similarly, the emotionally disturbed children, as far as we know, were not even taught social skills in their segregated setting. How can they be expected to have improved without having been taught any more than those left in the normal classroom?

'Although it has become fashionable to complain that special education flat out doesn't work (e.g., National Association of State Boards of Education 1992), reviews of research indicate that many special education programs are superior to regular classrooms for some types of children. (e.g.; Carlberg & Kavale 1980, Madden & Slavin 1983, Sindelar & Deno 1979.)' (Fuchs &, 1995, p. 24)

(Also see O'Neil, p. 9; as well as Fuchs, Fuchs & Fernstrom, 1993; Baker & Zigmund 1990; McIntosh, Vaughn, Schumm, Haager & Lee, 1993 in Vaughn & Schumm, 1995, p. 264.)

It is disgraceful that totally ineffective Special Education programs are permitted to continue, that there are no checks on the quality of most programs, that often the worst teachers are delegated to teaching children with special needs, that it is possible to be a mere babysitter and still keep one's job. However these serious problems noted via research reports in current physically segregated settings do not make segregation itself undesirable unless it is in a poor program. Rather, what is needed is determined policy by administrators to clean up the field as it is, to indicate which programs are succeeding and why, and to ensure their continued development. At least with some quality control over what exists some

realistic picture might be gained concerning future changes required of the integration/inclusion policy.

If as a result of 'slinging matches' desegregation is enforced by naive administrators, not only will many good programs be lost and some children suffer, but also the same lack of quality in some segregated settings will cause the ultimate decay of its replacement. A simple panacea such as physical integration and the resource teacher are not the automatic realistic alternative to segregated settings. Rather integration must be seen as involving the whole child, his/her future and as one option from the whole spectrum of alternatives. If a child can be physically integrated successfully, and profit from the experience academically and socially or personally with the help of a resource teacher, then that is right for *that* child. If another child cannot obtain or benefit from the same teaching in that setting, then common sense dictates alternatives such as a separate classroom and teacher be explored, which one can only hope are quality programs. Thus I would argue that to improve the normalisation aspects of existing programs quality must be demanded from what already exists and there should be added in, resources, staff and material, to permit varying degrees of involvement for certain children, between segregated settings and ordinary classrooms.

The integration/normalisation/inclusion issue has at least partly developed out of dissatisfaction with many current programs. It is unprofessional to not move towards total normalisation for each child, whatever the setting. However, the child attaining normalisation, his/her greatest development, cannot be tied to placing him/her physically with 'ordinary' children. **When people come to realise that the quality of programs is the real issue then perhaps they will have begun to put the integration/normalisation/inclusion* issue into perspective.**

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News and Views

From our Readers.....

Autism Tasmania welcomes contributions from readers particularly as the newsletter is an opportunity to exchange ideas which are of interest to others. However these articles do not necessarily reflect the opinions or thoughts of Autism Tasmania.

Giant Steps Tasmania

The program has moved into its third year of operation, largely experiencing the same sort of challenges that have been faced since commencement - sufficient funds to enable things to run relatively smoothly and enable staff to work with the children without being too concerned for the future.

Several significant financial development initiatives have commenced and the Board is confident that the required funds can be raised by the end of the year. The paradox that a project such as Giant Steps faces, is illustrated by the fact that while we are currently struggling to fund operating costs, over \$30,000 cash and as much again in kind has been donated for site improvements.

Savage River Mines generously donated and relocated a large house to Deloraine; the Lions Club of Deloraine and the Trust Bank Foundation have each donated \$10,000 towards renovations and the Variety Club of Tasmania has contributed \$12,000 for new playground equipment. This really is tremendous support and each organisation deserves (and has received) our heartfelt thanks.

Jane Hosking, our new Occupational Therapist has commenced. Jane brings a wealth of skills and experience to the program, especially in sensory integration, including specific work with children with autism spectrum disorder. Filling the vacancy of Play and Social Communication specialist has been difficult because of financial constraints but a solution is likely in the near future.

Several new children have started and two have moved (or are about to move) to full inclusion. While each child progresses at their own pace and the transition to mainstream school will be different

in every case, it is wonderful to see such tremendous outcomes for two of the program's original children and their families. Some excellent inclusion work is going on - the commitment shown by including school staff, parents and centre staff shows what can be achieved when people work together for a common goal.

A Giant Steps Tasmania Parent Group has been re-formed and has developed a clear functional role that will be of solid assistance to the program and the Centre's functioning.

A team from the Education Department has just completed a review of the Giant Steps program, in accordance with the service contract. This involved interviews with parents, some staff and the Chairman of the Board, as well as an assessment of the children participating in the program.

Discussions with Commonwealth politicians continue; Senator Brian Harradine continues his tireless support for Giant Steps and has had direct talks with Education Minister, David Kemp. The Commonwealth has allocated over \$20,000 to investigate the funding opportunities for Giant Steps; a report is being developed by external consultants. In the state sphere, the Board met with the Minister for Education, Sue Napier, to discuss some of the broader policy issues that are, in many cases inadvertently, complicating the functioning of the program. She invited discussions to continue on a number of matters.

Mick Clark

YOUNG AUTISM SUPPORT TASMANIA

(Supporting families teaching ABA)

We had a very busy two weeks whilst Jura Tender was in Tasmania. Jura is a clinical psychologist who is currently supervising the ABA program in Tas. She was here from the 28th July until the 8th August and saw 20 families in their homes. We have the Variety Club of Tasmania to thank for paying Jura's expenses during the visit.

Several workshops were run during her visit

including a parents and therapists workshop, a parents discussion workshop and a teachers workshop which was aimed at those teachers who have children utilising the ABA program in their classes. The parents discussion workshop was an opportunity for parents to voice any questions or concerns with the program. Jura's visit also included a presentation to the psychology department of Tas. Uni which was extremely well received.

There has been a great deal of positive feedback from all concerned since Jura's visit and parents are now busy implementing program updates. Jura will be returning to Tasmania in November. Anyone needing more information regarding her visit should contact Rosemary Rush on (03) 6229 5760.

YAST is in the process of becoming an association. I see us being closely associated with Autism Tasmania and would like to thank Rose Clark and the committee of Autism Tas. for their support in the implementation of this process.

YAST meets on the third Wednesday of every month at Albeura Street Primary School, Hobart from 7:30 pm onwards. All interested parties are welcome.

Grace Talbot

The Siege: The first Eight Years of an Autistic Child With an Epilogue, Fifteen Years After By Clara Claiborne Park (1982)

Lisa Minchin recently joined the committee of Autism Tasmania and is the parent of a young son with Autism Spectrum Disorder. Lisa is a keen reader of books on autism and has recently read The Siege. Her article which follows, may be of particular interest to parents looking for inspiration.

Originally published in 1967, The Siege is a mother's detailed and perceptive record of her autistic daughter's development during her first eight years. Jessy's autism is quite severe, she is "behind walls", to use her mother's words, yet, through gentle and loving "work", developed intuitively, and patiently implemented by her mother, the "walls" are breached and she begins to relate, to talk and to be formally educated.

Jessy (born in 1958) is just a little younger than the original group of children studied by Leo Kanner and for whom he coined the term "autism". Set in its historical perspective, Jessy's story reveals how little effective help was available for children with autism just a generation ago.

Mrs Parks own use of the word "psychosis" to describe autism reveals the degree to which she herself accepted some of the prevailing views of the disorder, although she vehemently rejects Bruno Bettelheim's theory that autism is caused by poor parenting, particularly poor bonding between child and mother.

Mrs Park's experiences with professionals are mixed, varying from exasperating to inspirational. She was fortunate that, being part of the college educated upper middle class (her husband is a physics professor and she has since gained a Ph. D. in literature), she had many well read and well connected acquaintances who helped her find some professional assistance.

Jessy benefits enormously from the quiet determined patience of her mother who keenly observes and astutely judges when to push, when to wait, how to create unpressured opportunities for Jessy to demonstrate what she can do. Indeed, Mrs Park is so attuned to the particularities of Jessy's disability that her descriptions of the features of autistic behaviour and her speculations about the essential elements of an autistic mind foreshadowed the writings of several "experts" in the late 1980's. She writes,

"...what seems impaired is not only the capacity for affect, but another capacity perhaps even more fundamental, the capacity for undertaking exploratory behaviour and sustaining it ...[....]"motivation"... The inertia of such a child might affect even cognitive functions, so that ideas that normal babies associate without apparent effort would be connected only with difficulty and past experience would be only minimally available for use. The autistic child does not move naturally... from one experience to another. Yet reality, as human beings experience it, is a web of connections to be made. (The Siege pp265,266,267)

Clara Claiborne Park writes intelligently, honestly and compassionately: She has compassion for all

four of her children, her husband, even the professionals. She acknowledges the invaluable assistance provided by housekeepers and a succession of "Jessy-girls" as well as the wonderful staff of Jessy's regional high school.

A member of the Autism Society of America from its earliest days, the author knew of the work of behaviour therapists such as Ivar Lovaas in the late 1960's yet in the Epilogue she admits it was her family's own inertia which prevented them from trying operant conditioning with Jessy any earlier than they did. Then the Parks met a young boy with autism who was responding extremely well to behaviour therapy and who was recording reward points on a golf counter in order to convert them into more tangible rewards later. Jessy actually asked for her own counter and this rapidly provided her with incentives to lose undesirable behaviours like verbal tics and to increase target behaviours. The counter has helped Jessy to anticipate the future, a deficit her mother never imagined she would overcome.

In the Epilogue, Jessy's life at 23 is described. Although still living with her parents, Jessy holds down a part time job as a mail sorter, she cooks, cleans, shops, banks, sews, gardens and paints. She is an artist; she has had her paintings exhibited and sold: a series of quartz heaters, a series of radio dials and electric blanket controls. Her "abstracting eye" read an object "to its essential design elements". She has travelled by air paying for her ticket herself from the proceeds of the sale of her paintings. She has surmounted a massive communications handicap and has learned to control "her strange obsessions and the strange behaviour that accompanied them". She remains socially immature, she has only one friend, yet the Jessy-girls" and other helpers assert that Jessy has given them "gifts of understanding, gifts of feeling" and her brother and sisters genuinely love her.

Clara Park reflects on life with Jessy and concludes "this experience we did not choose, which we would have given anything to avoid, has made us different, has made us better. Through it we have learned that one grows by suffering ... out of [the experience] has come, for all of us, an unimagined life. (p. 320)

Dr Oliver Sachs is correct to claim that *The Siege* is one "of the first personal accounts of autism and still the best Beautiful and intelligent".

Lisa Minchin

Interesting Quotes

Peter Westwood at a Professional Development seminar at the University of Tasmania, July 1997:

"Simply by placing a child with a disability in a regular classroom or school does not necessarily mean that the child will be accepted".

"Research seems to indicate that total inclusion may be responsible for an increase in teacher burn-out, particularly when inadequately resourced".

BOOK REVIEW IN BRIEF

The Student with Autism/Asperger Syndrome in the School Community
Author - Anne Berzel
Assisted by Sheila Muncey.

Although this book is written primarily for teachers it is a booklet I readily recommend to parents, students of disabilities and others with an interest in autism spectrum disorders. It provides the reader with clear and concise descriptions of some of the characteristics of autism and how it impacts upon learning and behaviour.

The booklet illustrates strategies for managing behaviour in the classroom setting but these could equally be useful in other environments, particularly the home. It is full of useful information which will assist teachers to maximise learning outcomes for their pupils with autism and has a helpful section on Social Skills with a number of contributors describing behavioural and cognitive approaches to social skill training.

Written for use in schools in South Australia it has a few references to support services in that state, however, the booklet is a useful resource to parents and professionals throughout Australia and is available from the Autism Association of S.A.

Paula Barnes

LETTERS TO THE EDITOR

From time to time we get enquiries from our readers asking for advice on a number of topics. Often they ask whether other parents are having similar difficulties and what strategies, if any, they find useful.

We decided to print some of the enquiries and invite readers to contribute their solutions and to use the Letters to the Editor section to ask their own questions. Often, the answers lay within our own or others' experiences as parents but we will endeavour to find the answers to those tricky problems, when we do not know, by consulting with the many professionals who support Autism Tasmania.

So let's have your contributions - parents and professionals, your experiences are invaluable to others.

Can You Help?

Has anyone any hints on how to explain to a 10 year old boy with Autism Spectrum Disorder why he is different? Our son has been very sad and dejected recently; he watches other children intently but doesn't really know how to join in or what to do when he does. From his actions and some things that he has said, we think that he is starting to realise that he is different.

Dear Editor

Our son hates visitors and will disappear to his bedroom whenever people arrive, even those people whom we have known for several years. Regardless whether the visit is impromptu or he has been prior prepared he does not hang around and is clearly uncomfortable if pressured to stay. I discourage people from calling because it upsets him. I think the stress of controlling some of his strange behaviours is difficult for him. Whilst we are encouraged that he now recognises that these behaviours are inappropriate, the stress in suppressing them when visitors are in the house is difficult and frustrating for him. When the visitors have left, his peculiar behaviours increase for a

while. My son is approaching adulthood and is high functioning.

*Thanks,
Concerned Parent.*

Are you able to help with suggestions to either of these problems? Send any comments or letters to the Editor, Autism News, PO Box 1552, Launceston 7250 by 4th November 1997.

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Living with a Rare Disorder

by Dr Mark Flappan PhD

This booklet contains articles of effects of a rare disorder on the emotions and on relationships.

Mark Flapan is a psychologist who has a rare disorder himself. The personal experiences and feelings he describes in his articles will be familiar to many people with Meniere's Disease. They are written in such a way as to strike a chord with many people who have a rare disorder.

The cost of \$10 covers the printing, postage and handling costs of this booklet. Make cheques payable to: Meniere's Australia Inc. and post to PO Box 202 Moonah Tas 7009.