



# RHUBARB

*The ISADD Newsletter*  
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## EDITORIAL

As this issue will be the last before the end of the year, I will take this opportunity to wish readers the compliments of the season, and a happy and prosperous New Year.

And so we are drawing to the end of another year. Possibly, by the time you read this, the Federal Election will be over, and we will know who will be governing us for the next three years. Whichever party won, we will supposedly see much more money being poured into the field of Autism. How this money is “poured in”, and with what result, we are yet to learn. I, for one, hope it is poured in wisely – that means the bulk should go to funding ABA programs. But for many reasons, I’m not expecting that to happen, and I anticipate we’ll see a lot of potentially good funding wasted on “band-aid” and “stop-gap” treatments and projects.

Daryl Cooper.  
Executive Coordinator, Editor.

## CONGRATULATIONS to: (Baby Boom Section!)

Tania Dawson on the birth of her daughter Mya.

Amelia Kenny on the birth of her son Lewis.

Lina Skaisgirtye on the birth of her daughter.

## CHRISTMAS HOLIDAYS OFFICE CLOSURE

ISADD’s office will be closed from 3.00 pm  
Friday December 21, 2007 until 9.00 am  
Wednesday, January 2, 2008.

## Advertisement:

### *ABA Therapy Supplies*

Laminated Flashcards (7x10cm) 30c each

Laminated Compics\_

Small (24 to page) 15c each

Large (15 to page) 15c each

Call Derryn Butler on **0403 962 624**, let him know what you need (eg shapes, colours, categories, etc.) and how many you would like and he will make them up for you.

## Did you pick the mystery picture in the previous issue?

At least one reader did – it is the underside of the Sydney Harbour Bridge. (It's anniversary)

## Disability Services Commission moves in the right direction.

I recently attended a series of three workshops organised by DSC, the purpose of which were to assist in developing outcome-based measures by which services funded by DSC could be evaluated.

The move towards outcomes-based evaluation is a very positive one, and such evaluation is certainly to be preferred to process-based evaluation (which is currently used).

Of course, how the system will work is another matter, and it remains to be seen as to how it shapes up in practice. Providing it does not require a huge increase in administrative time,

it should ultimately benefit both providers and their clients.

### **But people in DSC are human too...**

Our Directors, Jennifer Bolland and Jura Tender, recently received correspondence from the Disability Services Commission addressed to:

“Dear Ms. Boll & Ms. Tender,”

Easy to see how the error occurred!

### **MORE ON STAFF TRAINING**

In my report on the ABA Conference in the last issue, I mentioned Dr. Lou Arco’s paper on staff training. Now, an article in the Journal, *Behavior Modification*, has been published, again showing that training to competency, using a combination of information giving, demonstration, role-play and on-the-job-feedback produced rapid and long lasting training outcomes.

This study, conducted under the auspices of the May Institute in Massachusetts, involved training four direct-care staff to implement a PECS program with an adult man with autism and intellectual handicap. After training, three of the four staff were implementing the program with between 80% and 100% accuracy (compared to 20% - 30% before training), while the fourth only achieved 50%. While the poorer performance of this person was explained in the article as due to the fact that his behaviour during the training was “consistently negative and oppositional”, it is also interesting to note that this person was aged in his late forties while the other three were in their twenties. Perhaps there is some validity in the expression, “you can’t teach an old dog new tricks”!

Reference: Wood A.L., Luiselli J.K. and Harchik A.E. (2007) Training Instructional Skills with Paraprofessional Service Providers at a Community Based Habilitation Setting. *Behavior Modification* Vol.31 No.6 pp847 – 855.

### **CASE MANAGER TRAINING**

The next Case Manager Training course is scheduled for the first two weeks of February 2008. It is shaping up to be the biggest yet held,

with three people attending from Indonesia, two from Ireland, two from Lithuania, one or two from Singapore, three from Victoria, not to mention local attendees.

### **“BALI BELLY”\* STRIKES EXEC. COORDINATOR IN JAKARTA.**

In my role as Patron of YISADDI, I recently spent a week in Jakarta. After two days, despite the usual precautions of not eating raw foods and using only bottled water, I was struck by an attack of what is best politely described as “Bali Belly”. While the first day (fortunately a Sunday, when I had no work commitments) was the worst, the attack continued the rest of the week of my stay, - and for the next week at home! Fortunately, while at times quite painful, the ailment did not interfere too much with my work, and the trip proved very worthwhile.

I had opportunity to meet with all Case Managers and many of the Jakarta therapists, and was brought up to date on Yisaddi’s operations in other Indonesian towns. As always, I was impressed by the dedication and enthusiasm of the YISADDI personnel, who always appear as a bright and cheerful group of people.

One of the things achieved during my visit was the development of a Mission Statement for YISADDI:

*“YISADDI exists to improve the quality of life of persons with autism and/or other developmental disabilities through the provision of ABA programs and other related consultative services.”*

\*For readers outside Australia who might not have heard the term, “Bali Belly” is a term applied to a stomach ailment, so called because it strikes many visitors to that Indonesian Island.

### **NEVER GIVE UP!**

How long will my child need an ABA program? This is a question most parents will ask at some time. If we answer purely on the basis of the scientific research so far, the answer will be equivocal, as all we can reliably say is that, *with sufficient intensity*, (30-40 hours/week) somewhere close to half of children starting a program, will no longer need it after approximately two years. As for the

other half, we do not know when “enough will have been enough”.

We do know that something like 10% of children with an ASD make only very limited gains on an ABA program, but we do not know of any alternative treatment which could produce better results for this group (or any group, for that matter). The remainder of children DO continue to make gains on an ABA program, but progress can be slow, and the rate varies considerably between individual children.

What we have found here at ISADD, is that some children, typically those not getting “sufficient intensity” who have continued for five or six years on the program, are progressing to a level where they are leading a “normal” life, and in all important aspects, are almost indistinguishable from typically developing peers. Or to put it another way, they are giving every indication that they will be able to lead an independent adult life, needing no special support.

Thus it may be that “sufficient duration” may (partially, at least) compensate for lack of “sufficient intensity”. It might also be that there are a number of children who do not fit in the category of the 50% who do well within two years, who will eventually do as well, or almost as well, as children in that category. Of course, I would love to see some research to confirm or refute either of those assertions. But in the meantime, I think it is important to work on the assumption that both are possibly correct, and in terms of sticking with an ABA program – NEVER GIVE UP.

Daryl Cooper

## **NEWS FROM HERE AND THERE**

From our roving reporter (and Director)

### **Lithuania:**

ISADD is expanding in Lithuania and is working with a parent organization ‘Kitoks Vaikas’ which is seeking funding for ABA.

On Jura’s recent visit parents and therapists received a workshop on reinforcement and its central role in ABA techniques. On the surface rewarding a child seems simple, but the techniques of reinforcement are complex, and critical to success.

Two therapists have also been promoted to Senior, Marjan Stasiukevic and Jevgenija Lotach.

### **Ireland:**

Unfortunately the Irish government still insists that only teacher and psychology trained therapists can be funded for early intervention. This of course reduces the number of hours which each child can receive.

We recently had an introductory workshop and a workshop on Reinforcement in Limerick.

One therapist, Sean Hurley, has been promoted to senior.

### **Singapore:**

Work continues with five Case Managers. At a Case Manager meeting plans were made for a big workshop next year, possibly on the emotional development of people with ASD.

Two therapists were promoted to Senior, Johnny Fok and Theresa Fan.

### **Indonesia:**

See Exec. Coordinators report in this issue.

### **Eastern States:**

Sarah Thomas is leaving the Adelaide team to work as a special education teacher in Melbourne. We will be sad to lose her but wish her all the very best.

Jura held a workshop for parents on how they can promote their child’s social development.

In Melbourne work is progressing and we are pleased to welcome a senior therapist from Belfast, Ireland. Sarah Charlton.

In Hobart ISADD is exploring new frontiers. Hopefully, we can tell you more in the next Rhubarb.

### **New Zealand:**

Jura will be visiting in a few weeks - and there will be a workshop in Wellington on the social emotional development of children with ASD.

## AND OFF THEY GO TO SCHOOL

As another year is coming to an end parents are facing some serious decisions; should they be sending their child with ASD to school, should they delay another year, if school then which school. They are usually faced with conflicting advice. How should they respond? What if they make an error?

What are the facts parents need to consider. Here are a few, many conflicting, for a start.

It is compulsory for children to attend school - or alternatively undertake some form of education accredited by the local department of education, usually at the age of 6.

It would give parents some breathing space to have the child out of the house for most of the working day.

If home schooling is at all possible it is a very major commitment by parents and can be stressful.

Children with ASD learn best in a 1:1 setting.

ABA is the most effective form of teaching and has data to show it can have a most positive effect on children with ASD.

Inclusion is beneficial for children with ASD as they have age appropriate role models.

In the Special stream there will be inappropriate behavioural models.

Children with ASD have difficulty in the local school setting if they are not adequately supported. They may suffer stress, and regress.

In a Special Education setting children with ASD may be restricted in learning opportunities as teachers may need to focus on a number of other children with very high support needs.

Most Special Schools are fenced thus children are less likely to abscond.

Children attending Special Education Facilities are provided with transport to school.

Children with ASD who have not reached a level of functioning which is close to that of their typically developing peers tend to regress when they enter the school system.

A repeat year in the Kindergarten/Preschool setting will benefit many

children with ASD and help them focus on social peer interaction, having gained confidence in the environment.

Grade 1 and the structure it provides will help many children with ASD who cannot cope with the open ended social environment of a Kindergarten setting, by reducing stressors.

Children can achieve most long term gain in the developmental period which ends at 7 years of age with the completion of myelination of the brain. After that more skills can be taught but intellectual levels remain static.

Children with ASD who have not reached a level of functioning where the skills are self maintaining will lose skills if these are not rehearsed. Will this happen best in the inclusive or the integrated setting?

The Special education setting is usually staffed by teachers with experience in working with the child who has special needs.

In a special setting your child may have reduced expectations placed on him/her.

In the special setting there may be more access to advice from various specialists and access to more special equipment.

And there are probably many, many more aspects to consider

What is the parent to do faced with this conundrum?

Firstly it is important to take a realistic look at the child, and take stock of the total situation. What exactly are your child's needs? How would you prioritise them? You need to think ahead. What can realistically be achieved given your child's age and current learning rate? Remember that academic skills in the absence of behavioural and independent living skills will be of little relevance in adult life. Write down the most important things your child will need to learn this year in order to reach his potential in the future. Where are these skills most likely to be achieved?

Now look at the potential setting, one by one, and remember that there are major individual differences between the various schools within a type. First look at the physical setting? How will your child cope in this environment. The best time to look at a playground is at play time. Is there anywhere your child can retire to if stressed? What are the noise levels? How

crowded is it? Is it well supervised? Is it fenced if that is needed. Also look at the classrooms - particularly the one your child will be in.

Next look at the children who are there. What are they doing? How will your child fit in, cope socially? Will your child be welcome? What behaviours is he/she going to learn from these peers? How do they play - interact with each other? What are their language levels?

Finally, if all looks good, take a good look at the staff. They may be nice and welcoming, but will they understand your child's individual and specific needs? Are they willing to be flexible enough to meet his needs? Will they cooperate with you and the people who know your child best, or will they just treat your child as just another child with ASD? Be wary of the 'know-all experts' who assume that all children with ASD are the same. In the long run the attitude of the Principal and the teachers is the most important factor, as with an inappropriate attitude the most modern and well equipped educational setting will not deliver the individualised attention your child needs. You need a supportive Principal, as without that support, even the most devoted teacher cannot function. You need a teacher who sees your child as an individual and is organised and flexible enough to cope with the extra work this will provide. If the teacher cannot cope with the task, the most enlightened school policy and the most understanding Principal will not be able to provide for your child.

And let me finish with a word of warning. It is always better to err on the side of caution. Some decisions are not really reversible. Be careful sending a child off to school without the maturity and skills needed, as skills will not be easily gained in the group setting and the developmental period is limited. There is much less risk of possible harm in delaying school entry. Be careful deciding on a Special education setting. It is very easy to make the decision later when you see that your child is not coping. Transition from Special Education to inclusion is a very steep road, and very few children have travelled it.

Jura Tender

## **Thank You ISADD**

Our move to England is looming and we couldn't leave without penning a few words of thanks. Our journey with ISADD started in

February 2005, when our son was diagnosed with autism just before his 3rd birthday. The initial shock for us turned into a search to give our son the best possible outcome, and that soon led us to ISADD.

The highs and lows of the rollercoaster ride that we have held on so tightly to for the past 3 years has significantly changed all of our lives, and this is mainly due to the partnership that we have developed with our Programme Manager, Case Manager and Therapist, and the huge amount of support and guidance they have shown us during this time.

We have emerged as a happy and functioning family, that 3 years ago seemed a total impossibility. The skills that we have developed, the commitment that we made to embrace the programme, the confidence that we have gained in our ability as parents, and the huge amount of hard work we have put in has paid off for us. Our son is now nearly 6 and has the strong foundations to allow him the best possible opportunities for his future.

The words "Thank You" really don't seem to be enough when expressing our gratitude, as without ISADD life could have been very different right now. Please pass on my appreciation to all your wonderful team members, that have inspired us with their dedication, love and patience for the children they teach – they deserve to know what a tremendous job they do, and how much they can change families lives.

Although this is just the first stage of the long road ahead for us, it will be remembered very warmly as it has taught us so much, about our son and ourselves.

Kind regards

ISADD clients (Name supplied)

## **SOME TIPS FOR TOILET TRAINING**

As we are coming up to toilet training season (warm weather, children want to drink more, less clothes to take off etc), a number of you will be trying to toilet train your child. In order to make this time as stress-free and successful as possible here are some hints and tips as to what to do/not to do no matter what approach you plan on taking.

- **Set aside time.** Learning to use the toilet is a big step in any child's life and will take time. In order to get off to the best start make sure that you plan on having quite a few days at home where you can easily concentrate on toilet training. Your child needs to learn to recognise the 'feeling' of needing to go to the toilet and to get themselves there in time. There are also the associated undressing and dressing skills involved.
- **Independence.** With most children, the goal of toilet training is that they will eventually just take themselves off to the toilet and complete their toileting by themselves. In order to get to this stage you need to start off as you want it to be. The hardest prompts to get rid of are verbal and we have found through experience that it is easier not to use them at all from the beginning than to try and fade them out later.
- **Toilet seat.** The best (and cheapest) toilet seat is the simple insert seat, available at any Target, Big W for around \$6 -\$10. There are many other "fancy" ones around but they are usually more problematic than helpful. For example the padded seats actually raise the child above the height of the normal toilet seat and many children do not feel safe or comfortable and if they don't feel relaxed it is unlikely they are going to be able to wee. There is also a combination toilet insert, step ladder seat about which, while good in theory, actually is very unstable and is easily pulled out from under the toilet seat as the child is attempting to get on the toilet using the handles (which just get in the way of them turning around to sit down).
- **Foot stool.** It is very important that once your child is sitting on the toilet his/her feet can rest flat on the stool (preferably with their knees raised higher than the level of their bottom) as he/she will need to spend up to 10 minutes sitting on the toilet at a time and he/she needs to feel secure and comfortable enough so they are not holding onto the toilet seat. Most of the usual steps are too low for this. An easy way to make a step that is the perfect height (and very stable) is to sit your child on the toilet and stack telephone books under their feet until their feet are flat. You can then wrap them snugly in plastic.
- **Pull-ups?** No. Once you have made the decision to start toilet training it is important that your child is kept in undies all the time that they are awake (you can put a nappy on overnight and for naps). This allows your child to feel the difference between wet and dry. Putting your child in and out of a nappy will get him/her confused and send them mixed messages as it seems that it is ok to wee in their pants at sometimes and not others. Some children also learn to hold on until they are put back in a nappy.
- **Start with wee.** It is much easier to toilet train a child for wee first as the event happens more frequently than poo. If he/she happens to do a poo on the toilet, by all means make it a positive event and reward big but do not have any negative consequences for any poo accidents as many children have/may develop poo "issues"(eg. sneak off to do it or hold it in) if they are made to feel that pooing is wrong or dirty.
- **Stand or sit?** It is easier to begin toilet training by having you child sit all the time, even if they are a boy. It is easier to teach your child to poo on the toilet if they are comfortable sitting on the toilet to wee and as they may need to spend extended periods of time on the toilet, it is more comfortable for them (and easier for everyone else to manage) if they are sitting rather than standing.
- **Rewards.** Make sure you have an extra special reward available for when your child does wee in the toilet so he/she gets the message that they have done exactly the right thing and that everyone is very pleased with him/her.

Lisa Cleary, Psychologist/Program Manager

**PHOTO CORNER**



**Lithuanian therapist team at training session in Klaipeda**



**Case Managers Europe at in service training**



**Case Managers Europe at in service training**



**Adelaide ISADD team**



**Tania Dawson, Dave and Mya**



**Just a nice picture – scene on way to see a client – Cashell Castle**