



RHUBARB

The ISADD Newsletter
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EDITORIAL

Seasons Greetings to all our readers

The year has almost ended, and this is only the second Rhubarb! It really has been a "full-on" year, and other tasks have had to have priority over the compilation of this newsletter. I apologise, therefore if some of the "news" herein is rather old, but I'm counting on it still being news for at least some readers.

In the last issue, we asked that readers give us an email address, so that we could send electronic copies of Rhubarb, and thus save a few trees – and costs to ISADD -, however the response was very low.

We have since learned that "softcopy" communications get read less than "hardcopy" communications, so we have decided, at least in the short-term, to continue mailing copies – when we finally get an edition to press!

Daryl Cooper

ISADD is growing up!

This November, ISADD celebrated its 15th birthday. It seems no time since we celebrated our tenth birthday: so I suspect it will seem like no time at all until we reach our twentieth, and then in 2015, we will finally reach a mature 21!

THE FACTS

By the time you read this, I have no doubt at all that the news will already have spread, and rumours will be rife. So, in the interests of putting the record straight, here are the facts.

Jura Tender and Daryl Cooper are planning to reduce the extent of their involvement in the day-to-day management of ISADD by the end of 2010. In their judgment, it is time for "younger blood" to be having some managerial input into the organisation: however they intend to continue their Directorial responsibilities. Jura also intends to reduce her involvement in clinical work.

As part of this plan, they will be selling their Roleystone property which has been ISADD's headquarters for the past fourteen of its fifteen years. They intend to put it on the market mid-2010. This means that ISADD needs to find a new headquarters by then, but as yet, no final decisions on location, size of premises – or anything else, have been made.

It is not anticipated that any personnel will be negatively affected by the changes which will be necessary because of these plans – and it remains to be decided whether any changes in the administrative structure will be needed.

In short, for ISADD clients and service-delivery personnel, it will be "business as usual".

FAREWELL

Just as we were getting to know Melissa Fuller (and used to her Indian accent!), and just as she was getting on top of her role as Office Assistant, she had a major medical emergency. On medical advice, she had to quit the job.

We were sorry to see her go: in her short time with us, she had proved to be an efficient and cheerful colleague, and had made a very positive contribution to ISADD's administration.

WELCOMES

We extend a warm welcome to Heidi Joyce who has taken over the role of Office Assistant from Melissa.

Heidi has been on a steep "learning curve" over the past few months but is proving herself up to the task, and is settling in to the job well.

DOPE GIVES HOPE !

Of all the mad, magical and mysterious "cures" promoted for Autism, this one appeals to me more than most – if only because I would also enjoy taking the medication! (and because it allowed the headline above).

It has been reported (by the child's mother) that medical marijuana helped calm, and reduce aggression in, a child with autism (reported in Healing Thresholds 1/12/09). The medical marijuana was prescribed by a "cannabis doctor", after the child had already tried conventional drugs which proved to have no benefit.

I don't know of any "cannabis doctors" in Australia: this news comes from - where else - the good ol' USA ! Not that I'm recommending the treatment (there is only ABA if you want real benefit), if it were available here; and I'm wondering if the reported benefit might have more to do with the child's mother ingesting some of the medication herself?

IRISH NEWS

Jura Tender and I visited at the end of August. Unfortunately, the news is not good. Ireland must be one of the worst hit countries in the global economic recession, and this, together with Irish Government policies on the treatment of Autism, has led to a downturn in client numbers there – to the extent that continuing to operate there is becoming increasingly unviable.

LITHUANIAN NEWS

In contrast to Ireland, client numbers there are increasing, despite Lithuania, in common with the rest of Europe, feeling the effects of the global economic recession.

Lithuania has come to the western fold only some 20 years ago and attitudes to ASD and disability in general are still as they were here some years ago. To help spread a general

understanding, our parent partner organization, Kitoks Vaikas, organized 4 day long seminars in 4 different cities across the country in May. Jura participated in this 'tour' and contacts were made, attitudes changed. (We had to face comments like "Autism, isn't it just an American disease" – wish that it were).

In August the National TV health program featured Autism as we see it. This included lengthy interview with Jura and a couple of our local parents, as well as Zenia our case Manger, and also some footage of our children at work. It was well put together, emphasized early intervention and was well received.

SINGAPORE NEWS

Singapore has said Farewell to Case Manager, Emily Birch. Emily was with us for several years, and we thank her for her contribution, and wish her well for the future.

Some changes to the way in which services are delivered to Singapore families will commence early in 2010. These have been notified to families.

We are also delighted to welcome Vyda Chai to her new role as Singapore Program Manager: she will take up duties mid-February.

NEW ZEALAND NEWS

Everyone at ISADD was deeply shocked when in May, we learned that Susan Farmer, ISADD's senior Case Manager in New Zealand, had been diagnosed with leukemia. At this stage we can report that Susan is responding well to treatment, and is showing remarkable fortitude in a situation which no-one would ever want to be in.

It goes without saying that all of our thoughts are with her, and we are all wishing and praying for her recovery.

We would also like to thank all Wellington personnel who have rallied round to help maintain service delivery to Susan's clients in those periods where Susan has been unable to work: and we would also like to thank client

families for their cooperation in these difficult circumstances.

Also, sadly, in Wellington, we have had to say Farewell to Angela Southam who has resigned as Case Manager there. We thank Angela for her service, and wish her well for the future.

On a more cheerful note, we would like to acknowledge the contribution that our Coordinator Debbie Blakeborough is making to New Zealand operations. Debbie's highly competent work is very much appreciated – from an administrative point of view, New Zealand has never run so smoothly.

INDONESIA

While the events reported in the previous Rhubarb have caused some disruption in Jakarta, it is pleasing to report that things are now looking much more positive, and we are returning to the position of being able to offer the quality of service to our Jakarta clients that they expect from ISADD.

We are also pleased to welcome Ms. Nouke M Lontoh as Coordinator.

AND CLOSER TO HOME:

South Australia.

Client numbers are gradually building in South Australia, and psychologist Jaimee Smith has had to extend the length of her visits there to cope with the demand.

Victoria.

The Victorian Branch of ISADD are over the moon with their new offices in Williamstown. The acquisition of their own office is certainly a major milestone for the organisation there, and, in a sense, marks the "coming-of-age" of the service.

We are now servicing the Gippsland area, where previously psychologist Sue McDonald was "holding the fort" (or was it "carrying the banner"?) for ISADD on her own. Regular Case

Manager visits are now occurring, and local Therapists being trained.

Tasmania.

Client numbers, in Tasmania, as in South Australia, are gradually increasing. We welcome several Launceston families into the ISADD fold, and Case Manager Peta Kelty is being kept busy visiting from Hobart.

CASE MANAGER TRAINING.

This year, Case Manager training will be held Feb. 7 – 19, 2010. We are expecting participants from Indonesia, Lithuania, New Zealand and Singapore, as well as a few Aussies.

NEW ISADD INTRODUCTORY PACKAGE INTRODUCED

Thanks to some excellent work by Psychologist/Program Manager, Larni Mullan, we have finally produced a new information package for prospective clients. This package takes the form of a number of "fact sheets", presented in a folder. It replaces the "Introducing ISADD" booklet which has served us well for many years.

The new package will cost us more to produce, but it is an unavoidable cost in a market with increasing competition. (- who says competition reduces cost?). We need to present an "attractive" image to maintain our share of business, and the unfortunate reality is that people are impressed as much, if not more, by style as by substance. So we have to match or competitors' presentation (even though we outdo them all on substance).

ABAI International Conference Oslo.

This conference was attended by three ISADD personnel – Jura Tender, Daryl Cooper and Vyda Chai.

Time has not permitted a proper review of the conference for Rhubarb, but Jura has reported back to personnel; and those parents who have attended Parent Nights have also heard Jura's report.

In very brief, the themes that seemed to emerge from the research papers presented were first, it

is important to keep refining techniques within the ABA model, to ensure that we are teaching as efficiently as possible, secondly, the need for intervention to be tailored very specifically to individual needs (not a lot new in that!), but also recognizing that individual behaviours need to be studied using Functional Analysis

Some further comments from Jura:

High points for me were

- The emphasis in paper after paper on Sidman's theory of Equivalence – something that has been around for a few years, but now is being used to explain learning in situations beyond direct reinforcement. To somewhat oversimplify it if we teach a child to associate A and B, and then also A and C, the child is greatly helped in making the association between A and C or may do it without much teaching. This explains how children can suddenly pick up the spoken word after working with Compics.
- A paper from Bangor pointed out that typical toddlers at 12 -16 months had 25 words, by 24 they had an average of 300 and by 6 years 14,000. No reinforcement conditions could explain the language spurt around the age of 3 – but equivalence could. However equivalence will not take place if attention span is too short and relationships between stimuli are not made (hear-see associations). If attention gap is too short we will have a language dribble – not a spurt. Attention needs to be addressed in programs.
- Eikeseth of Norway did a Functional Analysis of Autistic behaviours. If we see ASD as dependent on 2 elements – neurological and behavioural, understanding the behavioural will help understand the neurological better. We know that sensory stimulation is reinforcing for many of our children (because they would not do it if it were not). They can help themselves to this highly rewarding activity when and how they wish, stimulating the pleasure center in the brain. They need neither language nor social contacts. However if they instead are rewarded by repetitive topic, collections, or activities which they need human contact to access, they will look towards social contact and some necessary language skills will emerge. In this way we may be able to discriminate between high functioning and low functioning children with ASD. He also added that like with any powerful reward, we can develop addiction. Sadly this does describe some of our children, and emphasizes the need to monitor self stimulatory access to self indulgent sensation right from the start. It also stands in contrast to the sensory diet theory, which has no logical support and no data anyway.
- Eldevik of Norway did a study of papers on Early Intervention. He started out with 2150 on the topic, of which only 34 were relevant and only 9 met the stringent criteria for serious and convincing research. These showed that Early Intensive Behavioural Intervention was effective at gaining considerable changes in IQ and Adaptive behaviours (EIBI average IQ gain was 29.8%, Control groups, which did nothing extra, only 8.7% while comparison groups, that is other treatments even less 2.6%).
- There was also emphasis (Holmes of Lifespan service) on working beyond the early intervention period, where we know we can achieve most while the brain is flexible. Ages 7 – 12 still allowed children to gain some life changing learning. But for adults, when neural pathways hardened change is more difficult. It was important to move in before symptoms developed, but ABA also had much to offer the adults to make life more easy for them, and their plight and life style needs should not be ignored. I am afraid I continue to hear of paediatricians and psychologist who refuse a diagnosis or access to intervention as the child is 'too young', and others who still wrongly believe that children with ASD will grow out of it.

PARENT CONTRIBUTION

Compics and language: our story so far.

We could never forget that day – some days in December that, in fact a precise recall of the date becomes far less significant compared to its implication – the first time our son, 27 months old then, was able to make a request (e.g. a valid exchange) on his own: asking daddy to play the guitar. A simple request that thought to be so easy by other kids of his age, but for us, it was a breakthrough. It was the “want” compic strip that he brought to daddy to request for the guitar.

Looking back, though, it was just the beginning. On one hand, we should have been happy because he had just learned a new way to communicate his request to us, breaking the typical habit of manipulating by hand. But on the hand, the reality bites when seeing him with the compics – will those pictures and compics be forever a part of his life? Will he ever be able to speak? Does compic really facilitate the development of language as it claims? As with any parent I guess, it was extremely depressing to think about these questions, and worse, hypothesize on their consequences. We kept asking our case manager again and again (to the level that we thought she probably got very annoyed) the implication of compics, if it would actually facilitate his language development. *Doubtful!*, of course, when the future is no way to be certain and it is the human, our son, whom we are ‘experimenting’ with. Of course, it has been used for many children, but that was the first time we ever witnessed it. We were told that it definitely would help and he would use his voice when he was ready – so, we trusted our case manager’s experience, but frankly, with anxiety. We were so worried that what would happen if he was just too comfortable with pictures. However, one step leads to another - as soon as he realized he could also “exchange” his speech for lollies, or guitar, as he did with the compics strip, he wanted to do it the easier way by just saying it aloud. That was it, the simple principle, to our knowledge, that reveals the effectiveness and powerfulness of using compics – help him to achieve his request (things that he wants) and introducing language

along the way. By doing so, he realizes the *function* of language, and why would one want to choose a hard way if a much easier way exists! That was when we realized and acknowledged the power of compics, seeing it working, truly grateful that it was there, when again for the first time, the memorable moment of hearing him say “Gau want guitar” *without* compics.

It was truly heart-breaking that language didn’t come to our son as it should – spontaneously and effortlessly. But in our case, compic is helping him to achieve this goal. These days, the use of compics has become less frequent in both our son's ABA sessions and his every day communication. We still return to it though, for example, when he needs to be reminded of some learned language or when a difficult concept needs to be taught – that simple and powerful principle is applied again – compics then language, fading away visual aids when time comes. ‘Spontaneously’ and ‘effortlessly’, we hope language will come to our son just like that one day – positively, we should say.

A big Thank You to the parent for this contribution – it neatly sums up the doubts and fears of many parents – and is a great testimonial for the use of Compic.

CONTRIBUTIONS WANTED!

If you have any news, views, or anything else you think might interest other Rhubarb readers, the Editor would love to hear from you.

Contact Daryl at Daryl@isadd.org or phone 9397 5970

PARENT SURVEY 2009

Reported below are the results of the annual survey of WA client families.

Approximately 30 per cent of questionnaires were returned, with respondents providing the statistical information reported in Table 1.

Table 1. Number of responses, age at diagnosis, age commenced with ISADD and hours/week of therapy by length of time with ISADD

Time with ISADD	Less than 6 mths.	6-12 months	1-2 years	2+ years
No. of respondents.	6	4	7	6
Av. age at Diagnosis	3 yrs	2.75 yrs	3 yrs	2.75 yrs
Range	1.5 – 4.5 yrs.	2 - 4 yrs.	2 – 4 yrs.	1.5 – 3 yrs.
Av. age commenced	3.5 yrs	2.5 yrs	3.5 yrs	3 yrs
Av. No. of hours therapy/week	7	7	12	11
Range	2-15	6 -11	6 – 15	6-21

Question 1.

Did you have any difficulties accessing ISADD services?

22 responded "No" to this question on difficulty accessing ISADD services. One who answered "Yes" indicated that it was a difficulty accessing Therapists, not the organisation itself.

Question 1.2

When you first contacted ISADD, how were you treated?

An average rating of 6 on the 7-point scale (1= poorly/rudely, 7= very courteously) was obtained on the question as to how clients were treated on first contacting ISADD. One respondent (client for less than six months) felt that the person to whom s/he first spoke made him/her feel uncomfortable, but also reported being happy with all future contact. Another (client 2+ years) also reported discomfort with first contact. It appears to be

the same report as made by a respondent to the 2007 survey.

Question 1.3

How useful was the written introductory information provided to you by ISADD?

An average rating of 5.8 on the 1 -7 scale indicates that respondents found the information provided to be useful, one commenting that it was the most information they had from anyone; another that s/he had read it numerous times, and still refers to it (someone who has been with the service 1 – 2 years).

Question 1.4

How difficult to understand was the information provided?

An average rating here of 5.5 indicates that the information was not difficult to understand , although one respondent stated "some things were a bit confusing" and another that "there is a lot to take in".

Question 1.5.

What could ISADD do to improve the introductory information provided?

Only a few respondents chose to answer this question. One commented "All was clear to me. All questions answered to my satisfaction". Another said "Not overly difficult – just a lot of information". Another, "I think it is good and easy to understand, I can't see anything to be changed". Another simply wrote "Continue".

Question 2.1.

How was it decided what would be in your child's program?

All respondents provided answers indicating that decisions were made in consultation with ISADD personnel – some mentioning Case Managers, others, Program Managers, others, Psychologists. The key point is that all respondents indicated that they were involved in decision making.

Question.2.2

Has ISADD provided you with the services you wanted?

All respondents answered "Yes" to this question, although one added the qualifier, "eventually", and another commented "although I would have liked more information on options for schools".

Questions 3.1 – 3.6

(Developing child's skills to enable participation in the community)

Results are shown in Table 2 below.

Table 2. Improvement since commencing with ISADD.

(1 = No Improvement, 7 = Very much improved.)

	1-5 months	6-12 months	1-2 years	2+ years	All
No. of respondents	4	3	7	6	20
Self Help Skills	3.8	6.0	5.3	5.6	5.1
Communication	5.5	6.5	5.0	5.0	5.4
Social Skills	4.8	5.5	5.3	5.8	5.3
Cognitive Skills	5.2	6.0	5.6	6.0	5.7
Academic Skills	4.8	4.0	5.1	5.5	4.9
Overall behaviours	5.0	6.0	5.9	5.5	5.4

Notes:

In the 1- 5 months category, two respondents said it was "too early to tell"

In the 6 – 12 months category, data from one respondent who reported no improvement, has been omitted, as this, given the small number of respondents, would have skewed the results in a misleading manner.

The above data indicate that ISADD's program would appear (at least in the estimation of parents) to be making significant improvements, in all but one case, in all aspects of their child's functioning.

Question 4.1

How does ISADD treat you?

All respondents reported being treated well, comments ranging from "fairly well, thanks" to "VERY well", two also mentioned understanding and compassion.

Question 4.2

Does ISADD respect your privacy and confidentiality?

20 respondents answered "Yes" while three responded "Don't know" (two of these were in the 1-5 months category, one in the 2+ years)

Question 5

Would you make a complaint to ISADD if you didn't like something they were doing?

18 respondents answered "Yes" 3 didn't know and 2 responded "No".

Two respondents, 1 "don't know" and 1 "No", commented that they would approach their Case Manager and that they felt confident they could discuss any problems.

Question 6.1

What is your opinion of how ISADD is managed?

A range of positive responses was received to this question, including "managed very well" "It works for us", "the whole family is happy with ISADD" and "everything running smoothly so far".

Question 6.2

What are ISADD's strengths?

Respondents identified knowledgeable, caring staff, the ABA program, genuine concern for families, and the good initial information provided.

Question 6.3

What are ISADD's weaknesses?

Many respondents answered "none". One identified "paperwork" and three mentioned the lack of sufficient therapists to meet demand. Two thought that new therapists should have more training.

Question 6.4

What things could ISADD do to improve its service?

Comments here again mainly related to therapist training (2), supply of therapists (2), and more parent training (2). One suggested ISADD needed to be more "tech savvy", and one suggested having resources available on our web-site which could be printed off by families.

Question 6.5

Any other comments?

Several respondents thanked ISADD for our help. Comments included "I think ISADD do

a great job and are great people", "ISADD provide a wonderful service", "A+++",

Discussion.

From the statistical data, it was both surprising and alarming to note that of the respondents who had recently joined ISADD, two families were having only 2 hours of therapy per week. It is perhaps significant to note that these were the two respondents who did not rate their child's improvement, both commenting that "it is too early to say". Given the access to Federal funding, there is no question of financial constraint, and therefore the reasons for the low hours of therapy should be investigated.

The statistical data also suggest that, on average, clients are accessing our service within six months of diagnosis. We would consider this an acceptable time.

This survey continues to indicate very high levels of satisfaction with ISADD services. As in previous years, lack of supply of therapists remains the major source of any dissatisfaction – this is likely to continue into the future! It should be noted, however, that the advent of Federal Funding late last year significantly increased demand for Therapists, and the fact that the actual level of dissatisfaction, as measured by the number of respondents mentioning the issue, remains low, indicates that ISADD responded in a timely and appropriate manner to meet the increased demand. (A major recruitment drive was carried out at the end of last year).

The other issue regarding Therapists (mentioned by two respondents) of more training for therapists, was also addressed at the end of 2008 with the creation of a new position of Training Manager. This person is able to provide an increased level of support to trainees. It would have been interesting to know why the respondents felt more training was necessary, they did not provide this.

In regard to the one respondent who reported that his/her child had not shown improvement on the program (in fact s/he recorded a little

improvement – rating of 2 on scale of seven - in two of the domains), it should be noted that the research literature indicates that approximately 10% of children fail to make significant gains on ABA programs. In this survey, the one client failing to make significant progress represents a figure of less than 5%, and is therefore acceptable, and does not suggest any failing on the part of ISADD's program.

Finally, it was pleasing to note that respondents were more than satisfied with the information provided to them by ISADD, that they found the information reasonably easy to understand, and also found it useful. As ISADD has worked hard over many years to provide prospective client families with clear and comprehensive information which is also accurate and factual, the responses in this survey suggest that we have achieved our aims.

SANTA CLAUS– ITS NOT ALL “HO,HO,HO!”

- by Jura Tender

Many parents will remember the rather embarrassing first exposure of toddler to Santa and. After all, stranger recognition is part of our innate social protection mechanism, and Santa certainly looks different and sounds different from the familiar people the toddler knows well. However the toddler soon notices that parents are comfortable and accepting of this weird stranger and that other children are happy to meet this guy, sit on his lap and walk away with toys. So children learn to love Santa, because he stands for presents, surprises and all things nice. It is part of the mystery of Xmas and adds to that time of year being special, different and something to look forward to. When they are old enough to evaluate what may be real and what is unlikely, they gradually, and at times a little reluctantly, give up the Santa Myth to replace it with mundane reality and a consumer mentality as they check the catalogues and put in their orders to parents. It is part of

growing up, and it represents the child's move from the innocence of dreamtime imagination, when fairies might just have been real and magic could fix all problems. Parents see it as sadly the end of childhood, but children mark it as a passage of rights to growing up and are proud of their new view on life.

So what about the child with ASD?

Firstly as toddlers they may have some very real fears of the stranger who looks and sounds so different. After all they are not as aware of the reassuring smiles on the faces of parents and the joy and the toy other children come away with. They may only be focusing on the strangeness which to them will be as real as something from Dr Who or the X-files is supposed to be to the characters on screen. Be very careful, and do not force an exposure as too many of our little clients have phobias of strange human-like faces, clowns, face painting, and similar. It takes time to desensitize them so let them set the pace. Remember many children with ASD are also prone to anxiety.

Once you have achieved friendly acceptance of Santa you will have another problem in a few years. How do you tell your child that you have lied about Santa? Children with ASD can be very rigid about facts and they do not evaluate but accept life and its rules, and this is why social stories and schedules are so powerful as teaching tools. They may argue vehemently with peers at an age when the peers will have already moved on, making themselves the butt of jokes. They have genuine difficulties in discriminating between reality and fiction, and many believe all they see on TV well after peers know that the superheroes are a myth, and that no matter how hard they try they will not grow up to be Spiderman. We must teach the 'Likely, Unlikely, Impossible' drill to ensure they are not gullible and will not be used by others. Our children need to grow up to assess reality accurately or else they remain vulnerable.

So parents, do not push the Myth too much, let your child enjoy the presents, but leave

plenty of clues as to what is really going on as your child gets older. Make sure your child does not stand out in the crowd where he can be laughed at by peers, or where he may feel

that a deep belief has been shattered and the world is not to be trusted. I guess this applies to Easter Bunny too, though at least he is not as scary on first meeting.

PHOTO CORNER



Lunch during parent and Case Manager day in ISADD's new home base in Lithuania, in the village of Zarenai,



A working meeting in Singapore



What do we remember Oslo for, other than ABA of course? A park with thousands of life size statues of mankind in its various forms and expressions – all the life work of one sculptor. Here the differences between girls and boys is well illustrated – the girls are more social I think.



Therapist training in Jakarta – where YISADDI is alive and well, despite some small hickups.



Melbourne CMs unlocking the door to their new office.



Laura is getting to me with the new office in Melbourne which they are very proud of..



It may be small and unfurnished – but it is ours (Laura and Nelly) and we can use the meeting areas if needed