

ASSERT

Angelman Syndrome Support Education & Research Trust



ISSUE THIRTY SIX AUGUST 2003

REPORT

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Letter from the Trustees

Hello, we apologise for the delay in the newsletter this time, but as Sally Walburn can only write this when time permits, we are in her hands! If you could help with the Report please contact Sally.

Jim Brennan is now free from the ASSERT paperwork, and is extremely pleased to have his spare room back! All the trustees have taken on parts of his role between them, including Sally which means that we have to fit in ASSERT with the rest of what goes on (we are sure you can imagine how busy life is as you must all experience the same demands on your time).

Anyway, it's here – we have been busy as you know and we have already held, thanks to Nick and Sharon Bartholomew, one regional meeting this year. We have yet to have dates confirmed for the East, South East and Central regions. If anyone would like to organise a meeting, please contact ASSERT. Those who attend the meetings have a great time and enjoy getting together with the other families. Of course next year it's the conference, so write that in your diaries now. See the full advert on page 4.

Since the last newsletter the ASF/IASO conference has been held in Washington and in the next edition of the Report we hope to bring you the latest information and an update on what happened. Dr Jill Clayton Smith was a Keynote Speaker and Dr Angela Reason made a presentation. ASSERT did not send a representative this time.

We have been asked by Jim to remind you all that if you change address and/or phone number you let us know we have had several newsletters returned as 'Gone Away'. Our service is free to you but costs us postage so we would appreciate a quick phone call to let us know where you are – plus you will miss out on the newsletter and any updates and information in future. On the other hand if the ASSERT Report is no longer of interest to you, at your request either by phone or in writing, we will remove you from the mailing list.

Well that's all for now. Please note the new ASSERT PO Box address on page 4, all correspondence is now going to Gerry Egan.

Hope this finds you and your families well and we look forward to hearing from you.

Fundraising



Caption

Those Scots have been at it again – well done to Karen Robertson et al who raised the fantastic sum of £2,842.24 for the conference, this is what Karen wrote:

Dear ASSERT

I am writing to send you a cheque for £2,842.24, which we raised by having a fundraiser event at our local hotel. We had an excellent night of entertainment, which was provided to us by some risqué comedy of Aberdeen's comic maestro Patrice and John Mcgruvie. We had an excellent turn out and we had a raffle of hampers of alcohol, which went down a storm. I have enclosed a photo of us all with the hotel manager and the comics. Kieran got a mention in the local paper, saying thank you to everyone coming to the night and also bringing awareness to Angelman's Syndrome and ASSERT.

I hope this will help towards next year's conference, which we are all looking forward to seeing everyone again and of course learning so much.

Karen Robertson

Article on Development and behaviour in AS by Dr. Angela Reason

We have received some comments from people about the first part of the research that Dr Angela Reason carried out with some of our families and reported on in the last newsletter (March). Angela has kindly penned her response to the points raised and we are pleased to bring them to you. Articles are always there for comment so if you would like to make any point on something we have printed you agree/disagree with, please get in touch. The professionals involved with ASSERT all value your opinions.

RESPONSES TO FEEDBACK

1. **“The author admits that there was uncertainty that the performance was representative. Doesn’t this make her findings fundamentally flawed?”**

When I talk about the findings possibly being unrepresentative what I am highlighting is the issue of generalisability. It is good practice in scientific research to be clear about the parameters to which findings can be extended. In this specific instance I highlight that my results indicate an approximate level of development, and raise caution about saying this is all the individual is capable of cognitively.

2. **“Tasks aimed too high...at a level which is unachievable...”. Surely this applies to anyone, adult or child, with or without a disability?”**

Yes! I am highlighting that like anyone, we need to think about an appropriate level in which we pitch interventions and tasks, and individuals with AS are no different. What we often see clinically is people referred for behavioural problems, which are often associated with frustration at things feeling out of reach.

3. **“This study gives the misleading impression to parents of the capabilities of children with AS deletion. It could be interpreted that the developmental attainment of a child aged 14 in the study was no more than that of a child aged 3 in the study, and that the level for both children would never be more than 7-14 months.”**

I refer back to the issue highlighted in point one regarding generalisability. The results referred to in the above question are what I found in this study with these specific tests on these specific children. What I was also clear to illustrate was that caution should be exercised in respect of generalising these findings to the wider AS population. I also highlight the evidence from this study that parents/caregivers thought ability was higher. Really, this research is a starting point in the absence of other similar research. We still know relatively little about cognitive development in AS. I acknowledge the point but reiterate that these results should not be taken as a concrete cut off but rather an example of developmental investigation based on a small sample in AS.

4. **“Where are the “parent/guardian perspectives on their child’s development”? There was no information about cognitive ability which did not feature on the test and which may be more relevant to everyday living hence incorporating motivating situations.”**

This is indeed an area in which further research could focus. Every study has its limited focus and as no similar research had previously been done in this area it was important to use standardised measures initially for the results to be reliable in the scientific sense. Thus, parent/guardian perspectives were sought via the use of the Vineland. This is a focused measure with preset questions, and I agree that it would be useful to explore perspectives on development in a more open and qualitative format.

And we also received the following in an email:

Dear Editor,

I was so glad to see that you had published the research by Angela Reason. As you know, due to my own personal experience with my daughter Molly, I have, for a very long time, been a passionate advocate of the developmental approach as opposed to chronological age appropriateness approach. So it was for me especially refreshing to see this. (I still feel that I am justified in my view largely because at 26 years old, she is still very happy and has a good sense of self)

One of the problems is that, as in Angela’s research, most studies use a scientific methodology and are based on analysis with small samples over a short time span. This is the scientific era after all and people like clear-cut qualitative data. Unfortunately this means that when it comes to evaluating the effectiveness of certain therapeutic interventions the long term picture and the qualitative/subjective (softer) information is very often not taken into account, or even worse totally ignored and regarded as irrelevant. The result is that evaluation of many of the commonplace interventions is based on small sample short-term studies.

Unfortunately there is a lot of (social science) evidence to suggest that condition specific support groups such as ours lay themselves open to this sort of hijacking by the medical scientists and therapists – the experts – who have not only our interests but – unfortunately – also theirs to take in to account. One way that we might tackle this might be to encourage researchers who want to do longitudinal scientific studies or perhaps better still to use non-scientific methodologies – e.g. ethnographic research or grounded theory. The advantage of the other methodologies is that the voice of parents (who are after all the people with real experience) may become more audible, and if we want give place to the emotional developmental issues that concern our children as well as everything else, this could be very valuable.

It seems to me that the jury is still out on how we get from genotype to phenotype in AS and on the long term benefits of many of the commonplace interventions, so for the sake of a better understanding do lets try to encourage research of all types. I wonder what other people would think about this.

Susie Evershed

Breaking Point

Following the letter we included from Gail Hanrahan Barnes in the last newsletter, we have received this information from Mencap from Gail. Mencap are taking a stance with the campaign for respite and this is their press release:

Mencap launches e-campaign to get carers the support they desperately need

Mencap is launching a major new e-campaign, Breaking Point, on the crisis faced by thousands of families caring for children and adults with severe or profound learning disabilities. These families love their children and want to care for them but Mencap has found that many are nearing breaking point because of a failure by local authorities to provide support.

The e-campaign is launched during the build up to National Learning Disability Week 15-22 June 2003, when new research into the extent of the problems for families will be published.

Mandy, one of the parents backing the campaign said: "I found myself at breaking point one morning in January. I broke down in front of my kids. I told them, I just can't take this anymore. I have to go. Can you imagine how scared they were?"

Mandy's story shows how close families feel to breaking point and why the issue needs to be urgently addressed by local and national government. Across the country thousands of parents are caring at home for children and adults with severe or profound learning disabilities, year after year without a break. No matter how much they love and care for them, there can come a point where they just can't go on.

The e-campaign at

<http://www.mencap.org.uk/breakingpoint> will allow people to:

- e-mail their MP asking them to support the campaign
- Complete a short survey on the realities of carers lives
- Join Mencap's campaign network to get involved in local and national activities

To encourage public involvement people who complete the survey will have the chance to win a Nokia Mediamaster 221T. This award-winning gadget gives free access to at least 30 free TV and radio channels from Freeview through your

existing TV and rooftop aerial without having to pay a subscription.

Jo Williams, Mencap's Chief Executive said: "These families either receive little or no support at all. They have to fight for years for any small amount of support they do get. They are often widely ignored until they actually reach breaking point, then local authorities step in and spend large amounts of money on residential care. If local authorities provided short breaks and invested in services for families before they reach breaking point, they could save time and money in the future. But more importantly, they could save the human cost of a family experiencing crisis and despair. Mencap wants every family who needs a short break to get one, before it's too late. So we urge everyone to take part in the campaign."

There are 210,000 children and adults with severe or profound learning disabilities in England. Of these, about 93% of children and 60% of adults live at home with their parents.

Short breaks were formerly known as respite care. The cost of a short break can be relatively inexpensive to provide. Costs range from £50 for a child to go to a foster carer for one night to about £150 a night in a residential service. This can be compared to the costs of placing someone in residential care when the family cannot cope of a £50,000 to £100,000 a year.

Mencap works with people with a learning disability and their families and carers, fighting to end discrimination and prejudice, and providing a wide range of quality services.

There are around 1.5 million people with a learning disability in the UK. Learning disabilities have many different causes but are always lifelong. A learning disability can affect someone's life in many ways, causing difficulties in learning, communicating or doing everyday things. A learning disability does not prevent someone from learning and achieving a lot in life, if given the right support.

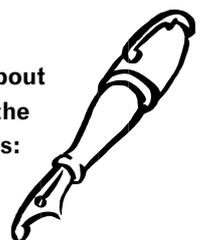
For information about learning disability issues please call the Learning Disability Helpline on 0808 808 1111 (England)

If you would like to read an article, which Gail wrote for her local newspaper to highlight the need for care, please contact Sally Walburn 01268 415940. ASSERT would encourage you all if you have access to the Internet, to enter the email campaign on the website – this is an opportunity for us all to express our views
<http://www.mencap.org.uk/breakingpoint>

Please note that the deadline for the next edition of the ASSERT Report is 15 September 2003.



If you enjoy these articles please think about writing one about your family, we really find this the most interesting part of the report. The address to write to on this or any other subject is: ASSERT, PO Box 13694, Musselburgh, EH21 6XZ



Conference 2004

When? Weekend of 3-5 September 2004
Where? Loughborough University, Loughborough, Leicestershire
For whom? Families/ Carers of children/adults with Angelman Syndrome
How Much? £70 per person for the weekend
£40 for a child under 12 years for the weekend
FREE to all with Angelman Syndrome
FREE to your carer for the person with Angelman Syndrome

Programme to include: Respite, Transition, Behaviour, Seizures, Genetics, Communication, Education, product displays and anything else we think will be of interest to you and we can arrange!

All this is included in the price:

Accommodation
Childrens Outings/Activities
All meals/special diets catered for
Entertainment
All of the conference talks and coffee breaks/conference lunch
Conference packs

Can you afford to miss it?

Once again we have had a few individuals who have generously donated sponsorship and fundraising money to the conference which allows us to reduce the cost substantially. Places will be allocated on a first come first served basis so when you get your initial forms early next year please reserve your place.

As last time if a parent comes as a parent/carer i.e. you look after your own son/daughter/siblings for the duration of the conference – you can come free – this does allow you or your partner to swap, for example Mum goes to the conference on Saturday, and Dad cares, then on Sunday Dad attends the conference and Mum does the caring, you will still have one free place. If however, you bring an additional carer (over the age of 18 years, please) which allows both of you to attend the conference you will have to pay for both of you but not the additional carer – we hope this explains the position but if you do have any queries on this please check with us and we will be happy to clarify this for you.

The conference will be extended to Sunday afternoon this time or we can start earlier on the Friday – if anyone has any contribution to make or suggestion or can help in any way please contact ASSERT. If you would like to be part of the organising committee we would be really grateful for your support.

DON'T MISS OUT !

The conference is a great way to network and make friends and learn from other AS families as well as the experts – we would say that everyone who attends the conference doesn't want to go home at the end – and wants to come back again. It is very relaxed and there is no pressure – we can all be ourselves and we don't have to make excuses or worry about how our children/adults are going to behave – we are altogether and know what life is like with Angelman Syndrome. It will be great to meet with you and see you there – we are looking forward to seeing as many of you that can attend in 2004! Please reserve your place.

SEE YOU IN LOUGHBOROUGH!

Please Note
New Address for ASSERT:
ASSERT
PO Box 13694
Musselfburgh
EH21 6XZ

Special Clothing

We have heard from one of our families that Bradford College Fashion Services will make up special clothing for a reasonable price. Sometimes families need clothing which is 'all in one' or will do up at the back to prevent undressing or getting into nappies. The telephone number is 01274 595926 and the person to speak to is Sandra.

Fledglings

ASSERT often gets phone calls from families who are looking for specific clothing or equipment – try Fledglings – they gather information on all sorts of products and either supply them or let you know where you can get them – their email address is enquires@fledglings.org.uk, or telephone Ruth Lingard/Lesley Mills 0845 458 1124 Fax 0845 458 1125

Contents of the Newsletter

You will notice that the pieces in this newsletter are drawn from a wide source of places. This is tremendous, and we hope you will agree that it makes interesting reading. However, while we are keen to promote discussion and to pass on many views and experiences, it is also important to appreciate that the opinions and views expressed by contributors to this newsletter are personal ones and not necessarily those of the trustees of ASSERT.

Just a thought

"I can assure you there is no more powerful advocate for children than a parent armed with information and options."

*Rod Paige,
U.S. Secretary of Education*

What is the Annual Review Procedure?

The LEA writes to the head teacher in advance to tell him/her when the report of the annual review meeting is required. The head teacher will then write to the parents, giving them a date for the meeting and also asking them for their written comments on how they feel their child is progressing and whether they have any concerns etc. The head teacher will also ask any professional specified by the LEA and anyone else he considers appropriate for a report. If parents feel that there is a professional involved whose report could be helpful to the review process then they can ask the head teacher to include this report. Once the head teacher has received the reports they should be circulated to all involved in the meeting. The reports will form the basis for discussion at the meeting.

Parents should receive copies of all reports at least 2 weeks before the meeting. If you are given any additional reports on arrival, request 15 minutes to read them before the meeting starts. Remember that as parents you can take a Befriender or Independent Parental Supporter with you to the meeting to give you support and to take notes on your behalf.

What happens at the meeting?

The annual review meeting will normally take place at the child's school and should be chaired by the head teacher or the teacher to whom responsibility for the school-based elements of the review has been delegated. The meeting will use the reports as the basis for discussion and will look at the following:

- 1) Does the statement remain appropriate?
- 2) Are any amendments to the statement required?
- 3) Should the LEA continue to maintain the statement, or should the LEA be recommended to cease to maintain the statement?

The review meeting may recommend amendments if:

- Significant new evidence has emerged which is not recorded on the statement.
- Significant needs recorded on the statement are no longer present.
- The provision should be amended to meet the child's changing needs and the targets specified at the review meetings; or
- The child should change schools, either at the point of transfer between school phases e.g. primary to secondary; or when a child's needs would be more appropriately met in a different school.

What happens after the meeting?

The head teacher must prepare a report which summarises the outcome of the meeting, any educational targets for the coming year and any recommendations of amendments to the statement. This report must be sent to all concerned in the review, including the parents and any relevant professional.

The LEA will then review the statement in light of the head teacher's report and decide whether to accept the head teacher's recommendations. In particular the LEA must decide whether to amend or cease to maintain the statement and within one week of making a decision, the LEA must send a copy of its decision to the school, the child's parents and anyone else they think appropriate.

What happens at year 9 reviews?

The annual review that occurs in year 9 and any subsequent years until your child leaves school should include a Transition Plan which will bring together information from a range of individuals within and beyond school in order to make plans for the young person's transition to adult life.

What is different about this review?

- The head teacher – must involve the Connexions Service in the review meeting to enable all options for continuing education, careers and occupational training to be considered.
- The Connexions Personal Adviser – must attend the Year 9 review meetings and any subsequent meetings.
- The head teacher – must invite Social Services to attend the reviews so that any assessment under the Disabled Persons Act (1986) can be made.
- The young person themselves – should be involved in the meeting and consulted about what their aspirations are for the future.
- A Transition Plan – must be drawn up in consultation with the Connexions Service.

What is the connexions service?

The Connexions Service took over the role of the Careers Service from April 2001. The role is to assist the young person and their parents to identify the most appropriate post-16 provision, provide counselling and support and have continuing oversight of and information on the young person's choice of provision.

It is important that at all meetings parents show confidence and this can be achieved through body language, listing what they want to discuss, being organised with paperwork and possibly taking someone with them to help or take down notes. It is equally important to know the time scales for the meeting so all points can be covered in the allotted time.

Parents say that the 6 important issues for them are: Honesty – Respect – Confidentiality – Communication – Support – Positive attitude.

This information came from a meeting with Network 81 at SNAP in Brentwood Essex. If you would like more help or support please contact Network 81 who operate a helpline for free advice and information:

Monday – Friday 10am to 2pm 0870 7703306.

Getting Help to Adapt your Home

Contact a Family wrote in their Share an Idea magazine, if you need to adapt your home to make it easier for you or your child to manage then you may be entitled to a Disabled Facilities Grant.

Disabled Facilities Grant – England, Wales and Northern Ireland

To be eligible for a DFG you must be an owner-occupier, tenant (private, Local Authority or Housing Association) or landlord with a disabled tenant. The grant can help with the cost of the works such as building safe play areas, installing a stair-lift, adapting a lighting or heating system, or building a new bathroom facility. Whatever the proposed works it must be agreed that these are 'necessary and appropriate' in meeting the disabled person's needs and also 'reasonable and practicable'. The question of 'reasonable and practical' takes into account the age and condition of the property. The grant is means tested and therefore income and savings will be taken into account. In the case where the disabled occupant is either aged under 16, or over 16 but under 19 and for benefit purposes is treated as a 'dependant', the income and savings of the parent(s) are taken into account. In most other cases it is the disabled occupant that is assessed.

There are two types of disabled facilities grant:

Mandatory grants are awarded where the works are considered essential to enable better access and movement around the home and to essential facilities within it. The grant can also cover the costs of building essential facilities where necessary. The maximum grant payable is £25,000 in England. Note that if the costs exceed the limit then the council has the discretion to give a further grant covering the full costs of the mandatory works.

Discretionary grants can be awarded to make the home more suitable in meeting the to disabled occupants accommodation, welfare and employment needs. There is no maximum discretionary grant. Note that from July 2003 the Discretionary Grant will be abolished and replaced with Local Authority discretionary powers.

How to apply

Application forms are available from the local housing or environmental health department. Once a formal application has been made the council must make a decision within 6 months. The housing department is required to consult with the Social Services to department to be satisfied that the works are 'necessary and appropriate'. It is important to note that applications for works already carried out will not be considered.

A further possible source of financial help is a Home Repair Assistance Grant. This is a discretionary grant to help

meet the costs of smaller scale works including adaptations, up to the value of £5,000. As well as being an owner-occupier or private tenant, applicants must also be in receipt of a means tested benefit such as Income Support or Working Family Tax Credit, or be 60 or over, or be disabled. You may also qualify where the grant on is to enable someone who is 60 or over, or disabled, to be cared for. This might apply where the applicant provides regular respite care for a relative. For further details and an application form contact the local housing authority.

Challenging decisions

If you are unhappy about the outcome of an application for a grant, or the length of time it has taken to reach a decision, then seek further advice. Ways of challenging decisions include talking to your local councillor, complaining using the Local Authority complaints procedure or asking the Local Government Ombudsman to investigate. The local Citizen's Advice Bureau or Home Improvement Agency may be able to advise further.

Further help and advice

Home Improvement Agencies sometimes referred to as 'Care and Repair Agencies', exist to help homeowners or private tenants improve their living conditions. This involves giving technical and financial advice as well as help and guidance through the application process. They may also be able to identify other sources of financial help if the grant is insufficient. For information about local agencies in England contact Foundations, telephone: 01457 891909.

Additional info

See if there is a local advocacy service that you can use to support you through the process – ask your Occupational Therapist or DIAL (Disability Information Advice Line) if you have one. Use the local library – they have a wealth of information and resources and you can usually access the Internet free of charge for even more additional support. The main thing is not to be fobbed off!! Apply for a booklet from Scope "In Good Repair" where it sets out what you need to do to get help. Telephone Scope: 020 7619 7100

Thanks to SNAP Brentwood

Thanks to SNAP, Brentwood Essex for giving us permission to publish the articles on the Educational Review and the Disabled Facilities Grant. The articles both appeared in their recent May 2003 Newsletter and came from Share an Idea from Contact a Family and Network 81 – thanks to them too for keeping us all informed.

Buggies and Seating

*Rosemary Teggins has written the following, which she hopes, may be of interest to some families:
(Rosemary lives near Dublin)*

We went to a "seating clinic" yesterday, to arrange for a new buggy – knowing the rate they work here, we will be lucky if we have it by next Christmas! I would like it in time for our holiday in June. We have had his Convaid Cruiser 4T now since 1996 and it has done thousands of miles – Nigel has pushed Philip in the Dublin City marathon every year since 1997. It has had a few changes over the years by Nigel using another buggy for spare parts. Unfortunately this is still the largest model, and Philip has outgrown it now. We were told two years ago there was to be a larger model and we wanted to wait for it, but they don't seem to have made it.

At the clinic we were told there is a man living locally (Dublin) who does custom-made wheelchairs (the Convaid Cruiser comes from California via UK which adds to the cost). We have an appointment next week. He puts wheelchairs together and not only takes the user into consideration but also the carer – Nigel likes to take him for long walks, so height of handles and adequate spacing between the wheels so Nigel can take long strides rather than stroll, and our roads are not great around here, so it eventually rattles to bits. Philip will be 14 this year, he is 5 foot 6 inches now and weighs 9.5 stone. His older two brothers are 6 foot 4 inches, so I wasn't in a hurry to get a new buggy, as I knew he would have a growing spurt, but he is going to have to get something to do him for another few years till he gets to his full height.

The 4T is designed to fit up to a young adult. Last year we requested new wheels, brakes etc as we wanted to wait for the larger model and afraid if they gave us same size again last year, they wouldn't replace it for a long time, even if he

outgrew it – they said they would, but we know these wheelchairs are expensive so it was our choice. Nevertheless they said they would prefer to replace it – but when we tried the same size model – it is a new design, much lower to the ground, he is more horizontal and therefore more difficult to manoeuvre, so we went back to the old one.

Back in 1996 when we got the original buggy, the health board would only pay the cost of a normal wheelchair. We got the larger 11" solid wheels on the back, then last year when replacing worn parts we got the slightly larger wheels which are pneumatic – better on rough terrain. (I won't go into the "red-tape" hassle there was obtaining these parts – that is a story in itself!!)

You know how strong our AS children are, Philip can bounce the buggy along – wherever he wants to go even with the brakes on! So tyres need replacing again because the brakes have rubbed the rubber smooth. He can also steer it by manoeuvring the wheels. People who see him in action say why don't we get the full sized wheels so he can steer himself, he doesn't understand danger and he would be everywhere we don't want him to be... I am sure most AS parents would know what I mean!!

Yesterday when we tried him in a smaller standard model wheelchair they said he looked much better in a wheelchair – I suppose he looks like an overgrown toddler in the buggy, but then I am used to him. The buggy is lighter and I can lift it fully opened into back of Nissan Serena, they said I wouldn't be lifting the wheelchair the same way!

Details for the Convaid Cruiser –
Mobility Aids Centre 88D South Street, Peterborough
Cambridgeshire PE2 8EZ Phone: 01733 344930

We hope you got in time for your holidays – as we write this the Walburn's are still waiting for a wheel chair assessed in November 2002 and ordered in January 2003 – so it's no different here!

Unfortunately there are only two types of people in this world:
Those who care and those who don't
those who give and those that won't....

Those who offer their time to share
those who stand, point and stare....

Those who play and share their game
those who SHOULD hang their head in shame....

Those who give their love away
those who wouldn't give you the time of day....

In the end it's not about them
It's about the love YOU give – again & again & again...



ASSERT Website
www.angelmanuk.org

ASSERT Email
assert@angelmanuk.org

Challenging Behaviour

As promised in previous newsletters we are pleased to bring the following article from Lucille Bennett, who presented at the conference back in September. She has given us permission to print and we look forward to her coming again next year.

A significant part of my work over the last five years as BILD Training Consultant has been providing training in the management and support of children and adults who present violent behaviour. In this article, I intend to show how the hormone called adrenaline may be responsible for much of the violent behaviour that we see. By sharing this view, I am aiming to broaden the knowledge base for practice in what is for many a perplexing and puzzling part of our work.

What is violent behaviour?

There are many kinds of behaviour that may be viewed as violent. Presland (1989) describes three categories of violent behaviours:

- Aggressive acts towards other people, such as kicking, hitting and biting
- Destructive behaviours that damage inanimate objects, such as throwing things, knocking items over and breaking objects in the environment
- Other behaviours which are likely to be perceived as violent in character, such as staring, shouting and physically showing that a violent action may follow.

So, if these are the kinds of behaviour that may be considered as violent, how can adrenaline cause them? We need to look at what adrenaline is and how it works.

Adrenaline and its actions

Adrenaline is a hormone produced by the endocrine system in the adrenal glands. It is released in response to demands and pressures. When released, it helps us to cope with difficult circumstances and situations. It does this by preparing the body and mind for physical exertion and rapid mental activity. In the short term these changes are useful because they make possible for us to do things like: moving quickly if we have to get out of danger: jumping over seemingly impossible obstacles; lifting weights that would ordinarily overwhelm us; recalling facts and details we thought we had forgotten and finding solutions for puzzles and problems we think we cannot solve. However, whilst adrenaline is useful in the short term, in the long term it can lead to problems by causing the condition described as stress.

Stress

Stress is a state that can occur when demands and pressures are persistently high over a period of time. In stress, the body responds in a number of ways, such as 'butterflies in the stomach', the mouth going dry, eating becoming unpleasant, regular desire to go to the toilet, muscles becoming tense, aching and fatigued, impaired concentration, thinking processes and memory and the mind staying in a constant state of alertness with rest and sleep almost impossible. Over time prolonged stress is harmful to physical and mental health. Typical stress-related health problems include digestive

problems, ulcers, skin disorders, heart attacks, high blood pressure, strokes, asthma attacks, anxiety states, depression and nervous breakdowns. High levels of stress can also trigger innate biological survival mechanisms. In biological terms, these mechanisms are referred to as fight, flight freeze or floundering responses. It may be that the biological survival mechanism called a fight response could account for some of the violent behaviour we see if people we work with are experiencing stress.

Stress and people with severe learning difficulties

Research studies over a number of years have shown that there are a number of factors that may cause stress for children and adults with severe learning difficulties. If this is so, it is likely that some of the people we work with will eventually be triggered into a fight response. To show what I mean, let's begin by considering some of the disabilities of people we work with.

Can these underpin stress?

- Imagine you have difficulty communicating.
- Now imagine being thirsty and unable to get anyone to understand that you need a drink.
- How would you feel?

You might feel many things but, chances are, you will probably feel uncomfortable, maybe a bit unhappy and as a result you may become stressed.

Let's now turn to another area, namely the demands we put on people we work with. Can these cause a stress response? Again let's use a simple illustration:

- Imagine you can only concentrate for three minutes at a time before you need a rest to let your brain recover its ability to concentrate.
- Now imagine what it would be like to be asked to continue doing a task for 15 minutes without a rest.
- How would you feel?

The chances are that you would feel a degree of concern, maybe frustration because you cannot function well after your concentration goes, possibly irritation that the person asking you to continue does not understand. As a result you would feel stressed by ordinary everyday demands.

Let's now take a look at the manage people and interact with them. Could this be the final trigger that provokes the distress survival mechanism in someone who is stressed? Again, let's use another simple illustration:

- Imagine you are very hungry and desperate for your dinner
- Now imagine you have been asked to sit down in the dining room and wait are sitting quietly waiting for three minutes while your tummy rumbles for food
- Now imagine how you will react when your food is brought over and you start to eat it with your hands your dinner is taken off you and you are told off for eating with your hands
- How would you feel?

You might feel so hungry that you would do anything to get your dinner back, possibly grabbing the plate or even striking out at the person who has it. The way we manage people and interact with them can act as the final trigger that provokes the fight response.

After considering, these simple illustrations, you may suspect that some of the children or adults you work with are presenting violent behaviour because of the fight response caused by stress. How can we be sure? Let's take a look at the fight response.

The Fight response

The fight response is a powerful biological response in which the body and mind are instinctively and innately prepared for and thrust into a state of confrontation. This state follows a predictable pattern (Arnett and Hewitt, 1994). However most people are unaware that exposure to the early stages of this predictable pattern produces a powerful reciprocal confrontational response in others (Lanciotti and Hopkins, 1995). So we should be looking for predictable signs and signals that warn us that either the fight or the reciprocal confrontational response is in operation. The signs and signals for both these responses begin with behaviours such as glaring, staring, body posturing and physical gesturing. As they escalate there may be instinctive use of insults and obscene language, screaming and shouting and explicit or implicit verbal threats. Should the responses continue unimpeded they will lead to physical threats and violent behaviour.

So there we have it, a set of signs and signals to help us identify the fight response and the reciprocal confrontational response provoked in others. What can we do to help if we recognise that these processes are in operation?

How we can help

There is a comprehensive set of strategies we could consider using if we recognise that the fight mechanism and reciprocal confrontational responses appear to be in operation.

These include learning techniques and skills to:

- Reduce stressors and prevent stress arising
- Teach coping and calming skills to service users (aid staff)
- Identify people who are stressed and use relaxation strategies to decrease their stress levels.
- Identify helpful ways of managing people and avoid interacting in ways that trigger the fight response
- Identify and use calming techniques to de-escalate the fight response and diffuse the reciprocal confrontational response.

Conclusion

In this article, I have attempted to shed light on the biological processes which can govern our behaviour and to provide some suggestions as to how we can work more effectively. It is my view that by working in these ways we can do a lot to prevent violent behaviours arising, even though they are controlled by innate, instinctive biological processes. In sharing this view with you, I hope you will consider this biological perspective alongside the other theories we use to illuminate and inform our practice.

References: Arnett, A. and Hewitt D. (1994) Safety First Community Care. March 94. pp 26-27
Lanciotti, L. and Hopkins A. (1995) Breaking the cycle Nursing Standard. Vol. 10. No. 11. pp-22-23.
Presland, J. L. (1989) Overcoming Difficult Behaviour: A guide and sourcebook for helping people with severe mental handicaps. Kidderminster: BIMH Publications
Lucille Bennett Consultant to BILD

We do have a follow up article which has graphs and diagrams which is more difficult to reproduce in the newsletter – if anyone would like a copy, please let me know – Sally Walburn

Sleeping Sheet

You may remember an article we published in the March 2002 edition of the Report about a sheet which Karen Jones had used successfully with her son Tiger. Since then a couple of you have borrowed the sheet, but as yet had not found a UK supplier. However, thanks to Tammy and Peter Munro, a supplier has contacted us with their information. The sheet size 1 (which fits a cot) costs £57.75 + postage and size 2 which will fit a single bed is £70.50 + postage. If you needed the next size to fit a larger child (age 6 and above) they will find out a price and get one for you. For more information contact www.spoilt.com or Barbara Brudenell Bruce 0207 2873033. They supply baby products so disability issues are new to them but they are very willing to help if they can.

2000 Club

The last draw of the 2000 club was at the last trustees meeting on 1st June 2003. Congratulations to the winner Mrs L Davies and the runner up Mrs G Scowcroft who received £40 and £30 respectively. If you would like to enter the draws for the next year please complete the enclosed form and return to ASSERT, the first draw will be at the next Trustees meeting on 14th September so get your entries in quickly! Remember the more entries the higher the prize money and the more we make for ASSERT!!

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Donations

Thank you, to everyone who has donated to ASSERT since the last Report back in July, your contributions no matter how small all make a difference, without you, there would be no ASSERT and we know what a lifeline we are at times. We also collect foil, cans and stamps; stamps must be trimmed as close to the perforations as possible (don't trim those or the stamps will be no use). Please send stamps to Jim and contact Bernie Silver concerning the details for our account with Alcan and recycling aluminium.

Many thanks to:

Robert Anderson
Barkingside Rotary Club
Nicki Barrass
Jim Brennan

In memory of Betsy Brown (Zoe Smith's nanna):

J Carroll
P J Hawkins
J Hedge
H F Hewins
E Mahoney
Pam Smith
D F Wernham
M Wernham

Paul Chick
Jayne Clarke
Customers of the Coach & Horses
LR & JA Davies
Mrs L Davies – 2000 Club Winnings
Matt Day
Mr & Mrs Doo – In memory of Ben's Gran
Jenny Greenland
In memory of Mrs Dorothy Hawkins Pam Roberston
Gilbert Knight
Gilbert Lister
Sheila Meadows
Myers
Karen Robertson
Mrs Smeeton
Alan Smith
Mr & Mrs Swallow – In memory of Ben's gran
Sally Symons & The 18th Edmonton Scout Group
Mrs H M Tait
Tunbridge Family – 2000 Club Winnings
All who sponsored Ken Walburn for the London Marathon

London Marathon

We are pleased to report that all five people who ran for ASSERT completed the Marathon. Many thanks to all who sponsored them.

Nicky Barrass whose niece Amelia Barrass has AS raised £1,700.00.

Ken Walburn raised just over £2,000 for ASSERT.

Jason Thornton (his nephew Brandan Jones has AS) wrote just after the Marathon:

"Had a great day as usual, I finished in 4:38 & raised over 2k. **Justin Drake** finished in 4:36 & raised nearly 2k. **Phil Neate** finished 4:49 & raised £700." Their money is being split between White Lodge (which provides support to families of people with Learning Disabilities) ASSERT should receive approximately £2,000. ASSERT thanks them all for their efforts as we have said before there are many months of training which means that they have all made a great commitment to ASSERT more than just 'on the day' – so very grateful thanks to them all.

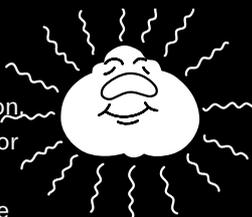
So you can see how well we did at this one event. Ken has pledged his fundraising to supporting carers to attend the conference next year. If you would like to raise funds for the conference, please let us know.



Smiling through the pain at 20 miles

Holidays

It would be very helpful if you have any articles, information or practical experience on holidays that you have loathed or enjoyed to share with our readers. It is always a challenge to find a holiday suited to all the members of the family. Please send your ideas and info to Sally Walburn who will be compiling a file on holidays which we can all use as a resource base for future reference.



Websites

www.multi-sensory-room.co.uk

Symbols – <http://trainland.tripod.com/pecs.htm>

Mosaic Angelman Syndrome

www.merck.com/pubs/mmanual/section21/chapter286/286d.htm

Quality Services for Disabled Children is the latest issue in the Research Works Series by the Social Policy Unit. The study, by Patricia Sloper and Wendy Mitchell explores the concept of quality services as defined by disabled or chronically ill children and their families. To read the study visit: www.york.ac.uk/inst/spru/pubs/rworks/sept2002-2.pdf

Contact a Family has been awarded a grant from the Lord Chancellors Department to research the impact on marriage and relationships of having a disabled child. The research will be carried out in the autumn and they are looking for people's views on what impact, if any, having a disabled child has had on your relationship. Please send your views to: jill@cafamily.org.uk

Medical Engineering Unit (MERU) is a charity set up to help disabled children. Their work involves designing and making any one-off piece of equipment for individual children with various disabilities. They aim to give children

a greater quality of life and help them achieve their full potential in any way they can. To find out more about the work of MERU visit: www.meru.org.uk

1 Voice – Communicating Together is an organisation that aims to bring together families with a non-verbal disabled child through a network of support and information. They have an email support group and a comprehensive website, visit: www.1voice.info

SNAP! Childcare (Special Needs Agency Partnership) offers a nationwide service providing nannies and carers for children and young adults who may have a range of special needs. For information about the services they offer including a newsletter, SNAP! News visit: www.snapchildcare.co.uk

A website listing **hotels, motels, guest houses, self catering, caravans and holiday centres** that are accessible to those with mobility difficulties can be found at: www.abletogo.com

The Sensory Trust promotes inclusive design in public outdoor spaces for the education and enjoyment of everyone. Visit their website to find out more about their work and to see examples of good practice. www.sensorytrust.org.uk

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How ASSERT Can Help You

ASSERT is currently receiving an average of two or three phone calls a day from parents and professionals, and more recently enquiries via the website. The telephone also accepts faxes. All calls are going through to Sally Walburn. If you would like to speak to a particular trustee, Sally will be happy to put you in contact, or arrange for that trustee to call you back. Sometimes Sally is around but the answer-phone cuts in before she can answer and often people cut the call as soon as they hear the machine. If the number is withheld, obviously we are unable to call you back. So, please do leave a message!! In your reply it would be appreciated if you would let us know a time when it is best to contact you and also make sure your details are clear and not rushed, sometimes it can be difficult to decipher the number and name.

The support line and website enquiry form, is there for us to respond with suggestions and support, we cannot fight your battles but we may be able to put you in touch with someone else in a similar position. We can offer a listening ear and try to point you in the direction of further assistance. As with all support and advice, please remember that ASSERT is no substitute for professional assistance and if there are queries around medication etc., we are happy to talk to you but you must always seek the advice of your health professional. ASSERT will not endorse or support any one course of action but make suggestions for you to decide for yourself.

Newbury Regional Meeting

The meeting was held on a very sunny Sunday on July 20th 2003. 11 families attended and we all appreciated the opportunity to get together and chat. The venue was entirely appropriate, being a Mencap Centre and had the facilities of a sensory room, garden, swings; roundabouts etc (especially for disabilities) and we had the obligatory bouncy castle, which everyone enjoyed. We also had sand and water play and as you can see from the picture Thomas Baker took enormous pleasure in actually sitting in the sand!

We were due to have Kate Horsler as a speaker (she is doing the current research into Smiling and Laughter Behaviour in Angelman Syndrome), however she was unable to attend at the last minute. This did not spoil the day everyone was happy to meet and chat, some for the first time. Bob Griffin brought along a trike for people to try and hopefully there were some orders for him.

Lynne and Mark Assinder attended the meeting, it was their first meeting of other families here in the UK, having just attended the ASF/IASO Conference in Washington – they were buzzing with information and had brought along the comprehensive book containing all the presentations from the conference. They have suggested that some of the sessions were really useful, particularly the one on Behaviour from Tim Freeman and if families would like to purchase tapes of the sessions, they are available on the ASF website



Thomas enjoying the sand pit

www.angelman.org. We will be bringing you a report from Lynne and Mark in the near future.

Many thanks to Nick and Sharon Bartholomew for organising the day and also to the Bartholomew family for all their help with tea/coffee/food/bouncy castle supervision etc, they were a great help.



Sally (left) receiving the cheque from Estelle

Barkingside Rotary Club

As mentioned in the October 2003 report Estelle Gudde (sister-in-law of Bernie and Jackie Silver), chose ASSERT as her Charity of the Year during her term as President of Barkingside Rotary Club. Sally Walburn collected a cheque for £1000 in June, which was raised over the year through raffles, garden parties and other events. Many thanks to the Rotary Club for all their support and for their kind donation to ASSERT and of course to Estelle for choosing our charity.

If you know of any organisation that would be interested in supporting ASSERT in a similar way, please contact the help line.

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