

Angelman Syndrome Support Education & Research Trust

Information Sheet No 8

"ASF Conference Report 1993"

Registered Charity No. 1021882

In August 1993 ASSERT were pleased to be able to sponsor Dr Jill Clayton-Smith for her trip to the Angelman Syndrome Foundation Conference in Florida. The following is her report of the conference.....

MEETING OF THE NORTH AMERICAN ANGELMAN SYNDROME
FOUNDATION

5-8 AUGUST 1993

DELTA ORLANDO RESORT HOTEL/CONFERENCE CENTRE- ORLANDO,
FLORIDA

GENERAL INFORMATION

This was the third time that the North American AS parents had been together. The first was in 1990 in Orlando when 40 families met at a meeting organised by the staff of the Department of Genetics at the University of Florida. The Angelman Research Group was then formed. In August 1991 90 families got together, again in Orlando. At this meeting parents decided to take over the management of the group and to elect a board of directors mostly drawn from AS parents but with some interested professionals - the Angelman Syndrome Foundation was born and became ASF Inc. in February 1993 with charitable status. Instrumental in the organisation of the parent group right from the beginning were Jill Hendrickson, who worked as a genetic counsellor at the University of Florida, and Elaine Whidden, also closely involved with parents and families known to the Department of Genetics. Jill Hendrickson now works full-time as a salaried member of staff of the ASF. She works from an office based in her apartment in Gainesville, Florida and is responsible for the day-to-day running of the ASF. As such, the job of organising the meeting fell mainly on her shoulders, but with much assistance from members of the board and staff of the University of Florida who have remained involved.

Orlando was chosen as a venue once again because the conference centre attached to the hotel had reasonable facilities, and also because families travelling from other states could take advantage of the sunshine and attractions around Orlando and make it into a family holiday. In recognition of this the hotel offered a concessional rate of \$68 per night for a family room (compared to the normal rate of \$100-200) and extended the rate for 7 days before and after the conference. The hotel itself was definitely "AS friendly" with several outdoor swimming pools!

Listening to several families commenting on the site, most were satisfied and the siblings especially enjoyed their time in Florida. However, some felt the temperature (100 degrees every day!) was a distinct disadvantage. Also, as with most family

conferences, even with concessionary hotel rates it was very expensive to bring the whole family. The registration fees (AS children were free) did not include accommodation or meals and, although the children were provided with a packed lunch, only drinks were provided mid-morning for adults. All other food, except for the barbecue meal on Saturday afternoon, had to be purchased on top in the rather expensive hotel cafeteria or restaurant. There were no tea/coffee making facilities in rooms, although there were some vending machines. This meant that most families really were treating it as part of their holiday. There is, however, no doubt that families enjoyed getting together, and there was a tremendous atmosphere of warmth and friendship throughout the conference - more so than I've noticed at UK meetings, although that is perhaps because Americans are on the whole less reserved and more willing to pour out their hearts to each other. As a result friendships were made easily and each and every parent knew that people cared. There were certainly some emotional farewells on the last day, I can tell you.

ATTENDEES

126 families with 97 AS children had registered. However, more turned up on the day and there were around 125 AS children and members of 150 families. Many were from new families, and I noticed the preponderance of young AS children between the ages of 2 and 4. However the overall range of ages of those with AS who attended was from 2-28 years. One family who were attending their second meeting, had not had contact with any other AS families since the previous conference two years ago - a reminder that the site of North America poses problems with communication for some families

In contrast to the last two conferences, medical professionals were not particularly in evidence (I was one of the few !), demonstrating the shift (quite rightly) from a "professional-led" group to a "parent-led" one.

Apart from the invited speakers who will be mentioned later on, the meeting was attended by Harry and Audrey Angelman (who had been invited over from England), an Australian couple from Canberra, the Bradley's, who have been involved with the Australian Support Group and are also AS parents, one English family, the Bicknells, from the South London area, and one family from Mexico who have identical twin girls aged 18 months who had just that week been diagnosed as having AS.

Funding for this conference had come from several sources. Local firms had given donations, and supermarkets had provided free drinks and groceries for the children's packed lunches. Seaworld had provided free admission for the children (Walt Disney World Inc. had refused!). One of the parents, Jim Webb, who is co-owner of Ambassador Travel, had donated 3% of all flight monies to the ASF when booking through Ambassador Travel.

THE CONFERENCE

Thursday 5th August 1993

5pm- 7pm

Registration, Snacks and Cash Bar

Families met together, often for the first time. Alongside the registration desk were stalls selling ASF T-shirts and baseball caps which disappeared like hot cake

Friday 6th August 1993

9am - 9.15am

Welcome by Hal Lippman, ASF President

Some people may remember Hal who was at the Leicester AS conference. He welcomed participants, Harry & Audrey Angelman and visitors from Australia. He mentioned that the conference was being recorded by a professional team and audio video cassettes of the conference would be available at a future date.

9.15am - 12pm

Communication - Professor Stephen Calculator

The whole of this time was taken up by Professor Stephen Calculator speaking about communication. Although some of his points were controversial, on the whole I think he talked a lot of sense. He did distribute a handout, which is rather confusing without explanation, but here is a summary of the points he made

- (1) The aim of communication is to improve quality of life by improving interactions with the family, peers, teachers etc. When trying to improve communication skills, only work on skills which will be useful in real life, don't manufacture artificial situations.
- (2) Many parents are trying to use technology to help communication, e.g. with talking picture boards. Only use this type of thing to augment communication, not to replace initial skills, e.g. gestures.
- (3) To communicate you need things to talk about i.e. different settings. For example, keeping a child in the same classroom with the same children for three years is not advantageous. He/she needs to be in as many different settings as possible.
- (4) Many parents thought that the important thing about communication for them was so the child could indicate needs and requests. In fact, for a child speaking to another child, the most important facet of communication is comment, e.g. "that's a nice toy", because it promotes communication from others. children shouldn't need paid communication partners like a one-to-one speech therapist, they should be able to promote communication from other children. They need friends. With a normal child, it's easy to establish a circle of friends but many AS children don't have enough friends. Aim to introduce them into many settings and make them well known within the local community, but try to get your child to interact with other children, not adults.

There then followed a couple of videos showing children with cerebral palsy/AS, interacting with other children in a normal classroom. In one setting, an aide helped by drawing symbols relevant to the conversation and then the child used these (this wasn't an AS child). One teacher commented "We can't give her one-hour blocks of time working on communication, e.g. on the computer. She would get this in a special school but she wouldn't have anyone to communicate with."

One communication method I hadn't seen before was a symbol board for use with an eye-gaze system. You hold this up in front of the child who directs their eye gaze to the necessary symbol. You have different symbol boards for different settings.

- (5) Other people need to recognise when a child wants to communicate. If you ignore the subtle cues and pass over them then, like any child, they'll give up trying. We need to teach others to use their means of communication too. We need to get the class involved in cutting out symbols, signing etc. He asked the parents who signed to stand up and tested them on some signs. Very few of the parents could actually communicate with him; they had all modified their signs slightly until they were useless. He encouraged people to get their children to do the correct sign, not a modified version.

Communication Systems

There was a video demonstrating use of the "WOLF" communication system. The child touches a picture and a robotic voice says "I want a cookie" etc. It was useful in one child but the male robotic voice was awful. Is this the method of choice? Several other communications of this type were also on display.

Where do you put symbols?

You have to think about this. It is no use putting a cookie symbol on the cupboard door, because by the time the child is there it's easier just to open the door than to use the symbol. One parent mentioned that they had the symbols for hot and cold above the bath and this had been a good idea.

The Role of Technology in Communication

Q :- Is there a new piece of technology which will unlock my child's door?

A:- No

Don't buy a device from anyone if there is no ongoing commitment on how to use it, and follow-up. Also, you can't prescribe a system if you don't know the setting in which it is being used. Professor Calculator 'shadows' a child for a day before he comments on what sort of communication system would be best.

He also mentioned something called the Coach Process. In this process you discuss with the parents their goals and objectives for the child. You end up with 5 goals and work on these, but you make them useful goals, e.g.:

- For the goal "John will give an object on request", change it to:
- "optimise John's participation in show and tell time where he will need to give an object on request".
- Don't have silly goals like "John will keep his head up for 20 seconds".
- The family at home need to know what the child is working on at school and vice versa. He encouraged the use of videotape.
- He emphasised that you must try to use real situations rather than simulated ones, e.g. when ordering a meal at McDonald's take the child up to the counter to order rather than just practising this in school using symbols. It might seem hard work for the parents at first but it pays off.

Facilitative Communication

This has had a lot of press recently. The facilitator holds the child's arm for support and the child touches letters on a letterboard to spell out words. Using this system, some handicapped individuals have been able to communicate whole sentences, even write back, despite never being taught formally to read and write.

Several of the AS children at the conference were using facilitative communication and some parents were absolutely convinced that it worked whereas others were very sceptical.

Professor Calculator has spent some time trying to validate this technique, e.g. by blindfolding the facilitator and by asking questions which only the child could possibly know the answer to. He has experience with two AS patients & His study suggested that the technique did not work and that the facilitator was spelling out the words, although people had suggested that interfering with the facilitator/patient relationship had made facilitative communication impossible. He did report, however, that the children doing facilitative communication had developed an improved concentration span as a result.

Summary of Communication Presentation and Workshop

1. Integrate your child as much as possible into everyday settings with normal children
2. Make communication goals functional, i.e. something they need to do to improve their life and not artificial
3. Use a combination of different methods, with one augmenting the other.
4. Facilitative communication is not yet validated
5. Involve family and friends in the chosen communication methods, even if it is difficult at first.

1pm- 2pm

Seizure Disorders and Treatments - Terry Hutchinson M.D.

This talk was by Terry Hutchinson, a paediatric neurologist from Fresno, California. He was a very good speaker who knew what he was talking about. The talk began with some simple information about epilepsy in general and he showed a film from the Family Video Library of the Epilepsy Foundation of America about people having different types of seizure.

A seizure is an electrical storm in the brain leading to :-

- a twitch
- an absence
- loss of consciousness
- a drop to floor
- a generalised convulsion

He made very clear the distinction between a seizure and a movement disorder. A movement disorder usually indicates a fault in the part of the nervous system called the extra-pyramidal nervous system. This is the system which makes movements smooth. Examples of movement disorders are:

- truncal ataxia (staggering gait)
- athetosis (writhing)
- chorea (jerky, dancing movements)
- tremor
- myoclonus (a single jerk)

To diagnose whether an AS patient is having a seizure or if it's all part of the movement disorder, you need to listen to the history carefully. You can diagnose seizures from the AS EEG but you have to be an expert to do this in Dr Hutchison's eyes.

Most events brought on by a stimulus are not seizures. If you can cause the event to happen it is probably not a seizure. A seizure jumps on you out of the blue. However, fever and illness can predispose to seizures. Allergies do not cause seizures.

One parent said her child had been diagnosed as having Lennox-Gastaut Syndrome. He said this was a "wastebasket diagnosis" and not a specific syndrome. Any individual with drop attacks, myoclonic seizures and mental retardation can be labelled as having Lennox-Gastaut Syndrome but they won't necessarily have the same underlying disorder.

Do seizures cause brain damage?

For the most part, the myoclonic seizures that AS children have do not cause brain damage, although a lot of them will make the child "fuzzy-headed". Typically it is only the tonic/clonic seizures which cause brain damage, and then they usually have to last more than an hour.

Babies with AS do have jerky movements but so do all babies because the extra-pyramidal nervous system is not well developed. However, as time goes on the movement disorder in the AS patients becomes more recognisable.

In AS lack of movement rather than movement may indicate seizure activity. Absence seizures are very common, as are myoclonic jerks where the head may drop down momentarily and then recover.

In minor motor status you do not recover from one seizure before going into the next. Minor motor status doesn't usually cause brain damage.

Seizure Management (Workshop and Discussion)

The goals of seizure management are:-

- (1) Control of seizures
- (2) Minimal side effects

The overwhelming message was :-

- (1) Treat seizures
- (2) Don't treat movement disorders

Drugs recommended :-

Sodium valproate, Clonazepam (as long as it doesn't increase drooling) and also drugs similar to clonazepam, e.g. clobazam, nitrazepam are useful.

Phenobarbitone does not work. It causes sedation, worsens hyperactivity and decreases IQ.

If necessary, more than one drug can be used for maximum effect

Two new drugs were also mentioned

Felbamate (similar to meprobamate) has just been licensed for use in US and results are encouraging. Causes loss of appetite.

Imipramine, which is actually used as an antidepressant, had been used in some cases with good effect. It is especially good when the child is hyperactive.

Sedatives. e.g. phenergan etc. :-

He was not in favour of sedatives at all. You need to keep the brain alert. When you sedate someone you go from being alert to delirium, sedation and finally anaesthesia. Some people, especially with AS, stop at the delirium stage and get worse.

Finally a couple of warnings :-

Carnitine is a type of vitamin in the fatty acid cycle. He mentioned that patients under the age of 2 on valproic acid are given carnitine to prevent against toxicity.

ACTH, although it can be used short-term as an anti-convulsant (especially for drop attacks and infantile spasms), has overwhelming side effects if used long-term. He urged that use should be restricted to one month or less.

2pm - 2.45pm

Community Living for individuals with AS - A Model

Betty and Jim Webb have twins with AS, Stephen and Gregory, who are aged 11 years. They also have 5 other children. Jim is the twins' stepfather. They were concerned about long-term care for the twins in the future.

Jim runs several businesses, including one where he designs rather sophisticated log houses and also makes up log house kits for export

Betty and Jim went to their State Family Care Program to ask if they could have funds to build a purpose-built log house for 4 handicapped individuals and a carer, as the cost of running this and building the house would be less than that of caring for 4 individuals in an intermediate care facility.

The state agreed and the house has been built, taking the boys into account It is on a single level, with handrails all around the house. There are special windows with venetian blinds between the layers of double glazing. In the bathroom the shower/bath controls are on a panel on the back side of the wall around the bath. A wheelchair can be pushed under the sink etc. There is a Dutch door on the bedroom. The carer is state-funded

This is one family's method of ensuring that their AS children grow up in a family house. They were lucky as they had the finances to do this anyway, but the same State Care Program has now ordered 10 more log houses for further handicapped individuals.

3pm- 4.20pm

Peaceful, effective parenting

Bob Hoekstra and Julie Harrington who gave this presentation are a husband and wife team who have 7 children of their own (from previous marriages). They run a course in the State of Florida which consists of 5 x 3 hour sessions to improve parenting techniques. This talk covered some of the issues in their course. They pointed out that although their techniques do not apply specifically to AS children, they can be adapted for AS children and can certainly be used where the siblings are concerned.

The first three minutes were taken up by everyone thinking about what they didn't like about their parenting and in the next 3 minutes listing what they did like. It was considerably easier to point out the faults and they made the point that it is human nature to think about our faults and not about what we do well. However, parenting is stressful and you need to take care of yourself first, before taking care of your

children. They recommended that parents should actually think about their own needs more and this would make them better parents. Parenting styles were discussed They emphasised that you learn about parenting from your own parents and they used role play to demonstrate different parenting styles and discuss how they could be improved.

Why do children misbehave? They maintained that there are three reasons

- (1) They need to belong
- (2) They need to feel loved
- (3) They need to feel powerful

If children cannot get what they want they:

- (1) Seek attention
- (2) Struggle for power
- (3) Avoid things
- (4) Seek revenge

You don't treat each of these misbehaviours in the same way, e.g.:-

Attention Seeking.

If you are busy with me you must love me. Children will misbehave to get attention, e.g. hair pulling. They recommended overcoming this by making the child feel loved, i.e. touching them but trying to avoid eye contact or verbal communication and firmly stopping the behaviour.

Power Struggle.

You know you are in one of these when you feel powerless, They recommended trying to side-step the power struggle initially, because it's boring playing tug of-war with no-one on the other end. Then make a bargain with the child. Example

Parent	"Susan, tidy up your bedroom"
Susan	"No I won't and you can't make me"
Parent	"OK. When would you be willing to tidy up your room?"
Susan	"Never"
Parent	"That's not quite soon enough, when will you do it?"
Susan	"In ten minutes"
Parent	"OK, and what shall we do if you forget?"

In other words, you need to make an agreement with your child. Somehow, this seemed reasonable enough in theory but I suspect it would be difficult to

put into practice and would have to be adapted considerably for an AS child. The way to avoid power struggles is to give the child some power, e.g. by giving choices. One parent always had problems with bad behaviour in the grocery store but this improved when she gave the children their own shopping list so they could go and get things off the shelves themselves (goodness knows what she found in the basket at the checkout!).

All in all, this was a lively presentation with some interesting points but these points would be difficult to put into practice without some continued intervention, and of course each child's situation would be different.

4.20pm - 5pm

A Father's perspective as part of the support team

The parent who gave this talk, Hogan Hilling, has founded a group in his area for fathers who care for their children. Mr Hilling has three children, all boys, and the middle one, aged 5 years, has AS. He elected to take time off work to be the carer of the boys whilst his wife went back to work full-time and he described his experiences, making the following points

- (1) Men don't usually have much experience of nurturing normal children, let alone those with special needs.
- (2) They tend to be practical when dealing with emotions but find it difficult to cry. He described how much he cried about his son
- (3) They find it difficult sometimes to set their egos aside and ask for help.
- (4) They may not be as communicative with each other as women, e.g. they don't hold conversations in the "men's room".
- (5) They feel uncomfortable holding a nappy changing bag and there's not usually a changing mat in the men's room.

Mr Hilling said that men often find it more difficult to incorporate children into their daily activities, e.g. sawing and hammering, whereas women find this easier, e.g. setting the table. He encouraged fathers to participate more with their children in this way. He advocated that

- (a) parenting skills should be taught to both boys and girls at school
- (b) work places should be encouraged to allow fathers to do more parenting
- (c) the mothers should stop criticising and compliment the father's efforts, e.g. at changing nappies and choosing clothes. You can get your husband more involved by complimenting him on his efforts rather than destroying his self-confidence.

Mr Hilling certainly had a lot of empathy from other fathers who also aired their views, and the 'fathers only' workshop was very popular. Maybe this is something which could be arranged in the UK.

6pm 8pm

Social Event

A barbecue by the side of the pool in the evening sunshine with a steel band for entertainment. This was enjoyed by all. I sat with the Bicknell family, the only British family at the conference, who have a son, Jason, with AS. The children enjoyed swimming and dancing to the band

Saturday 7th August 1993

For the morning there was a choice of workshops. The following reports cover those I attended :-

Parenting the older AS child - Presented by - Kathy Hayduke (mother of Stacey, 28)

This never really got to grips with the issues of older children, although Mrs Hayduke presented her own story of her daughter who has AS and was only recently given a diagnosis. She also has another daughter with cerebral palsy. Parents enjoyed listening to Mrs Hayduke's personal experiences.

The main point of her talk was to encourage integration and to help the child to be included. She therefore urged parents to dress their children like their peers and to have their hair cut in a fashionable style etc. and to try to be involved in other groups with normal children of the same age so that they actually have friends. She described how Stacey's bedroom had been changed as she got older so that Peter Rabbit posters etc. had been replaced by Heavy Metal! It helped her child to be included and live a more normal life. There was no time for discussion in this workshop, which was a pity.

The Early Intervention experience

The Early Intervention Program is a State and Federal funded programme affiliated with Louisiana State University. A team of four 'interventionists' described their work with an AS child. She underwent a centre-based programme which meant that she was in a nursery where all the children had special needs and all were normal for 3 hours/day for 3 days/week. The team working with the children included the class teacher, speech therapist and occupational therapist. Also in the management team were the parents, a developmental paediatrician and a student 'interventionist'. First of all, the children are evaluated, e.g. their age of functioning is assessed. Next, the priorities or goals are discussed with the parents - i.e. What would you like to do?

The four main priorities appear to be walking, talking, self-feeding and improving attention span.

They described the routine for each day which involved free play, circle activity, small group activity, snack time, potty time, closing circle time. Following a strict routine helps children to anticipate what's coming so that they can participate more and be more communicative. They emphasised that you must always be verbal with AS children, whether they appear to communicate with you or not. You make a goal and work towards it. It takes a different length of time for each child. Parents continue the work at home.

One particularly useful tip was the use of a stick when teaching a child to walk. The AS child in question would walk quite happily aided, but was unwilling to step out on her own. They walked her holding on to a short length of stick held horizontally and eventually let go of the stick so that she was walking by herself holding the stick. Problems were experienced when the child would not do things at home that she did quite happily at school. All children learn who they can manipulate and they urged parents to be consistent.

Parents asked questions about their specific goals for their child. One parent was particularly keen for her child to brush her teeth properly. The approach of the team was to incorporate tooth-brushing into a rigid daily routine.

This university team trains other therapists. They emphasised that other universities may have similar teams and that people should enquire in their individual area whether this type of team therapy was available. It achieved good results but it seems to depend a lot, too, on the motivation and participation of the parents. It is not dissimilar to training programmes at some schools in the UK, although the child got more one-to-one attention. Therapy was begun with this child at 19 months.

Workshop - Behaviour Modification

There were two workshops on behaviour modification by Tim Freeman, a child psychologist with a special interest in behaviour therapy. Both workshops were very relevant as Tim has worked for over two years with an AS child. The first workshop covered the principles of basic behaviour modification techniques.

Basically it works like this:

- (1) choose which behaviour you want to modify, only one at a time.
- (2) Follow the ABC rule:
 - A antecedent. What happens before it? Can it be altered?
 - B behaviour.
 - C consequence. What happens after it?

You need to look at why the behaviour is happening. Can you avoid it? What happens after it? Does the bad behaviour get reinforced, e.g. by people laughing?

To reward good behaviour you can use "**reinforcers**", e.g. grapes, raisins. To acknowledge bad behaviour you can use punishment, e.g. "**time out**" (not usually physical). Reinforcers need to be phased out with time so the child can do good behaviour without reinforcement.

The golden rule is - **Be consistent**.

Talk as little as possible - it can reinforce bad behaviour.

In the more advanced behaviour modification workshop Tim actually worked with Katie in front of the audience. This was successful to a degree until Katie got fed up. At the present time he is working on communication skills.

Tim: What do you want Katie? Show me.

Katie had to show what she wanted by pointing to the object.

Tim: Show me the card.

Katie had to choose the correct card, even after they had been mixed up. I was convinced that she was recognising the words on the cards. Tim reckons that she can recognise 5-10 different words in this way She is the first AS child I know who recognises written words in this way, even though she has no speech.

If Katie went "off task", Tim sat her back on the seat firmly and began again. He rewarded good behaviour, i.e. successful attempts with small cookies

He reinforced the fact that behavioural techniques are useful in AS. He advised people to contact psychologists/ psychiatrists in their area but to ask specifically for someone with a special interest in behaviour therapy.

Workshop - "Non-deletion" AS

Chaired by Joseph Wagstaff, a molecular geneticist from Boston. I didn't get to this but have a report from another parent who has an AS child without a deletion.

Basically, he went over the genetics of AS. Whilst most patients do have deletions, there are a group of approximately 15-18% who do not. These individuals do have AS, and the clinical diagnosis is the most important. Don't throw out this diagnosis if you don't find the deletion.

A small number will have uniparental disomy for Chromosome 15. We know of three such individuals in the UK, five in the US, one in Australia and two in Germany. If there is no deletion you need to exclude uniparental disomy.

The remainder of the non-deletion AS patients will have a tiny change or mutation on Chromosome 15 instead of a deletion. At the present time no-one can detect these mutations but progress is being made. The Boston group are probably furthest ahead and, in time, mutations will be detectable, but until then there is nothing new.

Dr Wagstaff mentioned the **FISH** technique of looking at chromosomes which, surprisingly, isn't being used that often in the US. All deletions detectable by FISH can also be detected by DNA tests but not necessarily by routine chromosome analysis, but FISH is quicker as an initial screen for deletions.

In the other 'genetics' workshops on basic genetics and uniparental disomy, the genetics of As were discussed but there was nothing new to add. A great deal of time in the sessions was taken up by individual parents asking questions specific to their child and this emphasises that the genetic situation is different in each family and that all families are advised to discuss their particular situation with a geneticist.

1.30pm - 2.30pm

Sibling Panel Presentation

A panel of siblings of AS children were asked questions about themselves. In the morning they had been to a session called "**Sibshop**", run by Joanne Scaturro and Mary-Ann Tucker. They run Sibshops on a regular basis for siblings of "exceptional children". The siblings were aged from 7-15 years. These were some of the questions

- (1) What were some of your questions about your brother/sister?
 - What caused it?
 - Can you cure it?
 - Will my brother die?
 - Will she ever be able to talk?
 - How do you know if a baby has AS?
 - If I have children will they have AS ?

- (2) What are the good and bad things about having a brother/sister with AS?
 - GOOD
 - Getting on rides at Disney without queuing!
 - They don't feel pain, e.g. when parents divorce.
 - Don't get upset when they can't do things.
 - Always there to hug you.

 - BAD
 - Can't communicate.
 - Embarrassing going out sometimes
 - Putting up with hair pulling (biting).

- (3) What has been helpful to you ?
 - Having parents who never denied me any information.
 - Reading "Facts about AS" (note - copies of this are available from ASSERT on request).

- (4) What if your brother/sister is getting more attention?
 - My parents treat us the same. If she's getting more attention I tell my parents.

- My brothers live in a home in the week-time. It's only fair they get more attention at weekends.
- My sister has a lot of patience. We don't always know straight away what she wants and she often has to wait.
- My sister has a good sense of humour. She laughs at my jokes.

(5) If you could change anything, what would you do for your brother/ sister?

- Provide equipment.
- Do a lot more research into AS.
- Build care facilities
- Find a cure for AS.

There were more questions, too, from members of the audience. The organisers pointed out that Sibshops of this nature could be helpful to siblings. The group of siblings on the panel were very caring and well adjusted. It may be that the siblings who didn't attend the meeting had more problems. It was interesting that in the final analysis when they were asked how their parents might help them cope with their siblings they all wanted to have time with their parents so that they could feel special too, but none of them were interested in money or material things to "make up" for having an AS sibling with special needs.

One sister had a special friend called a "big sister" who took her out and this had helped her tremendously. The message was that siblings need to feel special too, and as long as this happens they had very good relationships with their AS siblings.

3pm - 5pm

Business meeting of the AS Foundation

This took the form of a formal business meeting with Hal Lippman in the chair. He introduced members of the board and gave the following information

There are now 1300 people on the ASF mailing list. The purposes of the ASF are

**EDUCATION
SUPPORT
RESEARCH
FUNDRAISING**

At the moment, Jill Hendrickson is employed full-time as co-ordinator but will need to increase staff. The ASF is organised in regions, with a person responsible for each region. There are now 12 regions.

The ASF had an income of \$87,893 in 1992/93 and expenditure of \$44,000.

Jill Hendrickson has approximately 20 telephone calls per day. One day she had 49 ! Each new parent receives a packet containing the newsletter and "Facts about AS". Jill and others have recently written a grant application to "Freddy Mac" for funds. Now the ASF has charitable status, the name can go on the Federal list to receive donations from Federal employees.

The constitution of the ASF states that the majority of board members must be parents, although it also includes medics, scientists and psychologists.

Plans for 1993/4 :-

- New promotional materials
- Communication video (\$8,000)
- Revising "Facts about AS"
- Fundraising.

Fundraising Efforts :-

- Golf tournament (\$15,000)
- Bikeathon
- Rodeo (11 Oct 93, North Carolina)
- Celebrity Golf
- Bowlathon (raised \$5,000)
- Ambassador Travel gives 3% of all bookings to the ASF Softball tournament.

All in all, the ASF appears very well organised and has some very motivated members.

Just prior to the meeting, Harry and Audrey Angelman were presented with a large "banner" which the AS children had painted with hand and foot prints to say thank you. Apparently, Dr Angelman had also mentioned that he would like to go on the Oprah Winfrey show and so someone was trying to "fix it for him".

There was also a slide show of AS pictures to music (Rod Stewart's "Have I told you lately that I love you?"). This was actually very emotive and there was hardly a dry eye left

There was a "silent auction" held in the lobby. Several items, e.g. signed American footballs, had been donated. Everyone was encouraged to write an offer on a piece of paper and hand it in. Each item went to the highest bidder.

Sunday 8th August 1993

The meeting ended on Sunday, 8 August with more workshops. In fact, many people were leaving that morning because the initial programme had been different and people had booked their flights accordingly.

As with other ASF meetings in the USA, you felt like you were leaving old friends when you'd really only known people for three or four days. Many friendships were forged over this period of time and there was a great sense of 'togetherness'. I am sure many people went home feeling much better just knowing that they weren't on their own.

I found the emotion hard to cope with at times, and it must be even more difficult for parents, but there is no doubt that the experience of attending a meeting such as this was of great benefit to many people, and worth all the hard work it took to organise.

Jill Clayton-Smith
August 1993

Thank you very much indeed Jill for covering the conference so comprehensively on our behalf.

Please note that we also have a number of leaflets and handouts on various topics covered during the conference including those sessions that Jill was not able to cover. Please get in touch if you wish to know more, or if you want a copy of the "Facts about Angelman Syndrome" document referred to in Jill's report

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