



# ASSERT

## REPORT

## Message from the trustees

Welcome to this third edition of the Report this year. Many thanks to all of you who have commented on how much you enjoy reading the newsletter; it is nice to have some praise every now and again!

We are pleased to report on the first of our regional meetings this year held in Basildon, Essex. We are looking forward as we write this, to the meetings on 7th July in Tidworth, Wilts, and finally 18th August Ayr, Ayrshire. However, if you could organise a meeting later in the year in your area, particularly if you are in the north of England (we feel you miss out up there but we can't put on a meeting unless you help us!), please let us know. We will not be holding any meetings next year as it will be the Conference in September, so if you are interested and can't wait till next September, why not give Dick Barton a call who will be pleased to help you.

Many thanks to all of you who spotted the deliberate (?) mistake with the ASSERT website address. The correct address is [www.assert.dial.pipex.co.uk](http://www.assert.dial.pipex.co.uk). We have some more information to be uploaded on our website and would appreciate any help from any of you I.T. buffs out there. John Outterson and Gerry Egan have done a marvellous job but could do with some extra support. Whilst you are surfing have a look at the recently updated IASO website [www.international.angelmansyndrome.org](http://www.international.angelmansyndrome.org).

Have any of you thought of becoming an ASSERT trustee? Our current Board have served many, many years between them, some have been with ASSERT from the very beginning in 1992. We need some 'fresh' blood to inspire us all and build some expertise for the future – we won't be around forever. You don't need experience or any qualifications, we are not special in any way, but becoming a trustee is a way of directly supporting other families just like you and sharing in the running of the organisation. We meet every quarter for a meeting but attendance at only one meeting a year is all that is required. We cover expenses and you are not expected to take on any huge tasks – the more of us there are, the more we can do. Trustees are very important members of the organisation because without us ASSERT would cease to exist. If you have any questions and are interested in joining with us, please contact Sally Walburn 01268 415940. (*On previous occasions we have had no response, it would be great if this time all you hesitant ones get in touch – we look forward to hearing from you!!!*)

That's all for now folks (as they say in the cartoons), hope you have a good read and we look forward to seeing some of you at the upcoming meetings, if not, next year at the conference.

## Basildon May 2001

The first meeting of the year was held on a very pleasant day in May at Elmbrook School in Basildon, Essex. 19 families attended. The school was a wonderful venue as we had use of the Hydrotherapy pool – very popular – and some (Tom Baker) were in the pool all afternoon along with Ken Walburn who was like a prune at 4.00 p.m. when it was time to get out!! There was an equally popular soft playroom, sensory room, sensory garden, outdoor adventure play area and playground all available for us to use. We had a buffet lunch and a time for families to chat. This was followed by a talk from Finn Emmerson (Speech and Language Therapist) on Communication. (After this article we have reproduced copies of the overheads she used in her presentation). Bob Griffin gave us an opportunity to see and find out about 'Tom's Trike', followed by a chance to 'try it out' in the Playground afterwards.

There was great fun and mayhem, and it was wonderful as some parents expressed that they had never thought their child would ride a bike!

It was a very well attended meeting and we believe that everyone who came gained something from it. Thanks to Jim, Dick, Ken, Dorothea, Finn Emmerson and Jane Clarke who were a great help and support to me on the day. Thanks also go to the extra carers we drafted in who came from Elmbrook and Ravensbourne schools, they were very helpful and allowed the families to have some quiet time in the hall for the talks. Mick O'Toole the caretaker from Elmbrook was a 'diamond' and did everything he could to make the day go as smoothly as possible so our thanks go to him too.

All in all the day went really well, thanks to those who gave us donations and bought T-shirts, this all helps with the work of ASSERT. We hope you all enjoyed the day and I know that this has given you all a taster for the Conference in 2002!!

**Sally Walburn**

# The Educational Progress of children with Angelman Syndrome in a School Environment

The school in which I teach has seven pupils with Angelman Syndrome, a high percentage when the number on roll is 92, so I made educational progress the topic of my long study for the Advanced Diploma in Educational Studies.

The aims of the study were:

- To explore the educational progress made by pupils with AS during three terms
- To compare the progress made by pupils of different ages
- To establish whether epilepsy and frequency of seizures have an effect on educational progress

The assessments took place over three terms and were conducted in collaboration with Finn Emmerson, speech and language therapist. The assessments were videoed so that the smallest response could be noted.

Six of the seven pupils were the subjects of the study. All the subjects have a diagnosis of deletion on chromosome 15.

A target group of these pupils was selected on the basis of age and were assessed once a term for three terms. The other three were a non-target group who were assessed at the beginning and end of the research and were a control group.

The assessment was based on child development skills, which are part of the pupils' individual learning objectives used in class. The skills assessed were communication, play and cognition (understanding). Attention level was also recorded.

When the videotapes of the first assessment of the target group were looked at, it was noticed that the imitation level of all three pupils was low, or non-existent, in comparison with other skills. The same pattern was evident in the non-target group.

It had not been the intention to include imitation in the assessment but because of the initial observations and because imitation is a precursor to communication, it was decided to include imitation in subsequent assessments.

As a result of the findings and to see whether the scores for imitation would improve if a greater emphasis were placed upon it, class teachers of the subjects in the target group were asked to focus on imitation specifically wherever possible.

The second assessment of the target group showed that all the subjects improved on their imitation scores. However, the scores for the third assessment were not so encouraging. Two subjects stayed at the same level as before and one subject demonstrated no imitation at all. It is possible that the six weeks summer break may have had a bearing on this.

The conclusions drawn from the study were:

- Every subject made progress in at least two areas, thus suggesting the effect of maturation has on development across all ages
- The difference in performance between subjects of different ages was not as evident as expected
- The evidence based on information from parents suggested that, in this study, epilepsy has little or no effect on progress although no firm conclusions could be drawn because of incomplete data and small number of subjects.

General observations within the school indicate that most individuals show a noticeable rate of improvement at a time of early puberty. Prior to this, progress would appear to be difficult to achieve.

## The Issue of Imitation

The research for this study began in January 2000. At the IASO Conference in Finland in July 2000, Angela Reason and Carmen Brun gave separate presentations of studies they had undertaken in which they too had noticed the lack of imitation skills in children with Angelman Syndrome. Three independently conducted studies with different aims have found the same lack of imitative skills. This poses various questions: Are the children with AS who have a genetic diagnosis of a deletion born with poor imitative skills? Do they have them to begin with and then lose them? Would intensive work on imitation at an early age improve communication skills?

From conversations with parents, it appears that their children are able to perform tasks at home, which could have easily been learnt through imitating, such as switching on the television. Does that mean that children with AS will imitate if the motivation is strong enough?

**Jane Clarke**

*If you would like a copy of Jane's study or would like more information please telephone ASSERT and we will contact her on your behalf.*

*We think this study does indicate the need for more longitudinal research into our children/young people with Angelman Syndrome, particularly with regard to whether therapies are appropriate and which 'seems' to work. If you know of anyone who is interested in carrying out any studies into Angelman Syndrome, then please let us know.*

## Fire fighters help Melissa

After attending the ASSERT National Conference in Loughborough university 2000, we saw how well Ben Robertson was doing with his adaptive communication aid. Pam (his Mum) had worked very hard with him, so we decided to try it with our daughter Melissa who is 23. Because Melissa is an adult she does not have the same rights as children, so we had to fundraise for the Cambridge Adaptive Communication Aid. Her keyworkers

at Ravenswood village where she lives, and the firemen at Camberley Firestation helped to raise the £700 to purchase it by having a fund-raising car wash. (Fiona Medley, one of the keyworkers is married to David, a fireman at the station and hence the connection.) This will now give Melissa a 'voice'.

**Jackie Silver**

## The Son-Rise Programme

In 1998 I attended a start up course for a home based therapy programme called Son-Rise. Abbie had no diagnosis at that time and I was looking for a way to help her when I came across a video of a BBC QED documentary about an autistic boy who had travelled to America to The Options Institute with his parents to receive training on the Son-Rise programme. I managed to find some further information on the Internet and found the start up course. I attended the weeklong course in Enfield along with 200 other parents all looking for some help. I went with the intention of just listening to the ideas on offer and had no intention at that time to start the programme at home.

The first thing that struck me was that the previous 18 months with Abbie had been one visit after another to specialists and hospitals and all of the feedback and information had been totally negative. I felt as if Abbie was a bit of a lost cause and was fed up with being told she didn't have much of a future. By the end of the first day of the course I had been filled with positive thoughts and information. The staff were so positive and enthusiastic that it was infectious and the ideas they were giving us were straightforward and exciting. Some of the ideas such as the suggestion that we join in Abbie unusual behaviours rather than try and stop them seemed strange but I was prepared to give anything a go. During the week I was taught how I could encourage meaningful eye contact, develop Abbie's ability to communicate with speech, sounds and gestures, respond effectively to Abbie's challenging behaviours amongst many other things. The most powerful thing I learnt that week was that my attitude to Abbie was so important. To be non-judgemental and loving sounds easy but I knew that I judged Abbie all the time. Why does she flap, lick the tv, suck my head etc I was unhappy about all of those behaviours but Bryn and the other teachers helped me to understand Abbie more.

Three years down the line I have a special playroom for Abbie and 10 volunteers who all come and play with Abbie on a one to one basis for between 4 and 6 hours each day. She has changed and so have we. Life is much calmer, happier and I can honestly say we are all at peace with Angelman Syndrome, it is no longer a terrible thing for Abbie to have, she is very happy and loving her time in the playroom and she is making great progress.

It doesn't matter how much time you spend with your child using the Son-Rise principles, it could be half an hour or two hours, whatever time you can give will make a difference.

The Son-Rise start up is in Enfield next year on January 13th to 17th 2002. If you would like any further information please give me a call, 020 8777 8659

**Tina Lockett**

## Thank You ASSERT!!

*We don't often 'blow our own trumpet', but it is encouraging when we receive positive feedback from families who contact the support line, the following was written by a family and we thank them for their appreciation.*

I am just writing to thank you so much for the support you gave me and my family when we were newly diagnosed. I still find it very hard to accept and to come to terms with it, but we do seem to be getting on with our lives....I have met a friend who also has a son with Angelman's who lives quite near. We meet every couple of weeks. We have got quite close. This helps me so much to talk about our children. Once again thanks for your help and support I will always be so grateful.

Please note that the deadline for the next edition of the **ASSERT Report** is **30 September 2001**.



### **NHS Direct**

New telephone number – 0845 46 47  
This will put you through to your local call centre. In Wales there is a bi-lingual service if you wish.

### **Contact a Family – Helpline**

0808 808 3555 Freephone for parents and families (10.00 a.m. – 4.00 p.m. Mon – Fri)  
E-mail: [helpline@cafamily.org.uk](mailto:helpline@cafamily.org.uk)

## Carers websites

[www.carers.uk.demon.co.uk](http://www.carers.uk.demon.co.uk)  
[www.cafamily.org.uk](http://www.cafamily.org.uk)  
[www.crossroads.org.uk](http://www.crossroads.org.uk)  
[www.carers.org](http://www.carers.org)  
[www.carers.gov.uk](http://www.carers.gov.uk)  
[www.sharedcarenetwork.co.uk](http://www.sharedcarenetwork.co.uk)

### **Covers for Orange/ Blue Badges**

[www.badgeguard.com](http://www.badgeguard.com)

### **Holiday Information**

[www.holidaycare.org.uk](http://www.holidaycare.org.uk)

### **Organisations**

[www.kids-online.org.uk](http://www.kids-online.org.uk)

### **New Address/ telephone**

Occasionally ASSERT gets Reports returned where families have moved and have not passed on their address. Please, in your time of up heavle, remember to let us know where you are so we can send you the latest information and updates from ASSERT, we can't do this if we don't know where you are!! Also if you have changed telephone numbers by going on to cable or back to BT please let us know.

*The following are copies of the overheads from Finn's presentation at the Basildon Meeting. If you have any queries or need help with any communication issue, please let us know and we can contact Finn on your behalf.*

### **What is Communication?**

Communication Occurs when a meaningful act relays a message.

What is Speech and Language?

#### Verbal Comprehension

How much of the native spoken language is understood? Can be assessed using any supporting mode of communication. Ascertained by "key" words i.e. the important words of a sentence.

E.g.: I understand

I don't understand

I don't understand much

I don't understand much when I first wake up

The number of "key" words indicates the "word level".

Children develop verbal comprehension in the following order:

nouns

verbs

noun + verb/verb + noun/attribute + noun/preposition + noun

noun + verb + noun/noun + preposition + noun/verb

+ adjective + noun

Individual linguistic concepts are understood at different stages e.g.

big/little versus other adjectives

man/lady versus boy/girl

he/she versus his/her/their

verb tense present (...ing) versus regular past (... ed) versus future etc.

### **Preverbal Forms of Communication**

Refers to any form of communication occurring in typical development before speech.

### **Expressive Language**

Refers to any mode of communication the person uses

e.g: speech/sign/object/picture/symbol

Ascertained by "key" words relating to word level and individual linguistic concepts.

### **Pragmatics**

What types of messages does the person use their communication skills for?

### **Speech Sounds**

Early speech sounds emerge in babble and continue to develop with maturation.

There is a known developmental pattern of emergence relating to stages and age.

### **Visual Aids**

Objects/ miniatures/colour photographs/coloured pictures/ black and white pictures and photographs/symbols

### **How do we communicate?**

- Crying
- Facial expression
- Vocalising
- Smiling
- Eye gaze
- Laughing
- Gesture/body language
- Pointing
- Speech
- Sign/symbol
- Writing

### **How Do We Use Our Communication Skills?**

Expressing feelings

Gaining attention

Making requests

Rejecting/refusing

Questioning

Answering questions

Commenting

Imparting information

Directing

Retelling events

Social greetings

## **Fundraising – London Marathon**

Ken Walburn finished his last London Marathon – yes – definitely his last! It took a gruelling five hours and eighteen minutes to complete, although the official time was longer. For anyone who has not watched the Marathon before, it takes approximately 18 minutes to get all the runners through the gates at Greenwich Park. Ken and Steve (who he was running with) were the last through the gates on 22nd April and even appeared on TV!! They both finished and were elated as Ken had some last minute health problems and just a few days beforehand we had been shocked by the death of Christopher Brown (in the last Report, May 2001) – hence Ken ran with a black arm band in respect and remembrance of Chris. Many thanks to all the families who gave so generously to us and we are pleased to announce that we have raised £2500 towards the cost of the conference next year.



**Ken and Steve**

# Augmentative and Alternative Communication (AAC)

## Low-tech Communication Aids

Low-tech refers to the type of communication aid which does not offer a mechanical voice. These systems do not rely on batteries or a power source, they therefore, never break down. They are cheap to produce, maintain, expand and upgrade. They usually offer greater portability than high-tech systems. *Low-tech communication can range from the simplest form e.g. offering two objects as a choice, to a highly sophisticated form e.g. a symbol book of a hundred symbols that can be sequenced into sentences.*

## High-Tec Communication Aids

High-tech communication systems are classically determined by the use of a mechanical voice. The voice may be synthesised (robotic) or digitised (recorded), depending on the device. They require a power source that may be battery or mains supply again depending on the device. All devices will require recharging whether that means simply replacing the battery or charging from the mains supply. Some devices can be too heavy or large to carry around. Most devices will breakdown and require repair.

High-tech can range from a single message depress action large button to a highly sophisticated multi-layered device incorporating thousands of messages that can link to a computer. Most devices can be operated using switches.

Many devices come supplied with a symbol system that may differ from the symbols the user is already using in their education/social services setting.

## Variables

When deciding on the choice of an augmentative means of communication, there are many variables to be considered. A Speech and Language Therapist via assessment will be able to determine the appropriate approach.

## Some Variables To Consider:

Level of understanding – word level and supportive mode

Vision – How large or small can the materials be?

Scanning – How many presented objects/ photographs/ symbols can the person scan at any one time?

Physical Difficulties – How will the person access the communication aid? Will they operate it with their hands or require a switch?

Portability – Can the communication aid be carried, if not how will it be transported?

Funding – who will pay for the aid? Who will fund repairs or upgrading? Who will be responsible for it in each setting e.g. recharging? Who will make it? Who needs to be trained to use it?

**Finn Emerson Speech and Language Therapist**

## Valuing People

Ian and Joan Lockhart kindly sent ASSERT a copy of the summary of the Government White Paper written by Mencap – many thanks to them for keeping us informed. If anyone would like a copy of the summary please contact Mencap on 020 7696 5593.

### Valuing People

- Valuing people aims for choice and inclusion.
- People will move out of long stay hospital.
- Day services will be more personal.
- Advocacy and information services will be provided.
- Everyone will have a health plan.

A brief outline on what it's all about is as follows:

The White Paper sets out how the Government will provide new opportunities for people with a learning disability, their families and carers. It is underpinned by four key principles:

- **Legal and Civil rights** – right to a decent education, to grow up to vote, to marry and have a family, to express opinions with help and support where necessary.
- **Independence** – we should presume independence from the start rather than dependence with public support to provide the support to maximise this.
- **Choice** – people with learning disability to have a say in where they live, work and who looks after them
- **Inclusion** – Enabling people with learning disabilities to do those ordinary things, make use of mainstream services and be fully included into local communities.

The Department of Health has produced various reports along with the White Paper and if you would like a free pack please contact Department of Health Publications, PO Box 777, London SE1 6HX or on [doh@prolog.uk.com](mailto:doh@prolog.uk.com). Quote reference number 23640.

### No Right to AAC

From the Royal College of Speech and Language Therapists Bulletin April 2001

Following Scope's report on the need for better funding for communication aids, health minister John Hutton (before the election) agreed making aids available was a civil rights issue. However he has made it clear that there will be no new funding beyond the £200 million which covers all disability equipment in the Community.

## HELPLINE

ASSERT Families/  
New Diagnosis/  
Support Line



# 01980 652617

# Information from Share an Idea (Contact a Family newsletter)

## **Carers and Disabled Children Act 2000**

### **Caring for a Child**

With the implication of this Act in April of this year comes an enhanced right for parents to an assessment of their own needs from Social Services. We are already entitled to a carers assessment (*editors note: has anyone managed to get one?*) but the new Act will mean that the assessment can be carried out at any time and not just when Social Services are assessing the needs of the disabled child. As well as this, parents can be given direct payments in lieu of services, allowing them to buy help directly. It is clear that the local authority should support any parent carer in employing a person to help care for their child. This includes carrying out a formal police check and alerting a parent to any risks.

Parents can refuse direct payments should they prefer services to be arranged by the local authority (Social Services Department). It is hoped that future legislation will mean that all local authorities must operate a direct payment scheme, thus allowing parents a choice.

*(Editor's note: Not sure what this means but it sounds like we will have to be financially assessed in order to receive a service)*

Parents, who receive Income Support, Working Families Tax Credit, or Income-based Job Seekers Allowance, are not financially assessed for services. Similarly these parents will not be financially assessed for any direct payments received in lieu of services so this means that the payments should cover the full cost of buying the necessary help.

### **Young Disabled People**

Once a disabled child reaches eighteen years of age, a parent will no longer be able to receive direct payments on their behalf. Those who are sixteen to nineteen can ask to receive the payments themselves for services they have been assessed as needing, but not for the services intended for the support of other members of the family. The local authority has to be satisfied that the young person can manage the payments and the responsibilities of being an employer-Tax, National Insurance, by him/herself or with assistance from another person or agency.

### **Caring for an adult**

The Act gives carers of adults a right to services for the first time (before it was the disabled adult who received the service including respite). This means that Social Services can assess the carer and provide services even if the disabled person refuses to be assessed. Carers aged sixteen and seventeen can be assessed under this Act where they are caring for an adult. Social Services can still charge for any 'carer services' but the carer's ability to pay should only be considered after a decision has been made about who should receive the service, the carer or the person cared for.

ASSERT suggests that if you have any queries about this you contact your local Social Services Department or look at the website [www.carers.gov.uk](http://www.carers.gov.uk)

### **Rare Disorders Week**

Contact a Family undertook a survey in March 2001 interviewing twenty groups who support families affected by rare disorders – these groups represented 3600 families. The survey found:

90% considered the most difficult aspect of living with a rare disorder was the lack of information and knowledge about the condition. They emphasised the frustration of having to explain the condition to medical professionals.

75% reported that on average it took over six months to obtain a diagnosis; 30% reported that on average it took over two years to obtain a diagnosis; and 15% reported that on average it took over six years to obtain a diagnosis.

80% reported there were significant variations for their members in receiving a diagnosis. Some groups felt it was "luck of the draw" if they were seen by a doctor who knew of the condition and could diagnose it. The delay in diagnosis meant that children went without treatments. For many of these disorders there are treatments which could alleviate, if not cure, the condition.

70% of the groups reported that a large number of families had to go through the appeals procedures to obtain Disability Living Allowance (DLA) for their child. It was generally felt that the Benefits Agency was not aware of the disorder and did not understand how it affected the child. Some groups also reported that claims for DLA took longer to process because letters of support had to be obtained from consultants or specialists explaining the condition.

60% of the groups reported that support from Social Services for families with each particular disorder varied considerably across the country. Service provision as well as medical care, being a postcode lottery.

Contact a Family is calling on Government to have rare disorders as a defined responsibility within the brief of a Health Minister and to ensure their inclusion into all health and social care programmes. They want to see more accurate statistics and increased epidemiological surveillance. Also improved teaching of rare disorders incorporated into training for all medical professionals, particularly paediatricians. Contact a Family also wants national efforts to strengthen research into diagnostic tests, treatment and management of rare disorders.

### **Grandparents**

Contact a Family now produces a leaflet for Grandparents of children with special needs – copies can be ordered from Contact a Family Factsheet 5j Grandparents ISBN 1 874715 31 9 single copies are free with an A4 Sae; multiple copies are 20p each. Contact a Family 209 -211 City Road, London EC1V 1JN.

### **New booklet for parents of children with special needs**

Contact a Family has just produced a new booklet, "When Your Child Has Special Needs – a guide for parents who care for a child with a disability, special need or rare disorder."

The aim of the booklet is to provide parents with some

practical pointers on the kind of advice, information and emotional support that is on offer. The booklet takes the reader through the various assessments carried out by Social, Health and Educational Services. It also identifies some of the services that may be provided such as respite care, childcare and the support offered by voluntary organisations. For a copy of the booklet the reference number is ISBN 1 874715 30 0 When Your Child Has Special Needs Single copies are free with an A4 Sae; multiple copies are 50p each, details as for Grandparents leaflet.

#### Information on Benefits

Community Care Grant (form SF300) Dept, of Health & Social Security is available for people on income support to financially assist the purchasing of equipment that is not provided by local authorities etc.

#### 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.

*The following was on some airline packaging and this made us smile:*

In a recent study from Scandinavia It has been found that taste buds and laughter are interrelated

The more you laugh, the greater your taste for life

**PROFESSIONALS  
HELPLINE  
01795 429061**

## Periods

*Many thanks to Jackie Silver for writing the following article which will also be available as an Information sheet. We often get calls on the support line about this sensitive subject and it is a topic, which is not easy to find information on when it comes to learning disabilities.*

As a mum of a young lady with Angelman syndrome, I have had many years of experience dealing with the menstrual cycle. My daughter is 23 years old, her periods started at 13 years of age. In the early days her periods were irregular which caused stress to us both, she had pre menstrual tension and would for example get upset at the least little thing and cry at odd times. She would be in pain and she would cry. Like most teenagers she had mood swings, and was irritable with all the hormone changes. She was becoming a young adult growing up. We went to the GP and were told to put her on Mesenamic acid tablets. She uses it a week before her periods are due. It helps manage pain and mood swings. She still has a few bad times but mostly is OK. However, it can cause fitting.

Another young Angelman person used something different. She was given an injection it is called Depox Provea. It is used for birth control as well as stopping periods. This 24-year-old young lady was unhappy with pads and used to pull them off, so everyone thought this method was good for this young woman. The injection is given every 10 weeks; the side effects are weight gain.

When this happens to your daughter it is useful to consult your GP, health visitor/ school nurse to find out about different methods of treatment for periods to see what suits your child and your family.

#### Some things to try

Consult your GP first before embarking on any treatment.

1. It has been said Evening Primrose Oil is very good for periods, and can be taken by mouth in capsule form. However, if it is rejected then it can be rubbed into the arm, it gets into the skin and will work just the same.
2. A diary is well worth keeping, so that you have a record of the pattern of your daughter's periods.
3. Try rubbing calf towards ankle, this is an acupuncture point and can help with painful periods.
4. Some young ladies will try to take their pads out, others don't worry at all. If they are using nappies, then keep using or change more often.

As with all suggestions it is up to you, what works for one, doesn't always work for someone else. Always go to the GP if you have any concerns as all people are individuals, this applies to Angelman Syndrome just the same as the general female population, we are all different!

**Jackie Silver**

## ASSERT 2000

For those of you who have joined the ASSERT 2000 club the first draw took place on Monday 9th July 2001. The numbers were drawn by Mrs Laura Jobson, Home-Start Sittingbourne & Sheppey Co-ordinator. Witnessed by Mr Kevin O'Daly, Home-Start Sittingbourne & Sheppey Chairman

1st prize £70 – Barry & Alyson Whiddington, Royston Herts

2nd prize £40 – Martina Quinn, Motherwell Scotland

3rd prize £30 – Mr WS Hynes, Westcliff on Sea Essex

4th prize £20 – Mr & Mrs J Warner, Sharnford Leics

# Report on a Conference attended by Paula Hills SNAP (Special Needs And Parents) Brentwood, Essex

I recently attended a conference entitled 'Keyworking: Opening the Door?' held at The Children's Trust, Tadworth, Surrey. The Children's Trust wanted to hold this conference to encourage professionals and parents to explore the reality of meeting the needs of children with profound disabilities and their families.

The speakers at the conference were: Humphrey Hawksley, (a journalist and parent of a 5 year old boy with Cerebral Palsy), Peter Limbrick from Handsel Trust, Manchester founder of the 'One Hundred Hours' model, (designed to provide babies and pre-school children with multiple disabilities and health needs with keyworkers) and Dr. Tricia Sloper, University of York, who has been involved in research on the needs and experiences of chronically ill or disabled children and their families for many years.

Dr. Sloper reported that since the 70's government policy and the Children's Act had recognised that families who had a keyworker were better prepared, had higher morale and were less stressed. Research had shown that families wanted, but didn't get a key-worker.

The definition of a keyworker was – a named person who the parent can approach for advice. Keyworker has responsibility to all agencies (Social Services, Health, and Education).

Dr. Sloper talked about a pilot keyworker scheme funded by Joseph Rowntree Foundation in Middlesbrough and Lincolnshire. Dr. Sloper and her team had implemented change in these areas, getting the managers of services' committed to this new idea. Activities of keyworkers are:

- emotional support, information and advice to families
- identifying and addressing needs
- advocacy
- service co-ordination (bridge with other services and families)

Parents involved in this pilot have been included in this research and their views of keyworkers are:

- Pro-active regular contact initiated by keyworker at agreed intervals of time
- Supportive and open relationship with trust
- Family centred approach with all family members
- Good keyworker can access all agencies (health, social services, and education) and is seen as independent.

Typical comments from parents who didn't have a keyworker were:

- someone else to help them through the maze;
- someone else being torn apart not me;
- someone else to do the nasty bits.

Some interesting points made at the conference of parents and professionals were:

- Parents' concerns over how long would you need keyworker for
- More suitable for children with complex needs who involve more than one agency
- Highlighted difficult times as: newly diagnosed, transition, lone parent
- Keyworker should only work with 1 or 2 families at a time a
- Some parents took this role on themselves

Humphrey Hawksley gave a very real and moving account of being a father of a child with multiple disability. His view of completing the DLA form, finding the right help for his child and the changes this has made to his life rang very familiar bells with me.

Peter Limbrick supported the keyworker model of practice but couldn't see how these changes in work practice could happen in any realistic time scale. One of his suggestions for implementing some immediate benefit for families was 'team around the child'. He used this principle 15 years ago in Yorkshire – it is not revolutionary but simple. Basically a child who is multiply disabled sees many professionals i.e. speech, physiotherapy, occupational therapy, education, portage, health visitors etc. Teaming around the child involves getting all these professionals together regularly to share joint working so that a plan can be made for the child, similar language can be used to the child and professionals will be able to compare goals. Generally Peter reflected that individually the professionals were fine at doing their job but he felt that the systems they worked in were not.

Call it what you will – holistic approach or team around the child. This is something that worked for me in the pre-school days; at least you felt you were not on your own.

**Paula Hills**

*Many thanks to SNAP for letting us reprint this article. If you have any experiences of good working practice such as that suggested, please write in and let us know.*



## Aunty Melissa

We were very proud to be made grandparents on Dec 24th 2000. A beautiful, healthy baby girl, Areilla arrived weighing 6lbs 11ozs – wonderful! We wanted Melissa to see her; we did not know how she would react. Melissa lives in Ravenswood village in Berkshire and comes home most weekends. When the baby and our son and daughter-in-law came to us, Melissa came as well. We showed her the baby, Melissa looked and turned away, but we kept showing her the baby. She then touched Areilla's foot very gently and then tried to pull it off! We had to keep telling her that Areilla was not a doll. I think she knew this when Areilla started to cry, Melissa then started to cry too! So we had to calm them both! Soon Melissa wanted to know what the baby was doing and kept looking for her all the time. It was very sweet. Melissa then held Areilla with our help, she kept looking down at her, and it was wonderful to see. Now after 4 months Melissa and Areilla are good friends. It is wonderful to be a grandparent; after all the hugs and kisses and cuddles, when she's worn us out, we can give her back – ha, ha!!

Jackie Silver



Aunty Melissa

## Early Videos

*ASSERT has been contacted by Dr Alison Kerr from Glasgow University Department of Psychological Medicine and she would like some assistance with the following:*

I have been looking for families who have children with Angelman Syndrome and have been advised to contact you by a colleague. I am a paediatrician who has been involved in research into Rett Syndrome. One particular line of investigation in Rett has been to try and detect the problems of these children in the first months of life so that support to the child and family can be provided as early as possible. Previously diagnosis has generally been made only after two or three years and this delay has led to much distress.

Families of people with Rett Syndrome have helped in the investigation by donating copies of videos before they have taken before a problem was suspected. This material has been very helpful in identifying signs of difficulties in

movement and exploration of toys between birth and one year of age.

With a colleague, Dr Bronwen Burford, Psychologist (Edinburgh University) it is now hoped to extend the investigation to study comparable video in other developmental disorders where delay is evident but diagnosis is frequently delayed. We anticipate that this study will bring the same benefits to these children and families as our work so far is bringing to children with difficulties due to Rett Syndrome. Our aim will be to characterise and to understand the earliest difficulties encountered by these children.

I will be very glad to hear from any family with a child/children with Angelman Syndrome who has such early video material dating from birth until 3 years of age and wishes to help in this investigation.

*If you can contribute to this valuable work, please either contact ASSERT or Dr Alison Kerr on 0141 211 0281 Fax: 0141 357 4899 or by email amk5m@clinmed.gla.ac.uk*

## Carers Assessment

The Department of Health has recently produced a leaflet entitled "How to get help in looking after someone – a Carers guide to a carers assessment". This leaflet states that "You are a "carer" if you look after a relative, friend or disabled child who needs support to live at home. Your local council Social Services Department may be able to help to make things easier for you".

You should ask for a carer's assessment so that social services can discuss with you:

- The help the person you care for needs
- The help you are giving the member
- The services your council may provide

Your carer's assessment is your opportunity to tell social services about the things that could make caring easier for you. Some things they suggest you look at are:

- Do you get enough sleep?

- Is your health affected in other ways?
- Are you able to get out and about?
- Do you get any time for yourself
- Are your other relationships affected?
- Do you want information about benefits?
- Are you worried you may have to give up work?
- Is the person you care for getting enough help?

What sort of services might help you?

- Services that give you a break
- Emotional support from other carers or people who understand
- Help with household tasks
- Help with caring tasks during the day/night
- Benefits advice
- Activities for the person you care for

# Sandy

Sandy was born in early 1960, a year that is often considered as a landmark in the history of a rapidly shifting social scene. Although we were unaware at the time, a significant change was also occurring in attitudes to what was then referred to as mental handicap. Parents facing such problems had previously often been advised to put their child away and have another one, but admission to long-stay hospital at that time was slowly becoming a thing of the past. However responsibility for services remained with Medical Officers of Health, as the children were labelled ineducable.

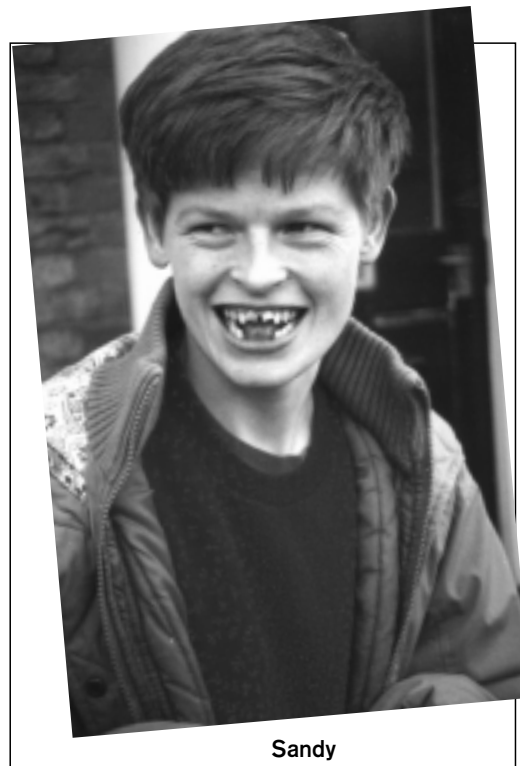
Many of Sandy's milestones were distinctly delayed, but with no brothers or sisters for comparison and, like most parents in such situations, we clung at straws. (It was only after her brother was born 2yr 9mth later that we realised just how difficult Sandy's early upbringing had been). She was bright-eyed, placid, and a very happy child but as time went on, it was clear that all was not well. After seeing local consultants, followed by a stay in The Hospital for Sick Children at Great Ormond Street, we finally accepted that our happy daughter had a mental handicap of unknown aetiology (scientific cause).

This in fact raised far more questions than it answered. It was difficult to come to terms with the unknown origin despite the fact that at that time it was said that about 90% of cases fell into this category. It seemed important to meet others and to share experiences with parents confronted with similar problems. We were active in setting up the local Mencap Society and a local club for people with learning disabilities. We were involved with the junior training centre (Sandy was suspended after a few weeks at the age of 5 – not ready for training!) and with the school for children with learning disabilities that opened in 1971 when our children were finally accepted into the education system. As a result, we met scores of children with learning disabilities of varying degrees who were living at home with their parents but surprisingly, we never came across anybody who shared Sandy's personality and well-defined physical characteristics.

Sandy grew up at home, and after leaving school at 16, transferred to the adult training centre. Our experience of people with a learning disability was widening all the time; but her nature still appeared to be unique. At 26, Sandy moved into a small group home opened locally as a transition arrangement by the local health authority. At 31, she moved on to a permanent group home where her horizons widened rapidly and she continues to enjoy a very full and happy life. Sandy has no speech but it is universally accepted that with people she knows, she is a good communicator. However, we still did not know why.

Then in 1995, when Sandy was 35, the breakthrough came. A local freebee newspaper came through the letterbox and there

was a picture of a three-year-old girl who lived locally who had Angelman Syndrome. The similarities were astonishing – it could easily have been Sandy at the same age. Contact was made with the child's Mother and her help led ultimately to a diagnosis. As they say, the rest is history.



Sandy

Sandy's diagnosis of Angelman Syndrome with a classical deletion brought a huge sense of satisfaction to us as parents. Furthermore, it did not stop there as it brought a whole new dimension of interest to her professional carers as well as to the more extended family.

History decreed that Sandy had gone through the child health system before Harry Angelman's observations had become part of established paediatric practice. Clearly, there are many of Sandy's generation who remain undiagnosed. Our own experience suggests that these parents, as well as their carers, would gain immense satisfaction from an understanding of the underlying reasons for their son or daughter's condition. The fact that Sandy currently holds the distinction of being the oldest on the ASSERT list suggests that there are many awaiting a coincidence of the type that befell us. Is there anything that can be done to make this a reality?

Our experiences, both before and since Sandy's diagnosis, have given us a comparison that underlines the importance of specifically directed support groups. The importance of seeking ways to bring publicity on the characteristics of Angelman Syndrome to the notice of those who have waited decades for a diagnosis cannot be underestimated.

We have now been learning the ropes for over 40 years. Our bubbly, happy and mischievous child is now a bubbly, happy and mischievous adult. We would always be happy to share particular experiences if we can be of help.

Joan & Ian Lockhart

**HELPLINE**  
**ASSERT Families/New**  
**Diagnosis/Support Line**

**01980 652617**



**PROFESSIONALS**  
**HELPLINE**

**01795 429061**

## Donations

It's always great to receive donations and is a good support to ASSERT, and we do thank everyone for their generosity.

However, it does not always mean there has been a specific fundraising venture. Some families in the past have acknowledged the death of a loved one by donating to ASSERT in their memory, either because of a small amount left specifically to ASSERT in that person's will, or by families asking for donations rather than flowers.

We are always pleased to print that it has been given in their memory, you may have already noticed this in previous editions of the Report, and we thank those for such a thoughtful gesture, at a time of sadness. We would also mention that a happy occasion could also be a way of donating. For example if an anniversary or special occasion is coming up, rather than giving a present not needed or wanted, the people involved may ask for money which can be donated to a single, or several charities of their choice. Again we would be pleased to acknowledge this and thank them for their generosity, so... next time please consider ASSERT.

Many thanks to all the people who have contributed to ASSERT since the last newsletter:

Bank of Scotland Edinburgh  
In Memory of Christopher Brown  
LH and Mrs JG Capen  
Mitchel and Sharon Crowther  
Karen Evans Hen night  
Glencore International AG  
Mrs Anne Hodgins and friends  
Mrs N L Keen  
(Tarkett Sommer Commercial)  
Leander Swimming Club  
Fundraising Committee  
Ken Walburn – London Marathon

## Christopher Brown

We have recently received a donation in memory of Christopher whom we wrote about in the last Report (May 2001). Christopher was involved in a tragic accident whilst in the care of HCPT at Lourdes during the Easter 2001 pilgrimage.

Our grateful thanks go to Sue and Mike who asked that half of the monies donated in lieu of flowers should come to ASSERT. The following people expressly donated to ASSERT in memory of Chris and it is only right that we should list every one of them in this Report many thanks to them all.

Mr & Mrs Broderick  
Mr & Mrs V Brooks  
Mrs B H Brown  
Mr & Mrs V Collier  
Michelle Davies, Pam & John, Josie & Ron  
Jean Davies  
Elizabeth & Alun Edwards Sharon Claire & families  
David Julia Ellis & Family  
A M Fisher  
Mr & Mrs WM Giltinan  
Mr & Mrs Harris  
Chris & Terry Jones  
Pat & Nev Jones & Family  
Brian & Anne-Leonard  
Eira Lewis  
Mrs F Lewis  
Margaret & Danny Sheehan & Family  
Mr D J Martin  
Pat Mike Natalie Helen & James  
Mrs Olwen Rees  
Irene Robinson and the Canadian branch of the family  
Mrs A E Sennett  
All the Shercliffs  
Mr & Mrs B Tavinor  
Mr & Mrs W A Toulcher  
Pamela Thorpe  
Mr & Mrs K Turner  
Mr & Mrs Bill Webster  
Mrs M M Wilde  
Aled & Ruth Williams  
Barbara Williams

### Hen Night

I am writing to let you know that I have raised £200 for ASSERT. I had great fun in raising the money on my Hen Night.

We all went to Glasgow to celebrate my Hen Night and the tradition is to go out with a potty, and collect money for your start in married life. I took out a bucket, as I didn't want to take out a potty.

We had a very successful evening collecting money from everyone that was out. I had decided to give the money to ASSERT and I told everyone that was the course. I had to oblige the guys with a kiss for their donation, what a shame, but it was all in a good cause.

When we counted the money up I couldn't believe there was so much in such a short space of time with very little effort as people were willing to donate to charity.

**Karen Evans**

*Many thanks to Karen. Hope the wedding went well!*

# How ASSERT can help you

## The Telephone Support Line

Each of the parent trustees takes an evening where they are "on-call". If you telephone the Families Support Line – **01980 652617**, the call will be automatically transferred. The

Trustees on the rota are as follows:

SUNDAY	Gerry Egan
MONDAY	Sally Walburn
TUESDAY	Bernie & Jackie Silver
WEDNESDAY	Elaine & Stephen Sears
THURSDAY	Sally Walburn
FRIDAY	Elaine Sears
SATURDAY	Elaine Sears

All calls are in the strictest confidence. A log will be made of your call and this means your file can be kept up to date. If any action is needed, it will be dealt with as soon as possible, and we do strive to avoid unnecessary delays.

We are here to share your good times, as well as your frustrations, and at times, your despair. We will help as much as we can although this may mean that we have to put you in

touch with another organisation, agency or another trustee. (All of the trustees "on-call" have children/adults with AS. We all have experience of different problems, for example, not all our children have epilepsy, some are younger and some are older, but we will do our best to put you in contact with someone who can help.)

If you get the answerphone, which sometimes cannot be avoided, we will endeavour to call you back as soon as we can. Please leave a clear message stating the day and time on which you called and where, and when best to contact you. We can't guarantee to solve your problems but we may be able to help and point you in the right direction.

We are here to support YOU, so please phone no matter how trivial you think your problem might be. Remember we are always happy to hear good news too!

**FOR ALL ASSERT CALLS WE CALL YOU STRAIGHT BACK IN ORDER TO PRESERVE YOUR PHONE BILL.**

**HELPLINE  
ASSERT Families/New  
Diagnosis/Support Line**

**01980 652617**



**PROFESSIONALS  
HELPLINE**

**01795 429061**

## ASSERT T-shirts

Have you bought your ASSERT T-shirt yet? You can help promote ASSERT, Angelman Syndrome, and the 'Planning for the Future' campaign by buying, and of course wearing, an ASSERT T-shirt. They are white with the ASSERT logo in blue on the front; on the back are the words 'Planning for the Future'.

Sizes and new reduced costs (including p&p) of the T-shirts are:

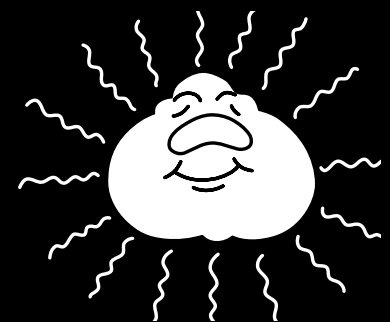
<b>Child's</b> (age 7/8)	32" chest, 19" nape to hem	£2.00
<b>Small</b>	34" chest, 25" nape to hem	£2.50
<b>Medium</b>	38" chest, 28" nape to hem	£3.00
<b>Large</b>	40" chest, 28" nape to hem	£3.00
<b>X Large</b>	42" chest, 30" nape to hem	£3.50
<b>XX Large</b>	45" chest, 32" nape to hem	£3.50

Please send your orders, with cheques or postal orders made payable to ASSERT, to ASSERT T-shirts,

Ken & Sally Walburn,

7 Nottingham Way, Langdon Hills, Basildon, Essex SSI6 6TR.

Tel: 01268 546612.



## 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.