



Message from the trustees

As we prepare this newsletter we have all been devastated by the news from the USA about the attacks on the Twin Towers of the World Trade Centre and also on the Pentagon. All of us from ASSERT would like to offer our thoughts and condolences to our American friends of the Angelman Syndrome Foundation, in their time of loss and grief as a nation. We have all been touched by this atrocity and we hope that from such evil, good will triumph.

ASSERT is busy preparing for the conference in September 2002 and contrary to what some of you think, it is next year, not 2001. We believe that some of you were confused that the conference may have been this year. Many thanks to those who returned the questionnaires, we now have a very good idea of the sorts of topics and issues you would like covered. If anyone can help with the organisation, or at the conference itself, we would welcome your support, Bernie and Jackie Silver won't be able to make it so we could do with some extra pairs of hands.

Look out for the launch of ASSERT's new logo. We are in the process of choosing a modern, snappy up to date image and will be bringing this to you next year along with a whole

new look for the website. Many thanks to those who came forward following the appeal in the last newsletter for help with our website.

We have had a couple of responses to the appeal for trustees, but no commitment as yet. We still need some more people to come forward. We know that many of you have been supportive of us and have really appreciated how we have helped you in the past, but as some of us are now needing some time out, or to resign for good (as we have been active for some years), we cannot carry on supporting families at the current level. Please consider whether you can help others as we have supported you, or whether you have another family member or friend with an interest in Angelman Syndrome who would be willing to become involved, even for a short time. We hope that you will take this seriously as we need your involvement to carry on the valuable work we do. It isn't a huge task and you can do as much or as little as you are able.

We hope you all have a good Christmas and New Year and look forward to seeing you in 2002.

The Trustees of ASSERT

Introducing Sophie

Our daughter, Sophie was born on 6th October 1999 and was diagnosed with Angelman Syndrome in February 2001. We are writing to say how proud we are of our little girl, she brings much love and joy into our family. My neighbour often tells me that when she feels down she only has to look at Sophie and Sophie will bring a smile to her face. We started to see the physiotherapist a few months ago and Sophie is making wonderful progress. It just shows how worthwhile it is taking her to the therapist. We carry out daily exercises with Sophie. She has learnt such a lot in such a short time.

Also a big thank you to ASSERT, we enjoy the magazine and enjoy reading all the articles.

Tammy and Peter Munro



Sophie aged 22 months

Regional Meetings

It's great to feedback that all the meetings we have held this year have been well attended and a good chance for you all to get together. Many thanks to the organisers and helpers. The following report is from a family who attended their very first meeting and their thoughts and feelings about it:

James and the Tidworth Meeting

Our son James was born on 25 Feb 1998. We suspected after a few months that something was not quite right. James did not progress as quickly as his older sister Charlotte (now almost seven) did at the same age, however he seemed quite contented.

When James was almost one and still could not achieve his developmental milestones, he was referred to a community paediatrician and investigations began. Eventually on 9/9/99 (not easily forgotten!) confirmed by blood tests, we received the diagnosis of Angelman Syndrome.

To date the most useful information we have accessed has been either found by ourselves through the Internet or via other parents/carers who are in a similar position to us and of course from organisations like ASSERT.

James attends part time the nursery class of the local school for children with severe educational needs. He really loves other family members; we are fortunate in having a large extended family. James really enjoys school, swimming, cinema, food, animals and being involved in family life.

We were delighted to receive our invitation to the Tidworth family meeting; we had not met any other person with an Angelman diagnosis. We had some fears ... would meeting older children make us face future realities quicker than we could emotionally cope with.... would anyone talk to us?

So on 7 July we (Mike and Jenny), Theresa (Jenny's mum), Charlotte and James set off for Tidworth, just over an hours drive. On arrival we collected our name badges and orientated ourselves to the venue. There was plenty of space and we eagerly accepted the free refreshments.

Eventually we became brave enough to talk to other families. Everyone we spoke to was very welcoming and full of useful information and advice. All carers seemed positive and good role models. The meeting had an optimistic feel.

We would certainly encourage other parents/carers to attend a regional meeting; we found it very beneficial. Thank you again to everyone involved in organising the day, also to all the other families for reassuring and welcoming us.

Mike and Jenny Gray

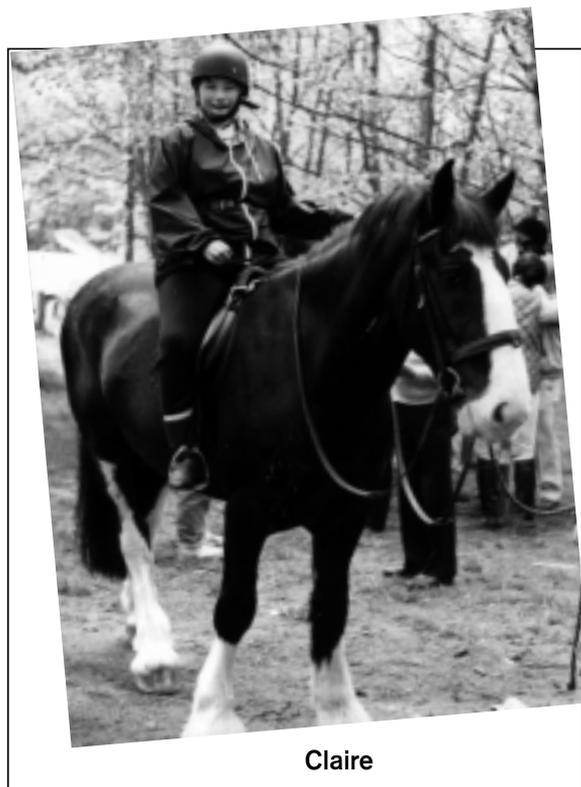
Claire Watson

We are pleased to print the following we received from Chris and Yvonne Watson about their daughter Claire.

Claire was born in 1974. When she was about 4 years old we were told she had AS and that it was extremely rare, no other information was given, so we went home and got on with it.

Claire rarely sleeps and demands so much of our time, despite this her brother and sister passed O'levels (GCSE's now) and A'levels and other exams and now have good careers.

Claire started going to playgroup at 18 months old with other disabled children and then to school at five. Claire had excellent teachers at school and she took part in school concerts and sports days and outings. Claire also used to ride with Riding for the Disabled and took part in gymkhanas, winning lots of rosettes. She left school at 19 and now goes to a day centre for activities. Claire will take cakes and soft drinks on her 27th Birthday to share with her friends. Claire has respite one week five times a year, I still don't like it, but our reunions are wonderful, we get our beautiful daughter back with her big smiles, wicked sense of humour and bone crushing hugs. Claire can only speak five words but has no difficulty making herself understood. Her interests are music, videos, perfumes, bubble baths, clothes, outings; she is a chocoholic and a biscuit babe! Claire's special friends and companions are Lucy our German Shepherd dog (biscuit clearer upper), Sam – cat sleeps on her bed (must be deaf!), Bluebell Marigold and Primrose Geese who tug at her sleeves and make her laugh. Henrietta Hen that lays eggs for her tea. Donald – yes Donald the Duck. And I hope maybe her parents count as special friends; the hugs and smiles say we do. I won't pretend it's all plain sailing, we've had life experiences we never expected; times money can't buy, and I hope more to come!



Claire

Yvonne Watson

Dolphin Human Therapy

Miss Katie

Where do I begin? I find it easy to stand in front of people and talk about our life and experiences with Katie, in fact I find it easy to talk full stop! (I think our editor Sally will verify this!!)

However, I have put this off for long enough and feel it is now time to record our experiences of Dolphin Human Therapy (DHT).

Our youngest daughter Katie was born in March 1995; she was diagnosed at the age of two with Angelman Syndrome. (Katie does not suffer from Angelman Syndrome, WE DO!!). Following a brief period of isolation, denial and frustration we contacted ASSERT and were gently guided in to our new world of living, coping and managing a child with AS.

Living with a hyperactive child poses many problems, as many AS families can relate to, we found the only way of coping was to adopt a proactive approach and address each challenge as it arose. We have adapted our house to provide Katie with a safe and secure environment and an area of sanctuary for the rest of the family.

As time went on we became increasingly aware of Katie's limited attention span, we felt that the key to her development lay with the need to increase her concentration level. With this in mind we searched for a therapy treatment that matched her needs. Triggered by an article in Woman's Weekly about the wonderful progress of an AS child following DHT, we decided to investigate how, and if, Katie could also benefit from this therapy.

Following a period of research we made the decision to enrol Katie on the program. This was a very difficult decision to make, we had to consider many things including cost, travelling to Key Largo in America, the heat and could we cope with Katie away from her home environment. We eventually decided that the benefits to Katie could far outweigh the obstacles we faced.

The main factor in our decision was the cost, we estimated the total cost for the trip would be in the region of £12,000, we decided the only way to meet this cost would be to fundraise. We had just less than two years to raise the funds, which seemed an awesome task at the time, however we managed it.

Thursday May the 3rd 2001 had arrived, the morning of our departure into the unknown (or so it seemed!) We had booked the coach for 04.30 in the morning, earlier than we had expected due to a rail strike, which threatened to congest the roads. Our first new experience was to wake Katie up in the morning (we felt like we were getting our own back!) We actually left on time, which was another first! Nine of us in total, we believe in safety in numbers. Katie enjoyed the trip to the airport and managed to stay seated for the whole of the journey (with much amusing from us all).

None of our party considers themselves hardened travellers so we were all nervous about flying (except Katie). We felt that



being in a plane with Katie for 9 hours there was no worry of Deep Vein Thrombosis. Katie loved the flight and the attention of the Virgin staff (that's Virgin Airlines!!). The sleep masks worn by some of the passengers proved to be a major attraction for Katie, we were amazed how far the elastic could stretch on some poor innocent passengers head!!

We landed in Miami on schedule and enjoyed the express route through customs, thank you Katie. Our first impression of America, my gosh it's hot, second impression, it's **** raining. Following a 50-mile taxi journey to our apartments it was time to be fed and drag ourselves to bed. We had been up for nearly 24 hours, the only member of our party to still be full of life was Katie!

The next morning we all arose to a beautiful hot day which was to last the whole of our stay. We were all up and about early due to our unsettled body clocks (not that Katie has one of these!). Our first therapy session did not start until Monday morning, which gave us all time to adjust to the climate and overcome the jet lag. The first job of the day was to collect the hire vehicle. We had pre-ordered a people carrier from the UK, however American hire companies have a reputation of not always delivering what you have ordered. Don our airport taxi driver had informed us about another company which we eventually hired from because they could provide a 15 seater cheaper than an 8 seater from the original company (including all the taxes and insurances they add on). I don't know why Americans have to drive on the wrong side of the road! However we soon got used to it and adjusted well to the lower speed limits (well we never got caught for speeding!).

Following a weekend of exploration, Monday morning had arrived, our first day of therapy, we were all apprehensive, had we come all this way for an alternative therapy that was more hype than results? Was it just an American razzmatazz money-spinner? We were about to find out. We arrived at Dolphin Cove, a beautiful natural lagoon that was home for 6 Dolphins, we were introduced to all the staff and made to feel very welcome. Our induction seminar outlined the forthcoming program and introduced us to Katie's one to one therapist. They had programmed Katie for afternoon sessions, which we were a little apprehensive about because we knew Katie was most attentive in the morning.

A mass invasion occurred at 4 pm that afternoon when all nine of us piled out of our vehicle and descended on Dolphin Cove, Katie excited as ever made a beeline for the water, heaven had landed in Katie's lap, wherever she turned there was water!

We sat down with Katie's therapist Le-Anne whilst the rest of our party amused Katie (well tried to keep her away from the water). Le-Anne is a Special Needs Teacher and her skills were matched to Katie's needs. Prior to our visit we had provided the Therapy centre with Katie's IEP, information from her Paediatrician, Social Worker etc, and this information was used to draw up a therapy plan and selection of the therapist. Other children were matched with therapists that specialised in Physio, Occupational etc. We were pleased with Le-Anne because Katie had advanced and responded well with her special needs teacher at her school. We were asked what our

expectations were and what key targets they could address. A joint decision was made to address her behaviour and communication skills and target her attention span to increase her concentration.



Setting off

It was at last time to start her first therapy session; wetsuits were used for the children even though the water was warm. The therapist escorted Katie to her dock; she had to hold her hand and walk beside her.

This proved to be the first turning point in her behaviour; even now Katie walks holding our hand staying by our side.

At the dock Katie worked with Le-Anne who was assisted by two interns (trainee therapists) and a Dolphin trainer. Katie was introduced to her dolphin 'Spunky'. Needless to say the only thing on Katie's mind was 'how quick can I get in the water'.

Le-Anne worked on the dock with Katie concentrating on eye contact and attempting to get her to carry out simple tasks, her reward was to swim with the Dolphins. This was to be the ethos of her whole therapy, if she paid attention and carried out the tasks with the therapist then in the water she went, of course Katie being Katie many times she felt it necessary to attempt to bypass the therapy and make a lunge for the water, hence the need for two interns assisting (or is that restraining her!) on the dock.

It was certainly a magical moment watching Katie interact with the dolphins, it was a feeling that we will always cherish and only with the experience could one truly understand our feeling and emotions. When you consider these mammals weigh around 30 stone and average 9 feet long it's hard to describe how gentle, patient and tentative they are with the children (particularly when Katie tried to pull his nose off!).

We only attended the therapy sessions for about 2 hours per day which seems quite a short therapy period, however by the end of each session Katie was absolutely worn out. During our first week it was decided to switch Katie's session to the first of the day, the therapists felt she would pay attention more with an early session. They also decided to move her from her dock to a dock on the far side of the lagoon; they felt that there was too many distractions being as the first dock was so close to everyone's viewing area.

In true Katie fashion during the first week of our stay she picked up a nasty cold and we had to pay a visit to the local paediatric doctor. No chest infection, however dad felt a little faint when he had to pay the bill!

The second week of therapy went extremely well with Katie paying attention and carrying out the key tasks more willingly. At the end of each session we had a full de-brief from the therapist and homework to be done then and in the future. At the end of our second week we were given a full breakdown of all the therapy sessions and a detailed agenda for when we returned home.

During our stay in Key Largo we met many families from all over the world who were attending DHT. We also met Amelia who has AS and her family who were also from the south of England, they were staying at the same apartment block as us. This gave us the opportunity to share our experiences (and many drinks) and compare notes.

During our free time we had the opportunity to visit many places including the many shopping malls where all the girls made an attempt to exceed the limit on the credit cards. Katie's sisters and cousins also enjoyed the experience of swimming and interacting with dolphins. A memory they will always treasure.

All too soon we were boarding the plane to come home. Once back home all suffering from jet-lag (except Katie) we started to reflect on the value of DHT. If we were to be honest at this point we had to question the benefits to Katie, there didn't seem to be any major significant improvements. However as the days passed we became aware that Katie had started to communicate with us, she now takes us by the hand to where or what she wants and will often put our hand on the sweetie tin (this doesn't mean she always gets them!). We have noticed a remarkable improvement in her eye contact and concentration levels; she now sits quietly with us and holds our hand when walking. The benefits to Katie and improvements in her quality of life did far outweigh the effort and cost.

Was it all worth it?

MOST DEFINITELY

Would we go again?

WE HAVE ALREADY STARTED FUNDRAISING



Making friends

If anybody would like to know more please feel free to get in touch.

Paul, Deby, Lucy (14), Amy (11), Katie (6), Chick, Jenny (Katie's favourite Aunty & carer), Sophie (11), Louisa & Kevin (Katie's cousins)

Tel: 01305 833741

Email: chickie@talk21.com

Information from INTOUCH Newsletter

Thanks to INTOUCH we can keep you updated with the following information. We would like to thank them for their contributions which let us all know what is happening around the UK. Unfortunately they still haven't managed to secure funding to print the newsletter next year, so this may be the last information we can bring to you.

Assessment of Care at Manchester Hospitals

The Commission for Health Improvement is assessing the services of Central Manchester and Manchester Children's University Hospital NHS Trust and would like to hear from local people about their good and bad experiences. The CHI looks at the patient's experience in relation to: the history and organisation of their journey through the hospital during the period of care, the outcome of their treatment, their views and opinions on the care they received and the environment in which they were treated, including protection of privacy and dignity. They will also look at clinical teams and the corporate strategy of the organisation. The CHI is seeking your comments on how good the care is at these hospitals, assisting the Trust to look at themselves from the outside, so that they will see their

organisation as others see it, celebrate successes, identify weaknesses and then find help to tackle any shortcomings. The CHI is not able to investigate individual complaints. They are, however, interested in the broader issues patients' experiences may raise and will be able to point them in the right direction to have their complaint dealt with. The information will be used to compile a report at the end of an assessment. This will be a public report, available to all and published on the CHI website – www.chi.nhs.uk There are several main ways to contribute views to the review:

- a) Informal private meetings.
For an appointment, ring 0845 601 3012
- b) Written comments can be made to: Maddie Blackburn, Central Manchester and Manchester University NHS Trust, Commission for Health Improvement, Finsbury Tower, 103-105 Bunhill Row, London EC1Y 8TO
- c) Comments can be made on the telephone, by calling 0845 601 3012 and the review manager will call back at an appropriate time for further discussion.
- d) Via e-mail on: maddie.blackburn@chi.nhs.uk

Holiday Care

Holiday Care is the UK's central source of holiday and travel information for people with disabilities. Their database comprises 170 different fields of information on all aspects of accessible tourism and travel in the UK and overseas. They also have a comprehensive database of respite care facilities throughout the UK, which offer short term stays for disabled people with or without their carers. Their service offers information on: accessible accommodation (hotels, B & Bs, farmhouses and caravan holiday home parks), accessible visitor attractions, accessible transport, activity holidays for people with disabilities, holidays for children with disabilities, respite care establishments, sources of holiday funding for disabled people on low incomes, accessible overseas destinations. Holiday care also runs an accommodation reservations service, based on hotels and other forms of accommodation under the National Accessible Scheme and publishes a wide range of publications on all aspects of holidays for people with disabilities, including: Holidays for Families with a Disabled Child and Holidays/Respite Care Breaks for Unaccompanied Children and Young Adults. For further details, contact: Holiday Care, 2nd Floor, Imperial Buildings, Victoria Road, Horley, Surrey RH6 7PZ Tel 01293 774535 E-mail: holiday.care@virgin.net Full details about Holiday Care can also be seen on their website: www.holidaycare.org.uk

Challenging Behaviour Foundation – update from Viv Cooper:

"The Challenging Behaviour Foundation Information Service is producing a series of leaflets, which should be available before too long. The long-awaited 'Who can Help' leaflet is being worked on at present and the first draft of the Functional Assessment leaflet has been written and should be available in the next couple of months. Unfortunately, the leaflet on self-injurious behaviour is not available at present but we are keeping a waiting list of those who have requested a copy. The Foundation would welcome accounts from parents for our Parents' Perspective sheet. This need not be pages long – a couple of paragraphs would do. It is always good to share experiences so that other parents know they are not alone in facing difficulties". Please send your account to Viv at: 32 Twydall Lane, Gillingham, Kent ME8 6HX Tel & Fax 01634 302207 or email vivcooper@theCBF.freeserve.co.uk.

HELPLINE
ASSERT Families/New
Diagnosis/Support Line

01980 652617



Blue Badge Scheme

The telephone number to call for government leaflets. The Blue Badge Scheme and European Parking Card for People with Disabilities has been changed to 020 7944 6100

National Association of Parent Partnership Services (napps)

This association was established in 1999 and now has DfES recognition. The purpose of Parent Partnership services to parents and carers of children with special needs, to facilitate communication between organisations and to influence policy and practice at local and national level. Parent Partnership Services are organised and run by both local education authorities and voluntary organisations. For further information, contact Dave Reid, Vice Chair, napps c/o Parent Partnership Service, Hampshire County Council Education, County Office, The Castle, Winchester, Hants S023 8UG Tel 01962 845970 Fax 01962 845 870 or email dave.reid@hants.gov.uk

Publications

The Disability Information Trust has published the second edition of *Children with Disabilities*. Contents include: The More Common Causes of Disability in Children, General Information, The Blue Badge Scheme, Services and Support, Organisations that can Help, Home Adaptations, Environmental Control Equipment, Seating (bean bags, chairs and tables), Wedges, Side-lying Boards, Cots, Beds & Accessories, Night Positioning Aids, Bathing and Showering (bathing aids, powered portable bath lifts, bath board and scat, showers), Toileting, Incontinence (pads, specialised products, bed protection, organisations), Clothing, Feeding, Eating & Drinking, Slings, Transfer Boards, Paediatric Moving & Handling Belts, Buggies & Pushchairs, Tricycles, Walking Aids & Gait Trainers, Upright Support (prone standing frames, upright standing frames, powered standing frames), Play & Development, Safety, Addresses, Product Index. ISBN number 1 873773 22 6
Published by:

The Disability Information Trust,
Mary Marlborough Lodge,
Nuffield Orthopaedic Centre,
Oxford OX37LD

Taking Care By Alison Cowen.

This book is for and by parents of disabled children. It combines the personal experiences and words of many families caring for a disabled child, with lots of useful information on who does what and how to get in touch with them. Contents include: Children First, Supporting Our Care, Making our Voices Heard, Inclusion in Mainstream Services, Laws and Services for Families in England, Northern Ireland, Scotland and Wales. It also includes details of research on families with more than one disabled child, families from minority ethnic groups and housing for families with disabled children. Taking Care confirms the uniqueness of each individual family and the need for an imaginative use of resources by service providers to enable families to care for their disabled children. The book is also suitable for professional health and social service workers by keeping them in touch with what it is like to be the parent of a disabled child. Taking Care is free for parents of disabled children – please send a self-addressed label or envelope (not stamped) with your order. For professional workers, single copies of Taking Care are available at £6.00 per copy, including postage and packing. Please send a self-addressed label or A4 size envelopes and make cheques payable to The Family Fund Trust. Bulk orders of ten or more copies are available at £5.00 per copy.

For more information or to order copies, write to: Taking Care, The Family Fund Trust, P.O. Box 50, York YO1 9ZX Tel 01904 550005 email ace@familyfundtrust.org.uk
The Family Fund website address is www.familyfundtrust.org.uk

Teaching Children with Severe and Complex Difficulties

By Christopher Fry. In response to the growing demand for fully inclusive education, this book explores the principles that should guide teachers in meeting the educational needs of pupils with severe learning difficulties and relates these to effective classroom approaches. It examines the special needs of pupils with severe learning difficulties from the inside out, so that teachers understand the 'why' as well as the 'how' of education. It also examines issues of behaviour and punishment, offering positive and appropriate methods of dealing with classroom disruption. 192 pages. ISBN Number 1 85302 951 3 price £14.95 plus 10% postage and packing.

Available from Jessica Kingsley Publishers, 116 Pentonville Road,
London NI 9JB Tel 020 7833 2307 Fax 020 7837 2917

A full list of the publisher's wide range of publications all aspects of special needs can be seen on their website www.jkp.com

Holiday Insurance

ASSERT often gets requests from families who are trying to get reasonable travel insurance. We have been advised that [andrewjamesknox](http://www.askajk.co.uk) specialises in pre-existing medical conditions and have low premiums and low excesses; the telephone contact is Tanya Marno 01792 522622 Fax: 01792 522623 email: sales@askajk.co.uk website: www.Askajk.co.uk. We haven't tried the company, but it may be worth giving them a ring. Address is 118 Walter Road, Swansea SA1 5RE.

Sally Walburn uses Travelcare Limited, and they have always been reasonable as far as cost is concerned. 68 High Street, Chislehurst Kent BR7 5AQ.
Telephone: 020 8295 1234 Fax: 020 8295 1345 Freefone: 0800 181 532
email: info@travelcare.co.uk Website: www.travelcare.co.uk

**Please note that the deadline for the next edition of the
ASSERT Report is xx xxxxx 2002.**



Information from Contact a Family – Northern Ireland

Social Care Council – NISCC

The NISCC will be established from October 1st 2001. The Council aims to increase the protection of those who use Social Care Services, their carers and the public, by ensuring staff and employers meet agreed standards of conduct, practice and training. The Council will have two key responsibilities:

- To register and regulate the Social Care workforce and draw up Codes of Practice for Social Care Workers and their employers
- To ensure that staff are properly trained and qualified to do their jobs.

The functions of the Central Council for Education and Training in Social Work (CCETSW) will be transferred to the new Council, as will the functions of the Training Organisation for Personal Social Services (TOPSS). The ultimate aim of the Council is to raise the quality of the services provided and put in place better safeguards for the protection of people being cared for.

The NISCC will be relevant to you whether you are a user of Social Care Services, a carer, a social care worker, a provider or purchaser of Social Care Services.

Contact: Ms Pat McAuley, Chair, NISCC Communications Sub Group, C3.2, Castle Buildings, Stormont Estate, Belfast BT4 3SJ Tel. (028) 9262 7552
Website: <http://www.dhsspsni.gov.ni/hss/niscc>

New Helpline for SEN Advice

IPSEA, the Independent Panel for Special Education Advice, has set up a helpline in Northern Ireland to provide help and advice on Education and Library Boards' legal duties towards children with special educational needs. They seek to guide parents and guardians through the assessment procedure, helping them make written contributions to their child's assessment and to understand professional reports. Contact Geraldine McAvoy, Tel. (028) 9070 4606. IPSEA also runs appeals helpline, designed to help parents and guardians challenge decisions made by Education and Library Boards. The Appeal Helpline is open Wednesday to Friday, Tel. (028) 9070 5654.

Contact a Family information for Scotland and Wales

Scottish Charities Law Review Commission Reports

In May the Scottish Charity Law Review Commission presented its final report to the Scottish Executive. A large number of recommendations were made including:

- "Self-help" organisations can be Scottish Charities if (1) they confer wider public benefit and (2) they are run in a way that reflects public benefit culture.
- The establishment of a new regulator for Scotland (the equivalent of the Charities Commission in England and Wales) to be called Charity Scotland
- All charities operating in Scotland should be registered with Charity Scotland.
- Charity Scotland should provide free advice and information.

A full list of the recommendations and further information is available from the
Website: <http://www.scotland.gov.uk/consultations/justice/cllr-02.asp>
or call the public enquiry line, Tel. 08457 741741.

The Children's Commissioner Hears From Disabled Young People in Wales

Peter Clarke, the newly appointed Children's Commissioner met with the Children in Wales Forum on "Issues for Disabled Children and Young People" at an event held at Sofia Gardens in Cardiff in July.

Around eighty people, including young disabled people from across Wales, as well as representatives from voluntary organisations and statutory agencies, attended the event. The event was an opportunity for the Commissioner to explain his new role and outline the powers he will have to champion the rights of children and young people in Wales.

The members of the Forum and young people were able to state strongly to Mr Clarke the issues that most concern them, such as equipment and adaptations, access, leisure, education and transport. The Commissioner's enthusiasm for the new challenges ahead was clear and he said that disabled young people would definitely be seen as one of his priority groups. He will be meeting with the Forum on a regular basis to keep up to date with the main issues for disabled young people across Wales.

If you would like to know more about the Children's Commissioner or raise a specific issue with him contact: Peter Clarke, Children's Commissioner for Wales P.O. Box 21, Swansea SA1 3YB Tel. (01792) 482453 email: peter@childcom.co.uk
For more information about the Children In Wales Forum contact: Louise Harries Children In Wales, 25 Windsor Place, Cardiff CF10 3BZ Tel. (02920) 449 e-mail: ciw@globalnet.co.uk

Information for England

Special Educational Needs Code of Practice for England

The revised SEN Code was withdrawn on 12th July 2001. The Department for Education and Employment (DFEE) will be revising the section of the draft Code dealing with quantification of provision in statements, to address concerns raised by parents and others. A revised draft will be laid before both Houses of Parliament after the summer recess and, if approved, will be implemented from 1st January 2002. The approved version will be posted on the DFEE website when it is available. The 1994 "Code of Practice on the Identification and Assessment of Special Educational Needs" remains as Statutory Guidance until such time as a revised Code is approved by Parliament. Information is posted regularly on the Website: <http://www.dfes.gov.uk/sen/>

The Special Educational Needs and Disability Act 2001

The Disability Rights Commission has issued two new Consultation documents which relate to access to education for disabled children and young people in England, Wales and Scotland: Consultation on a new Code of Practice (Schools) and Consultation on a new Code of Practice (Post 16).

The Special Educational Needs and Disability Act will impose new duties in relation to access to education and they will come into force in September 2002. From this time it will be unlawful for bodies responsible for such provision to discriminate against pupils or students with disabilities. Copies of the consultation pack are available from the Disability Rights Commission, Tel. 08457 622 633 Faxback service 08457 622 611 Website: <http://www.drc-gb.org> the consultation ends on 31st October 2001.

Parental Leave

Parental leave entitlement is to be extended from thirteen to eighteen weeks for parents of disabled children and is expected to come into effect later this year. The consultation period ended in August and new information will be produced on how the practical arrangements for this additional leave will be implemented. Until that time, the present parental leave arrangements are as follows:

- Each parent of a child born or adopted after 15th December 1999 can have thirteen weeks off work to care for a child during the first five years of their life. However, if the child is in receipt of Disability Living Allowance, this right is extended to the child's eighteenth birthday.
- The leave is unpaid.
- This leave is applicable to parents across the whole of the UK.

For further information on parental leave contact the Parental Leave Enquiry Line Tel. (020) 7215 5986
Website: <http://www.dti.gov.uk>

Carers and Disabled Children Act

Under this Act vouchers can be issued by local authorities for respite care. This part of the Act is not expected to be implemented until October 2001. Contact a Family will be monitoring how the voucher scheme operates throughout England and Wales and would be very happy to hear from parents and groups around the country about their experiences of this scheme as it develops.
www.cafamily.org.uk
Contact a Family 209 – 211 City Road, London EC1V 1JN Tel: 020 7608 8700 email: info@cafamily.org.uk
Helpline: 0808 808 3555

Home Responsibilities Protection (HRP) for Parents and Carers

In order to qualify for your full basic Retirement Pension, you need a certain number of qualifying years (years you have paid enough National Insurance contributions) over your working life. Years you have been getting National Insurance credits through the benefits system can be taken into account as long as you have actually paid some National Insurance in the past. Gaps in your National Insurance record, that is, years you have not paid enough National Insurance nor been credited by the benefits system, can mean you get less than the full basic Retirement Pension when you reach retirement age.

You can have a gap of up to five years over your working life without affecting your Retirement Pension. However, parents and carers can further reduce the number of qualifying years they need to get the full Retirement Pension because of something called Home Responsibilities Protection (HRP). Home Responsibilities Protection can also help you to qualify for Widowed Parent's Allowance and Bereavement Allowance.

What do you need to do to get Home Responsibilities Protection?

A parent who has been the main person receiving child benefit does not need to claim Home Responsibilities Protection. It will be given to her/him automatically when child benefit stops or her/his youngest child reaches sixteen years (whichever is earlier).

A person who has been getting Income Support as a carer, will be given Home Responsibilities Protection automatically at the end of the tax year.

Other people with caring responsibilities who are worried about gaps in their National Insurance record may still qualify for Home Responsibilities Protection. However, they will need to make a claim.

Home Responsibilities Protection was introduced in 1978 and you can claim for any tax year from then. However, new rules expected in 2002 will restrict the number of years you can have backdated – so check it out now!

For an information sheet on Home Responsibilities Protection, call the Contact a Family Helpline 0808 808 3555

Grandparents and Relatives

Following an article in Contact a Family about Grandparents and feelings around having a grandchild with special needs, ASSERT would like to remind you all that any friends or relatives are very welcome to join ASSERT. The telephone support line, email and website are available to anyone who needs support or information on Angelman Syndrome. If you haven't registered with ASSERT and would like to receive regular updates, please contact Jim Brennan on 0175 426081

**PROFESSIONALS
HELPLINE**

01795 429061

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.

**If you enjoy these articles
please think about writing
one about your family, we
really find this the most
interesting part of the report.
The address to write to on
this or any other subject is:
ASSERT
P0 Box 505
Sittingbourne
Kent ME10 1NE**



SNUG (Special Needs Umbrella Group)

Northamptonshire

This Special Needs Umbrella Group has been running in Brackley for just over a year. The group supports parents and carers of children of all ages who have any kind of special need, whether this is physical, emotional, medical, behavioural, developmental or undiagnosed, with or without a statement of Special Educational Needs. The group was set up by parents with the help of a Health Visitor and Social Services, and is run by parents for parents.

The group meets twice a month on a Tuesday morning to share experiences, ideas and information. Two or three times a term they have a visiting speaker to talk on issues of common interest. In the past this has included advice on benefits and grants available, talks from 'Special Needs Involving Parents', and visits from an Educational Psychologist and a Special Needs teacher. This term they will be having talks from the Parents in Partnership Team and from a Child Development Worker at the Social Services Department. All children are welcome at the meetings.

"We are a small, friendly and very approachable group and would love to hear from anyone interested in joining us. We welcome people from a wide area." Further details can be obtained from Gina Thorne, Tel. (01280) 704016.

Research Joseph Rowntree Foundation

The Impact of Childhood Disability on Family Life

This study carried out by the Joseph Rowntree Foundation (JRF) describes the actual spending patterns of parents and considers some of the adjustments families have to make because of caring for a child with a severe disability. A few key points of the research are:

- Parents of disabled children spent almost twice as much on comparable items as parents of non-disabled children.
- Parents were only able to spend half of what they felt was required to ensure a reasonable standard of living.
- Parents spoke about the love and joy they received from their child but also discussed the emotional costs and how their families adjusted to the needs of their child.

As one parent in the study was quoted: "I'm careful with money; I know I don't waste it. I buy what we need but Helen (disabled child) needs more than her sister, more nappies, more clothes, more creams, more things to occupy her because she is stuck in here with me all the time. I have two children and I know it costs more, a lot more for Helen and there is nothing you can do. You just have to pay it."

Consultation

Many recent pieces of legislation and policy have focused on the need to consult with children and young people on the decisions that affect their lives, including children and young people with disabilities. This research, which was based on two projects working with children and young people with disabilities, found that:

- Disabled children and young people have strong views about the society they live in, how they are treated, services they receive, their education, health and leisure.
- Disabled children and young people wanted resources, equipment and support so they can access everyday things, which most children take for granted.
- The experience of those involved in the projects was that all children can be included and enabled to express their wishes and feelings.

Copies of the full findings of these and other pieces of research are available on the JRF Website: <http://www.jrf.org.uk> but if you do not have access to the Internet, Tel. (01904) 615905

Care Co-ordination Network UK

Care Co-ordination Network UK has three main aims:

- championing disabled children, young people and their families
- evaluating and promoting best practice in care co-ordination
- information sharing

It has appointed its first Development Co-ordinator to develop and set up an umbrella organisation that promotes care co-ordination or keyworking for disabled children and their families. At the moment the organisation is compiling a list of care co-ordination/keyworking schemes throughout England, Northern Ireland, Scotland and Wales. In the autumn, it plans to have a membership pack and newsletter available. Membership for parents and young disabled people will be free and the network is particularly keen to promote the involvement of parents in the organisation.

The network is organising its first UK wide conference and official launch on Tuesday 30th April 2002 in Manchester. Details of the conference will be available in the autumn.

If you are interested in finding out more or want to receive details of membership, or the conference, contact: Katy Barton, Development Co-ordinator, Care Co-ordination Network UK, Social Policy Research Unit, University of York, Heslington, York YO10 SDD Tel. (01904) 433605 e-mail: kbl7@york.ac.uk Website: <http://www.york.ac.uk/inst/spru/ccnuk.htm>

Channel Swim

Our latest fundraising venture toward the 2002 conference is Bernie Silver's offer to 'Swim the Channel'. Before you all think, "Poor Bernie, the winter's coming – won't the water be cold?" He's not swimming the actual English Channel, but an equivalent distance in his local heated pool!! If you would like to sponsor Bernie, please complete the enclosed sponsor forms and return them to ASSERT with monies once we have advised you that the swim is accomplished. Remember this is a great opportunity to raise funds for ASSERT without even dipping your toe in the water – we will let you all know how much money is raised in our next ASSERT Report.

Junior Caravan Club (MCCC)

We are very grateful to another grandparent (Brian McGiveny) for nominating ASSERT as the recipient of £1330 which the Caravan Club Junior Division spent a whole year raising for us (Brian is a member of the Caravan Club). Apparently it was more difficult this year because of Foot and Mouth (many rallies were cancelled). So the young

people did really brilliantly and we are extremely grateful to them for all their hard work. Thanks also to Bonnie and her Mum Patsi (Whelan – Archer) for accepting the cheque on our behalf. The money will be used towards the cost of the conference next year.



Presentation of the cheque

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:

Annette Cheatham
Sue Donnarumma
D and L J Hendy
Mrs Myers
Anne and John Peniket
In memory of the Late Parents of Alan Pryor
Mrs M Smeeton
St Michaels Wednesday House Group
Mrs D Williams/daughter/friends

Crossword Winner

Many thanks to Margaret Kinnear of Shaftesbury (Grandmother to Isabelle who has AS) who donated her winnings of £100 to ASSERT when she entered and won a crossword competition in 'Good Neighbours News'. Elaine Sears (our treasurer) collected the cheque on behalf of ASSERT, thank you Margaret!

Assert Family Weekend Conference

Our second national conference is scheduled for the weekend of 6/7/8 September 2002 at the University of Loughborough in Leicestershire. We have already sent out flyers for this as you know and would reiterate that it is definitely 2002 and not 2001 as we believe some of you thought.

Accommodation

Butler Court – This block has 201 twin bedded rooms, over 4 floors, each with en suite shower, basin and toilet. The block is sectioned so that there are 3 rooms and a kitchen in each section. (Access to the kitchen is by special arrangement).

Shop

There is a small shop on the campus (ideal for those little things one forgot!)

Situation

Loughborough University is situated $\frac{3}{4}$ of a mile from the town centre and covers a large compact area.

Access

By Road Main entrance 1.5 miles from Jnct 23 of M1

By Rail 1.5 hours from St Pancras on the Sheffield line, bus service/taxi to campus

By Air East Midlands airport is about 8 miles North

Parking

Ample: close to all halls to be used.

Medical Facilities

There is a sickbay during normal working hours and a Doctor on 24 hr call. The nearest A&E is at Leicester about 10 miles away.

Recreational Facilities

Conference delegates are allowed to use all the facilities. Being a sports University these are very good.

Cost

As last time we have endeavoured to keep the costs to a minimum. Please bear in mind that most other conferences charge a registration fee; accommodation is extra and then on top of that you are expected to pay for your own food. Our price includes everything; the only additional extras would be drinks at the bar. For this fixed price you have accommodation, breakfast (full English), lunch (two courses), evening meal (three courses) and tea/coffee during conference breaks, [special diets can be catered for, as long as we know well in advance], use of all the University sports facilities including the swimming pool. ASSERT is subsidising some of the cost. Professionals will be charged at a different rate, please contact us for details.

Adults £50.00 per person per night

Children £25.00 per person per night

AS Children/Adults FREE

Parent carer/ carers FREE

Funding

For some of you, even though we are subsidising costs, the conference may still be expensive. We do have some suggestions for obtaining funding and you have plenty of time to organise this. The Children Act states that the Social Service Department (SSD) has the power to assist families who live with disabled children/young people, therefore families should consider asking their SSD to support their attendance at the conference by providing respite, using a known carer, either at home, in a respite unit or at the conference itself. However, families will need to push their SSD to make them understand that this sort of cash input in the short term is likely to save the need for greater input in the long term.

If your family doesn't have an allocated Social Worker you need to speak, or write, to the duty social worker stating clearly the need and the reasons for attending this conference.

Emphasising that by attending the conference families will have better access to understanding and support from those who KNOW about AS, and will also enhance the understanding and support of the whole family giving them a far better chance of surviving the ordeal of living with an AS child/ adult relatively intact! Which means the AS person will therefore be more likely to become a more acceptable and fulfilled person in their own right and less of a drain on services in the future.

Other areas of possible funding are local Lions and Rotary Clubs, Townswomen's Guilds, Women's Institutes, Masons and local businesses that may sponsor your child's attendance at the conference. If you, the families, don't ask you will NEVER receive.

If you know of any sources of funding which may be useful for other families, please let us know.

Children's Activities

These are to be arranged. If anyone has knowledge of the area and suggestions, please get in touch.

Carers

Due to strict guidelines within the Children's Act and acting in accordance with those of the Local Authority we are unable to provide carers. So, if you require a carer, they will need to come along with you. It is essential that if you are bringing children you have a full time carer, we feel that it is most important that there are NO children in the formal discussions and talks at the conference, it is distracting to both the speakers and those attending. We want everyone to get as much as they can out of the conference, there will be plenty of time for socialising during the course of the weekend, and this will be the time when we can all relax and enjoy our children being together. As this is an extra expense, ASSERT is fully subsidising the accommodation and food costs of all carers to enable families to bring a carer free of charge. However, we are unable to meet the employment costs of carers. This is thanks to the monies raised by Ken Walburn from the London Marathon last April.

Remember that parents are carers and therefore one parent, providing they are caring at the conference (even if you swap around) will qualify as a free carer. For example, Mum may go

on Saturday to the conference whilst Dad goes with the AS child/ adult/ children on the outing, then on Sunday it might be that Mum goes swimming with the child/ adult/ children and Dad goes to the Sunday session.

Exhibition Space

We will be selling exhibition space, so if you have used or developed a product or a service/alternative therapy, which could be of interest to other families, get in touch with Jim Brennan or Dick Barton and we will contact the companies concerned.

Posters

It would be nice to have a display of posters – so if you have anything you wish to share with other families and could make a poster display then please let Jim Brennan know. This can be on anything from Alternative Therapies to Equipment to Hints and Ideas, to Research both from parents as well as professionals. We have a large foyer area to use so this is a great opportunity to share your information with others during coffee breaks/lunch time/after sessions.

Expenditure

At the last few meetings the trustees of ASSERT have been looking at the costs involved in running the organisation and we would like to share with you where funds have been used over the last 6 year period between 1993 and 1999, the year 2000 accounts were being audited at the time these figures were prepared so we are unable to bring you those at present. Through fundraising efforts and the stamps/sale of t-shirts, and recycling a total of £101,503.00 has been raised over the six-year period. Of those monies, we have used £12,424.00 for the support line, £18,572.00 for the newsletter including postage and stationery, trustees expenses amounted to £14,929.00 and we have given £11,222.00 to research. We have also spent £4,764.00 on regional meetings, plus other funds used for insurance, equipment (computers, fax machines, telephones, photocopier, etc.) subscriptions, and sundries.

This gives you an idea that the cost to run an organisation such as ASSERT is an average of £11,400 per year not including conference years when the expenditure is higher. So any donations are extremely valuable to us and we hope represent good value for money.

ASSERT 2000 Club Draw

This was drawn on 31st October 2001, By Mrs Laura Jobson, Co-ordinator Home-Start Sittingbourne & Sheppey and witnessed by Mrs Mandy Gambel Administrator Home-Start Sittingbourne & Sheppey. Winners: **£70** Alan Whiddington, Herts. **£40** David Hemsley, Portsmouth. **£30** Mrs L Sowcroft, Bolton. **£20** Mrs A Pyatt, Pangbourne. Congratulations to all.

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	Sally Walburn
THURSDAY	Elaine & Stephen Sears
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