

ASSERT

Angelman Syndrome Support Education & Research Trust

ISSUE THIRTY NINE JULY 2005

REPORT



Website: www.angelmanuk.org

Email: assert@angelmanuk.org

Telephone: 01268 415940

REGISTERED CHARITY NO. 1021882

Newsletter 2005

Hello and welcome to the first newsletter of 2005. Sorry it has taken so long – but we are still here!!

First of all some good news on the ASSERT front. As you all know we have been appealing for some time for new trustees and people to help with ASSERT in general. We have to say that the response from everyone has been good and thanks to those of you who have put yourselves forward to help – in the main the trustees cover the work of ASSERT but should we need any extra help at any time, we may call on you. One of the best outcomes of the conference was the energy and enthusiasm generated and the following people have stepped forward as new trustees:

Finn Emmerson	Pete Munro
Suevia Perez	Jeremy Webb
Patsi Whelan Archer	Richard Williams

In this edition of the ASSERT Report, we have included a short introduction to all the new trustees, and some of you may have met them at the recent conference. As said before, Ken Walburn, Jackie and Bernie Silver stepped down at the end of the year and so we thank them for all their hard work and support over the years. I will be continuing with ASSERT for the time being to support the new trustees and the new chairperson, Jeremy Webb who took over this role as from 1st April 2005 – many thanks to Jeremy (who has designed and runs the website currently) for putting himself forward and this I have to say is a great relief to me! We look forward to working with a new team with fresh ideas and new blood, this will be another new beginning for ASSERT and will move the charity up a gear I am sure.

On the bad news front, Nick Bartholomew wishes to step down in his role of treasurer, and this is a space that we need to fill urgently. The treasurer is responsible for maintaining the accounts, preparing them for the auditor, writing and dissemination of cheques, thank you letters, Gift Aid and the collection boxes. The role is not a huge task and I guess an hour or so a week (maybe more if we have an event, or the Gift Aid needs reclaiming). If you can help, you will need to become a trustee, but we are a friendly bunch and you would need to only attend one trustee meeting a year – the new trustees have already taken on new tasks, so if there is anyone out there who could take on this role, please get in touch.

David and Maragaret Kinnear will also be leaving us in July, they have decided that as there is new enthusiasm to take the charity forward, this is a good opportunity to hand over. ASSERT thanks them for the help and support they

have given over the past few years and we wish them well in the future.

We have several projects planned for the year and may need help from you on these. One is a video as a basic introduction to Angelman Syndrome with the intent of being information for new families. It is hoped that we may look at producing specific videos in future, targeting professionals for example or subjects like epilepsy, communication etc, related to AS. Of course this will require some planning and development and may take some time. It has been a long-term aim of ASSERT to create a video library, and hopefully this will be the beginning. If any of you have experience in this field, we would be extremely grateful for your input.

We are also looking at revamping the trifold leaflet and we would like to review the packs sent out to newly diagnosed families. We would be very grateful if you could complete the enclosed questionnaire about this and other services, we are really keen to hear your comments and suggestions.

Also enclosed with this Report is an update form – this is so we can update our records – please do take time to have a read through it and amend where necessary – has your phone number changed? What about your email address? Have you now got a confirmed diagnosis? (This is especially relevant if we asked to put families forward for research purposes.) The form will also help us compile the Contact Register this year – which as you know is a valuable resource for contacting other families in your area. You will notice that we have incorporated part of the form to the type of ethnicity you and your family are. This is in line with many other organisations, and will help us if we need to apply for grants in the future. It also helps with research.

Regional Meetings – Do you want to host one this year? Do you have a good venue you could share with other families? As this is a non conference year, there will not be any opportunity to meet up with other families until next September....if you get a conference place...so think about organising a meeting in your area – we will do all the invites and help where we can, and provide finance – all you need to do is organise a venue and provide some food and refreshments....Have a think!

That's all from us at the moment – we are welcome to ideas and suggestions at all times so if you have anything you can share with us from adaptations, to holidays, to education and equipment, therapies or simply a story from your lives, please do pass this on to us.

Sally Walburn

London Marathon

We had two runners this year who have taken up our Golden Bond Runs – we are pleased to announce that all of them finished and in good time too! Well done to them, the race on the day is just the culmination of many months of training – so that grounding is where all the hard work and effort takes place. Of course there is nothing like finishing on the day itself!!

Congratulations to:

Marcos Perez 4hrs 04mins54secs

Stephanie Watchorn 4hrs 59mins 17secs

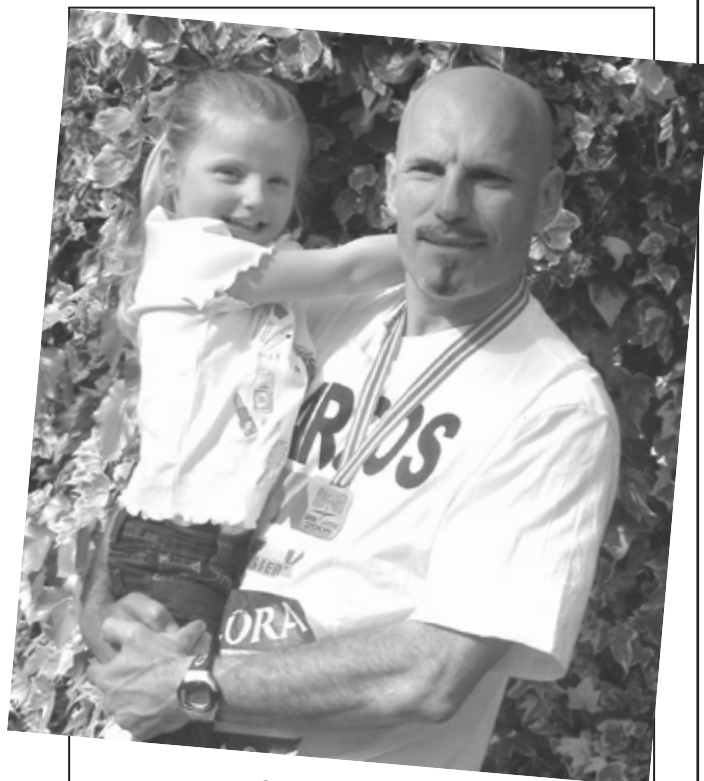
If you have been inspired by their efforts, please think about running next year – we have seven Golden Bond places up for grabs – you will be expected to raise a minimum of £1000 for each place – if you would like more details, please contact us, and register your interest (there is no obligation at this stage).

Why Did Marcos Run in the London Marathon?

When Marcos's grand-daughter was about to be born in England, he jumped on the first plane out of Galicia, northern Spain, to be there with her and his only daughter. It was love at first sight and he became the stereotypical doting grandfather even from his home 4000 miles away.

Months later when Jade was 21 months old she was diagnosed with Angelman Syndrome and Marcos, along with the rest of the family vowed they would do anything they could to make life easier for Jade and her parents. This began with finding out all about the Syndrome and this Charity.

His daughter recently became a trustee of ASSERT and through her encouragement Jade's family stepped up their efforts in supporting the Charity. Many ideas were thrown about between them but Marcos came up with the winner, he was going to run the London Marathon. And so began the months of training in the Spanish heat whilst his daughter was making the arrangements over here and sponsor forms were handed out left, right and centre to raise as much money as possible for this little known Charity. And so, on Friday April 15th, Marcos, with his wife Mercedes, flew over from Galicia to London to spend the weekend with their daughter, son-in-law and granddaughter and to take part in



My very special Grandad

the 25th FLORA London Marathon. By Sunday morning the family had spent a relaxing couple of days catching up with each other and spending some quality time together but the time had now come for Marcos to start this all-important run. Marcos crossed the start line shortly after 10 am and almost four hours later passed his family waiting outside Buckingham Palace cheering, shouting, waving and taking photos. They handed him the Spanish flag and he crossed the finish line after 4 hours and 4 minutes wearing his nations colours and having made an important contribution not only to the funding of ASSERT but also raising the profile of the Charity.

I am Suevia Perez Castro, I am Marcos daughter and Jade's mother and myself and my husband Mark are extremely proud of the time and effort that my father has put into supporting us, my daughter and helping to support other families like ours.

Thank you Dad, for your continued support, encouragement and love and I am entering you for next years marathon so lace up your running shoes and start training now!

STOP PRESS – Dates for your diaries!

Just had confirmation of Conference 2006 – Loughborough University 8-10 September.

Details will be revealed in due course!

Family Stories

Unfortunately we have no family stories to bring to you this Report. If you would like to see some in the next newsletter, please send in an article and photo if possible. Sally has been reliant on finding articles in other newsletters to bring to your attention and hopefully help families but, it would be really helpful if you could all look at notice boards, pick up leaflets and perhaps cut out articles which would be of help to other families, and send them in to us here at ASSERT, this would allow us to write a more regular newsletter as we would then have something to put in it!!

**Many thanks –
the ASSERT Trustees**

Christmas Cards

For some years now, we have been asked about Christmas Cards – we have been given a very generous



offer from Qd – Quarto design and Rivington Press, Jackie and Aleks Klimanski have offered to print Christmas cards free of charge, therefore 100% of the cost of the cards will come to ASSERT.

In order to assist us with this, we would like to run a competition of designs from families – there will be one winner from each age group – they will obviously see their design in print and they will receive a pack of each design free of charge. The age groups are as follows: 3 – 5 years, 6 – 8 years, 9 – 12 years, 13 – 16 years.

The artwork can be done by siblings or by Angelman Syndrome children/young people (no age restriction for AS) – all are welcome to have a go. Please send in your design on an A4 sheet of plain white paper, entries to be submitted by **1st September 2005** to the PO Box address – the trustees will judge the entries.

This is a great opportunity so please do support us.

Wheelchair Accessible Vehicles

Ken and Sally Walburn have had been looking into wheelchair accessible vehicles, for their son Matthew, who at 13 is still unable to walk unsupported. He was becoming increasingly heavier to lift in and out of the car, and therefore the time had finally come to give up and give in to having a wheelchair accessible car. Matthew was having a plaster cast for his spine done in February and therefore the vehicle was needed fairly quickly. (The plaster cast is for Matthew's scoliosis, in an attempt to maintain the curve for as long as possible without it deteriorating.)

Sally wrote: We sold our family car and therefore had the money to purchase a vehicle, but what? Some years ago we decided not to take up the Motability scheme and looking into having a vehicle adapted, that is not the way to go anyway. I made enquiries with all of the companies that do adaptations to vehicles, and looked into purchasing new, and even adapting a vehicle we already had (Citroen Berlingo) what shocked us was the price – at least £7000 to adapt, on top of the cost of a new vehicle. The other issue for us was that we couldn't wait the three months that most of these companies quoted as the time it would take to get the car. Some had second hand or demonstration vehicles for sale, but these were almost as much as the new ones.

In my Internet trawl I found some vehicles for private sale, but these seemed to be snapped up fairly quickly. Eventually I found a company in Kent, not too far from us here in Essex who sell second hand adapted vehicles.... we arranged to visit one weekend and saw all the different types of vehicle, from old to new, from Renault Kangos to Mercedes Vans, all different ages and types of adaptation – believe me they vary and it is very useful to have a good look and try them out. In the end we went back the following week and bought a VW Caddy as Matt's Van and this we use whenever we need to take him out. We didn't need a Ford Galaxy or anything of that size, since both our daughters drive and we rarely go out as a family, but there were these vehicles there as well. They are sold with a year's warranty, MOT where applicable and fully serviced. They also show you how to use the relevant tie down straps and seatbelts.

The company is Geoff Clarke Mobility and they will come out to you if you cannot get to them, have a look at their website www.gfclarke.com
Geoff Clarke Mobility, Holborough Rd, Snodland, Kent. Tel 01634 243596

Anaesthetics

Sometimes there is concern over our children and young people having general anaesthesia, particularly if they are epileptic. One of our parents is an anaesthetist and is willing to talk this through with you if you have any concerns. Please contact Liam Brennan on 01223 890690

**Please note that
the deadline for
the next edition
of the
ASSERT Report
is 31st August 2005.**



Help/ Support

We received the following information from Patsi Whelan Archer about Donna's Dream House Charity – they provide free holidays in Blackpool for children with life threatening illnesses along with their families – (AS falls into this category particularly if your child has severe epilepsy).

For further details phone Len on 01253 620790 or 627644 or write to:
Ref. LJC/3 39
41 Chapel Street
Blackpool FY1 5AW.

Patsi and family stayed and had a wonderful holiday there.

Kids Out

www.kidsout.org.uk

ASSERT has received this information from Kids Out, this may be of interest to you as families or also to organisations you may belong to:

They wrote:

Kids Out is the National Charity providing fun and happiness for disadvantaged children.

I am writing to inform you that we have established a confidential Help line, which offers an information and signposting service. Parents, teachers or other organisations can call us on 01525 385232 for help with respite care, special travel and holidays, fun days out or just a listening ear when things get too much.

Grants are also available to help make life more fun for disadvantaged children. We offer funds to help provide specialist equipment such as specially designed toys, terrain buggies or help towards fun days out, holidays and respite breaks for both parents and children. In 2005 we will be helping siblings of disabled children, young carers, children from women's refuges and youngsters moving from children's homes into hostels. All requests for grant aid are via our application form available through the Help line.

Should you require any further information, please do not hesitate to contact us.

Grants & Information Officer, KidsOut 14 Church Square
Leighton Buzzard Beds. LU7 1AE Telephone: 01525 385252
Fax: 01525 385533 Help line: 01525 385232
Email: kidsout@kidsout.org.uk Web site: www.kidsout.org.uk

Services they provide

- **Grant Aid:** Apply now for financial assistance towards the costs of outings, holidays, and entertainers, special play equipment and toys. We help individuals, groups and families.
- **Respite Care:** We provide information on day and residential homes and centres for special needs children and their families. Kids Out grants are available towards the cost – giving carers, children and their families a welcome and much needed break from what is often a very stressful routine.
- **Help line and Support Services:** Help and support is provided on many issues, including information on specialist parent support groups, special holidays, holiday play schemes, advice on respite care homes and a listening ear when things get too much.
- **Activity Days:** We work with many groups, such as children in Women's refuges and life limited children in hospices, to provide fun and laughter through special activity days such as a trip to a zoo or a creative workshop.
- **Child Carer Programme:** We provide days out, visits to sports events, cinema and activity weekends for child carers (whether they care for brothers, sisters or parents) as well as children whose siblings may have such severe special needs that they become isolated or socially excluded.
- **16 + years:** This scheme provides fun, interactive and social activities that help young people who at 16 years of age have to move from care into hostels.

Alternative Therapies

Dear Assert

I have just received your reading pack and although we were not able to get to the conference it was good to know people enjoyed themselves. I was very disappointed to see that the Alternative therapists were in such a poor show. It is on this point that I would like to talk to all the other parents whose child has Angelman syndrome.

My daughter Lucy who is 4 has Angelman syndrome, and when she was younger she did have physiotherapy once or if we lucky twice a month. Last year just a few weeks before her 3rd birthday she started to take her first steps on her own. Deep and utter joy for all of us. But as far as the physiotherapy was concerned that's all they could do for her. Unfortunately Lucy walked like she had got off a horse or gone ski-ing for too long. In the mean time I had been training as a Bowen Therapist and just as well. I took over my daughters physical side and she started having Bowen once or twice a week, it now over a year and what a

difference. She walks upright and because I worked a lot on her ankles as well, she is no longer in Pedro boots, I cannot tell you how emotional I was when we went to get her, her first real trainers and shoes. The only time she becomes a bit bent in her legs is if she is ill or very tired. Bowen has been a great success and I urge any parent who has not tried this therapy to at least have a go.

If you wish to check the web site first, which I encourage, you can either have a look on my web site, which is www.babowen.info or just put www.bowen-technique.co.uk this will give you all the information you need. I hope this will be useful to all parents.

Barbara-Anne Chapman

We do know of another parent at ASSERT who is also qualified in this technique, if you would like to speak to either Barbara or Sue Hathaway please get in touch with us.

Carers UK

www.carersuk.org/backmeup

Ever wondered what you need to think of in an emergency as a carer – here is a plan from Carers UK to help you plan.

1. Find out if there is a Carers Emergency Scheme in your area. This is a single contact number with an operator at the end of the phone who can put into action your pre-arranged emergency plan. A list of Carer Emergency Schemes can be found at www.carersuk.org/backmeup or by phoning 020 7566 7617
2. Find out about other emergency help in your area by contacting your local carers' organisation. Help includes
 - Emergency social services duty team
 - Emergency respite and sitting services
 - Community alarms
3. If you are relying on family and friends to help out in an emergency make sure you discuss with them in advance what's involved in caring. Let them have details such as
 - Medication
 - Contact number for emergency social services duty team
 - The person's disability, illness or condition

- The person's likes and dislikes
 - Any other people involved in their care e.g. day centres, care agencies etc.
4. If you need professional help to draw up an emergency plan contact social services (phone number in phone book) and ask for a carer's assessment. Carers have a legal right to an assessment and it should cover planning for emergencies.
 5. Fill out the list of useful phone numbers below. Keep copies by the phone and in your purse/wallet. If you use a mobile make sure the numbers are programmed into your phone. Include:
 - Local social services emergency duty team.
 - Out of hours GP service
 - Numbers for day centres and or other services attended by the person you care for.
 - Relative, friend or neighbour who knows about the person you care for

Remember National Carer's Week

Information from other organisations:

Thanks to SNAP newsletter for the following information:

Relationships and caring for a disabled child

Many couples find the stress of caring for a disabled child can cause relationship problems, but now a new fact sheet has been produced by leading charities Contact a Family and Relate to help parents cope.

The free fact sheet entitled 'Relationships and Caring for a Disabled Child', draws on the views of 2,000 parents surveyed in 2003. It details the main issues faced by parents with disabled children, puts forward practical solutions and lists a wide range of helpful organisations and resources.

The sheer hard work involved in caring for a disabled child, a lack of time for each other and the wider family, and worries about money, accessing services and the future all contributed to high stress levels, and all combined to have a negative impact on their relationship, said parents.

Taking managing relationships first, the fact sheet highlights parents' top tips for keeping relationships on track. Couples recommended:

- Talking things through. Being open about your feelings – be it disappointment, anger or grief
- Sharing the care
- Making time for each other by asking other family members for help or using professional respite care

Other sections deal with practical issues such as housing, finance and benefits and detail sources of support, for example, linking up with other parents. The fact sheet also looks at what happens if a relationship does break down, with information on how tax credits and benefits change, child access and maintenance arrangements, and dealing with domestic violence. Mark Robertson, Contact a Family's National Advice and Information Manager and author of the fact sheet said, "When a child is born or diagnosed with a disability, it can be an extremely difficult time for families. But, with the right help and support, people can pull through, and often parents find that their relationship is stronger than ever."

To order your free copy of the Relationships and Caring for a Disabled Child fact sheet, telephone Contact a Family's help line on 0808 808 3555, or email helpline@cafamilly.org.uk Contact a Family is a national organisation that provides support, advice and information for families with disabled children. It provides information on over 3,000 conditions and produces the Contact a Family Directory, which details specific conditions, rare disorders and UK family support groups. Website: www.cafamilly.org.uk

How do they manage? Income and expenditure of Families with Severely Disabled Children

The Family Fund has produced a research paper focusing on patterns of income and expenditure amongst families with severely disabled or seriously ill children.

The findings are based on an analysis of questionnaires completed by 98 families from the Family Fund database between November 2003 and February 2004.

The paper shows that these families have low incomes relative to average family income in the UK and are forced into higher expenditure due to the nature of their disabled child or young person's additional needs. In many cases, this extra expenditure exceeds the family income by a significant margin. Many families struggle on a daily basis to fulfil the needs of their child and use a variety of methods, including credit, to overcome their immediate financial hurdles. The paper also investigates how much families believe they require so that they can satisfactorily meet their child's needs. Families reported that they needed an extra £ 104.68 per week (£5,443.36 per annum) over and above their current incomes.

Key findings:

- Families with severely disabled and/or seriously ill children have low average income compared to families without a severely disabled/seriously ill child
- These families have significant additional expenditure related to the needs of the disabled/seriously ill child
- Many families cannot afford to meet these additional needs and use various forms of credit so that they can bridge the income-expenditure gap
- Families reported that, on average, they need an extra £5,445.00 per year coming into the household in order to fully meet their child's needs

For further information email: info@familyfund.org.uk

New online linking service for families

Contact a Family has launched a new website which enables families with disabled children to get in touch with each other over the Internet. For families affected by rare disorders there may not be a local or national support group, so finding similarly affected families can be very difficult through the usual routes. The 'Making Contact' website will enable families to link with one another across the world, electronically.

By visiting www.makingcontact.org families can see if there is anyone else affected by the same condition who is looking for contact with others. You can select to contact other parents or look for people in your area. Disabled adults may also use the service to contact one another.

Registration so that others can find you is free. If you wish to make contact with someone, there will be a charge of £5 per year. For more information visit www.makingcontact.org or www.cafamily.org.uk or telephone the Contact a Family Help line on 0808 808 3555.

Online Parents' Group

Scope has established an email parents' group specifically for parents of disabled children who are interested in influencing government policy. The group will feed parents' views and personal experiences into government departments in order to improve the lives of disabled children and their families.

If you are interested in joining the group, please contact Scope on 01432 370860 or email earlyyears@scope.org.uk

Disabled Facilities Grant

More than £101 million is being made available nationwide to help disabled people adapt their homes through the Disabled Facilities Grant this year. This compares with £99 million available last year. To apply for this funding, you should contact your local council. You will be assessed by an occupational therapist and means tested before a grant can be made.

Website for Young Carers

A new website from the Princess Royal Trust for Carers is the first UK-wide resource for young people who look after someone in their family who has a disability or health condition. The site offers support via email, supervised message boards, chat sessions and useful information. Visit www.youngcarers.net

Check The Map (www.checkthemap.org) has just been officially launched at the Special Needs Fringe Exhibition in Olympia.

- It is a groundbreaking, not-for-profit site that gives FREE promotion to all Learning Disability (LD) Services across the UK and Ireland.
- One place to find all your local and national services, psychology, education, health, companies, therapies, charities, projects, schools, clubs, sensory teams, information, support, consultancies, advocacy ... everything, across every sector.
- Likened to a LD Yellow Pages, you can search the site by town, region or category to find every service, no matter how big or small.
- You can promote any LD related service or resource quickly, easily and without any charge.
- Click on www.checkthemap.org now, to find out more. This is a powerful new site – not to be missed.

Imogen Wedgewood
imogen@checkthemap.org
www.checkthemap.org

"One place for all Learning Disability services"

Fax your Member of Parliament

A new website has been launched that allows you to fax your MP for free and let them know your views on current issues, like for instance, the plight of families with a disabled child. The address is www.faxyourmp.com

SIBS – For Brothers and Sisters

Sibs is a charity for people who grow up with a brother or sister with special needs, disability or chronic illness. Many siblings need support and information at different stages of their lives.

Growing up with someone with special needs can be very rewarding and very difficult at the same time. The charity's aim is to make a positive difference to the lives of siblings.

For more information visit the Sibs website at www.sibs.org.uk

Email: info@sibs.org.uk or

telephone the Sibs Information

Line on 01535 645453.

Pension Information

If you are a carer and NOT in receipt of Carer's Allowance you may be able to register for an additional state pension.

Your need to review your circumstances every year to make sure you don't miss out on the opportunity to build up additional State Pension through the State Second Pension.

What is the State Second Pension?

Since April 2002, certain carers and parents have been able to build up additional State Pension through the State Second Pension. Many carers and parents will build up State Second Pension automatically but some may need to take action to ensure they get more when they retire. For example, some carers and parents may need to make a claim for Home Responsibilities Protection (HRP) and there are time limits for doing this. (From the April 2002/03 tax year, claims for HRP need to be made within three years of the end of the tax year in which the caring took place.)

Further Information

To find out more about State Second Pension, who can benefit and who needs to take action please see the guide State pensions for carers and parents (PM9). www.pensionguide.gov.uk or you can 'phone for a copy 0845 7 31 32 33

Wills Information

<http://www.mencap.org.uk/html/legacies/legacies.htm?id=26324&NID=64>

By writing a will, parents can make sure their children get the support they need when they die.

Transition in Education – Information for Children with Speech and Language and Communication Difficulties

www.talkingpoint.org.uk/home.asp?type=9&uid=661

Transition Planning – Progress Fact File

Year 9:

- Your local education authority (LEA) invites you to the 14+ transition review.
- LEA notifies social services.
- 14+ transition review meeting takes place.

Year 10:

- Parents/carers are notified of 15+ transition review.
- Do you want any changes to your plan?
- Now is the time to approach personal advisers for guidance.
- Start to make a visit to local colleges.

Year 11:

- Is your transition plan still relevant?
- At 16, social services children's teams will liaise with Adult Care Managers about planning meetings.
- 16+ review should make firm plans about provision.
- Relevant approaches and applications for places made
- The Connexions Service/Careers Wales should attend to ensure that the transition plan is updated.
- LEA apply for funding from the Learning and Skills Council and Education and Learning Wales if relevant.

Year 12:

- 17+ review. Is your plan still relevant? What changes need to be made?
- Transfer to Adult Care Team may take place at 16, 18 or 19.

Source: Contact a FamilyWeb: www.cafamily.org.uk/ Transition planning in Scotland has just been updated and revised by the Education (Additional Support for Learning) (Scotland) Bill, and will become law in 2005. Coordinated Support Plans (CSPs) will replace the current Future Needs Assessment. The CSPs will consider the additional support a young person will need and will provide that information to other agencies such as colleges or universities.

Toy Story

There is now a website, www.tfhu.com for all special needs children; their families and carers provided by tfh, the specialist toy manufacturers. Check out the website or telephone: 01299 827820 for information.

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.

ASSERT Website

www.angelmanuk.org

ASSERT Email

assert@angelmanuk.org

All Change

Transition into adult life – a resource for young people with learning difficulties, family carers and professionals

Transition can be a particularly complicated and stressful experience for a young person with disabilities and his or her family. All change looks at the process of transition in England and the main issues and choices that may arise, both in the lives of young people with learning difficulties and for their families.

This new resource is aimed at young people with learning difficulties as they pass through transition into adult life, as well as their family carers and professionals. It covers what happens when the young person leaves school, the choices they might need to make about further education, work, housing and leisure, the transition to adult services and the different options and types of support that are available.

The material comprises two parts:

- Part 1 is for adults who are supporting young people with learning difficulties through transition, and is intended to increase awareness of the issues underlying Part 2, in order that adults can be of most help to the young person
- Part 2 consists of accessible illustrated text for young people with learning difficulties.

This innovative guide has been written at a time of much positive change, including new Government initiatives such as Valuing People: A New Strategy for Learning Disability for the 21st Century, the revised SEN Code of Practice and the new Connexions service. These mean that the path of transition will hopefully be smoother in future and will be very much focused on the needs of each individual young person. The material has a strong family carer viewpoint, to assist parents, and also help professionals understand the parental viewpoint. Of particular interest to: Connexions services, Mainstream SENCOs and special school staff, parents of young people with learning difficulties, parent partnership services within local authorities, transition workers in social services and health (in children's and adult departments), advocacy groups who work with young people, self-advocacy groups and community teaming difficulty teams.

Format. ringbound resource (approx 244pp)

Only £65 (plus p&p)

Parents discount price: £ 15 (plus P&P)

For copies please contact: 0870 161 3505 where you can purchase a copy by credit card.

Challenging Behaviour Family Support Network

The Challenging Behaviour Foundation (CBF) has launched a new Support Network for families. It is specifically for the families and carers of individuals with severe learning disabilities who typically display behaviour which may put themselves or others at risk, or which may prevent the use of ordinary community facilities or a normal home life. The CBF says that there are many local and national support groups for families with children with specific disorders. However, different children are affected differently by different disorders and you may feel you are alone in trying to cope with your child's aggression, self-injury, stereotyped behaviour or disruptive and destructive behaviours. The CBF linking scheme tries to put you in touch with another family for mutual support and encouragement. They say they may not be able to link you with another family in your area, but you may find it helpful to chat on the phone or via email with another family experiencing the same issues as yourself. Application forms for the CBF Support Network can be downloaded from the CBF Website www.thecbf.org.uk or can be obtained from:
The Challenging Behaviour Foundation,
c/o The Friends Meeting House
Northgate
Rochester,
Kent ME1 1 LS
Tel 01634 838739

The Cinema Exhibitors' Association Card

This is a new national card scheme, which was launched on 1st October 2004 through over 500 cinemas in the UK including Odeon and UCI. The card can be used to verify that the holder is entitled to one free ticket for a person accompanying them to the cinema. To qualify for a card, the person must be in receipt of disability living allowance, be registered blind or hold a disabled person's rail card. The card is valid for 3 years from the date of issue and a processing fee of £5 is payable with each application. Application forms are available from participating cinemas or can be downloaded from the website www.ceacard.co.uk

Talking Point: Website on speech and language problems

Talking Point is a new website bringing together the expertise of three organisations that deal with speech and language problems: ICAN, Royal College of Speech and Language Therapists and Afasic. The site has sections for both parents and professionals: www.talkingpoint.org.uk

HELPLINE
ASSERT Families/New
Diagnosis/Support Line

01268 415940



Holidays



Hello Henry!!

ASSERT has recently heard from the Way family who live down in Cornwall. Joseph their youngest child has been diagnosed with Angelman Syndrome in the last year and of course they have been in touch with us for support. As with all our families it is useful to interact and gain knowledge from each other and it was great to learn that Matt Way is a manager of a family owned holiday park in Newquay. It is a very large site, and Matt has kindly given us details should any of you wish to go and stay

there, of course they would like to meet up with you and co-incidentally one of our families is already booked a holiday in August. This is what Matt wrote to us:

Hendra Holiday Park welcomes AS families

Hendra is a family owned park in Newquay and boasts the biggest Indoor Fun Pool in Cornwall it also has all the normal facilities a large holiday park offers such as a kids club, Cabaret every night and high quality static caravans as well as market leading touring facilities.

I live on the Park with my wife Claire, Megan (3 years old) and Joseph (18 months old) who was diagnosed with AS in November 2004. Joseph enjoys the fun pool and we are looking forward to taking him on the new land train, we would love to see families who have AS children at the park.

Anyone who wants to visit the Park can call 01637 875778 or book on line at www.hendra-holidays.com. Have a look at the special offers we are currently running which are open to all our guests. If anyone wants to speak to Matt about access around the Park you can call him on 01637 870702 or look at the disability access Q&A on the web page. Please see attached a photo of Megan, Joseph and kids club mascot "Henry the hippo"

Hope Holidays

HOPE is a group of caravan owners at Hopton Holiday Village at Great Yarmouth. Together they raise funds throughout the year to run and maintain an accessible caravan, offering it to individuals with a variety of needs, free of charge. The site offers many activities including a fantastic heated swimming pool, arranged games and sports activities and excellent family evening entertainment.

To make a booking for a week's holiday, contact Pat or Ken Griffin after 6pm on 020 8262 7643.

Holiday Information

www.holidaycare.org.uk
– very useful website with lots of addresses and contacts.

Equipment

www.safespaces.co.uk

Swimwear

For those looking for swimwear that enables incontinent children or adults to swim without fear of accidents in the pool, the following suppliers may be able to help:

Ellipants offers made-to-measure swimming pants for any size of person.

Contact Ellipants at PO Box 16, Ellesmere Port CH66 2HA for details.

Telephone: 0151 200 5012. Email: info@ellipants.co.uk

Fledglings supplies Aquatherm swim shorts, which are close fitting and can be pulled over a nappy. Providing the fit is good, they will keep the nappy dry throughout the swimming session. The material used is waterproof, thermal, UV protective, stretchy, lightweight and breathes. They are available in a range of sizes for children and adults. Contact Fledglings at 6 Southfield, Ickleton, Saffron Walden CB10 1TE. Telephone: 0845 458 1124. Email: enquiries@fiedglings.org.uk

Urgent plea for help

ASSERT has heard from a social worker who is looking for a family who could give a permanent home to a two-year-old girl with Angelman Syndrome. She hopes that people with prior experience of Angelman Syndrome could give her the care and stability she deserves. For example, professionals or people who had children with Angelman Syndrome who are now grown up. People from all lifestyles and backgrounds can adopt a child and they will consider families all over the UK. She would very much appreciate it if we could help spread the word about this little girl's need for a family. Could you suggest any other way she can find a lifelong family for her. Please contact ASSERT to be put in touch with this person, who will be able to give more information - you will be under no obligation.

Fundraising

Many thanks for all the donations since the last newsletter. Unfortunately we are unable to bring you the latest list of contributors, due to accounts being at the auditors, but you all know who you are!! Grateful thanks also go to those who have nominated us to their business or workplace, who have generously donated. We especially thank those who have taken part in, or organised sponsored events or sales events – we know

how much hard work is involved and we deeply appreciate your support.

We heard about the following event in which Tony Ayres took part and the successful day it was, thanks Tony. It's great to get the support of friends and relatives of those with Angelman Syndrome, as it affects us all in some way.



Before...



... and after!

Royal Marines Commando Challenge Sponsorship

On Saturday October 23rd 2004 at a rain soaked Woodbury common near Exmouth I took part, along with 6 colleagues, in the Royal Marines Commando Challenge. Team 41!

To put it simply a 3 mile run over the cobble and boulder strewn Woodbury Common including the tackling of obstacles that the Royal Marines have to concur as part of the Green Beret training course. Only I did it for fun!

As a result of this madness the sum of £163.00 was raised for ASSERT to which all credit must go to my parents, Bob and Marion, who asked people throughout there places of work for any donations they would like to place and of course to those people who did kindly donate there hard earned money.

I was asked to take part by a colleague some time ago and could only think of one organisation to raise money for, ASSERT. My niece, Holly Williams has been diagnosed with Angelman syndrome which to be honest I had never heard of prior to this diagnosis. It is for Holly and all the other Angelman Syndrome children that I decided to take part in this challenge.

I'm the gent in the black long sleeved shirt with two white stripes down the left hand side.

I am planning on entering more events of a similar nature (or worse) and would like to publicise Angelman Syndrome (ASSERT) as much as possible and hopefully raise more monies.

Keep up the great work. Regards

Tony Ayers

Education Maintenance Allowance for 16 year olds

16 year olds who are staying on at school in England, Wales, Scotland or Northern Ireland may be entitled to extra financial help from September. From September 2004, those who are 16 between 1st September 2003 and 31st August 2004 (i.e. who become 17 this coming academic year) and whose household income is less than £30,000 may claim between £10 and £30 a week. This is called Education Maintenance Allowance and about half of all 16 year olds who are studying are expected to be eligible. Disabled students are equally entitled to apply and claims can be made now. A claim will not affect any other benefits a family receive. Contact a Family has produced a free information sheet about the allowance, available from their Help line on 0808 808 3555.

Stamps

Dick would like to thank everyone for sending in their used stamps – some packages have arrived without contact details, so thanks from us all for taking the care to send them to us. If you have any used (trimmed please – although close to the perforations – do not cut them off!) stamps – please send them to Dick Barton, Thistle Cottage, Winsor Road, Rolvenden Layne, Kent TN17 4NN

Introduction to the new ASSERT Trustees:

Suevia Perez Castro

Hi, I am 25 years old and I come from Spain. My daughter Jade was diagnosed with Angelman Syndrome at 21 months old. She is now four and to mine and my husbands delight has been walking for eight months.

Obviously her health, well-being and continued progress is my main priority which is why I was so interested in becoming a trustee.

As a new trustee, I hope I can bring some fresh ideas to the Charity and work alongside the other trustees to raise the profile of ASSERT in order to benefit everyone whose life is affected by Angelman Syndrome.

Finn Emmerson

Finn first came in contact with Angelman Syndrome while she was studying Speech and Language Therapy at university. After completing a research project with the Wolfson centre, she presented the project findings at the Italian conference in October 1999. It was here that she met Sally and became involved with ASSERT. Since then, she has contributed to the newsletter, attended regional days, national and international conferences, helped to organise the Conference 2004 and offered telephone advice and support to families and professionals. In her work as a Speech and Language Therapist in special education, she has worked with many children and young people with Angelman Syndrome. Although she does not presently work with children with Angelman Syndrome, she is asked for consultations in the geographical areas where she works. Finn was very honoured to become an ASSERT Trustee in February of this year.

Rich Williams

I'm 32 and live in north Wiltshire (although originally from Sheffield via Coventry). I'm married to Lesley and we have one child, Holly, 3, who was diagnosed with AS (deletion) during Easter 2004.

We have had a continuous learning curve with Holly, who was born with a congenital heart defect (repaired at 8 months). At 18 months, she was classified as severe special needs, and during spring 2004, Holly developed epilepsy. Shortly afterwards, we received the AS diagnosis.

As a result, the last three years have been a succession of highs and very lows. This experience has both given me the impetus to make the experience a positive and purposeful one, and also helped shaped the slightly warped sense of humour that has been an important emotional crutch.

Lesley and I both have a very laid-back hippy outlook on life, and this can be seen in the family website that is now part of the global AS Internet family. Through technology, we have been in contact with many families both here in the UK, but also Europe, US, Australia and Canada. The idea of helping each other is a core to these relationships. It is also the reason for my getting involved more closely with Assert.

As the old hippy saying goes, there are no such things as strangers, simply friends we haven't met yet.

Pete Munro

We were introduced to ASSERT in Feb 2001 when Sophie, our daughter, was diagnosed with Angelman syndrome She was 15 months old. We came to the 2004 conference and wanted to get more involved with ASSERT. The conference was so useful we wanted to ensure the future of the charity. I am a central heating engineer, currently involved in solar heating installations around the SE London area. Tammy, my wife, looks after Sophie (5 Years) and Katie (16 months) who is clear of AS, at our home in Hastings, East Sussex.

Patsi Whelan-Archer

My name is Patsi Whelan-Archer I am married to Carl and we have four children, Bonita who is 34 and has Angelmans, goes to a day centre and lives at home with us, Faye who is 32 married with one child Flynn who is three years old and another one due at Christmas, she works for B'ham Social Services as a person centred planner for adults with learning difficulties, then there's Ross 28 who lives with his girlfriend Siu and works with adults who have learning difficulties and sexual behaviour issues, and last but by no means least there is Alex 14 who has C.P. and is at school.

We have two dogs a cat and two budgies. We live in leafy Sutton Coldfield just outside B'ham in the West Midlands.

Carl works as a counsellor with people with learning difficulties and also the general public.

I work in a children's hospice on the bank staff so tend to work nights or twilight's (till 2 a.m.) so as to fit around Bonnie and Alex, it is a job that I enjoy a great deal, and it gives me a break from the caring at home, that may sound strange nursing terminally ill children but it does, I have recently qualified as a Reiki healer and my interests are my family, running, vegetarianism, local politics, interior design, gardening and driving my little Mini!

We have been in contact with ASSERT since finding out that Bonnie had Angelman Syndrome at the age of 29, because the condition wasn't picked up until such a late age it has made us realise just what we missed not having a support group like ASSERT and how important it is for families to have ASSERT to help them to share the good and bad times as part of a big family, to know that there is a person on other end of the phone who knows exactly how you are feeling is vital especially for newly diagnosed families.

So basically that is why I have become a trustee, to try and help/support everyone involved in the ASSERT 'family' and make sure that we all get together every two years at the conferences!

Jeremy Webb

So who am I? I am a computer consultant living in Watford with my wife, Claire, married now for 11 years, and my three kids, Ruth nearly 8 years old (with AS), Hannah aged 5 and Silas aged 18 months. Are they lovely, yes! Are they a handful, yes! Would I change them for the improved model, no, although I suspect at times they might consider changing me for the more up to date version.

Ruth was diagnosed with AS aged 19 months after six months of concern and various visits to GP's, paediatric consultant and physiotherapist. Whilst having her diagnosed with AS was a shock in many ways I think it was a relief as it meant we knew to a degree (well we thought we knew) what we were dealing with. When we were told by Ruth's consultant that 95% of children with developmental delay do not ever receive a diagnosis, getting a diagnosis is definitely a bonus even if you do not fully understand how this will affect your lives.

Ruth's falls into the deletion category for AS children. So how does it affect her? Well she cannot walk unaided (she is an expert crawler). She walks with a frame although steering is an issue so watch out any shins, objects or walls when Ruth is around. She does not talk and uses a combination of 3 signs, some natural gestures, pointing and vocalising to communicate – why whisper when you can shout, even if you are only inches away! In the last year she has started using pictures. She suffers from epilepsy although recently this seems to be more under control (no fits for 9 months which is a record!); and she suffers from developmental delay. This said, Ruth's aim in life is still to be the life and soul of any party, whether she is invited or not! She attends a special school, which she loves – fortunately they love her too – where she receives speech, physio and occupational therapy. Ruth seems to love all aspects of school,

especially that so much of the communication work they do with her revolves round food!

So why did I become the chair of the trustees? Having been loosely involved with ASSERT for a few years, and then involved with the web site, I wanted to help with a national charity which I felt was doing a much needed work in supporting the families affected by Angelman Syndrome and raising awareness of this little known condition. I suppose my vision for the future is to build on the solid foundations that have already been set, particularly in the support that we offer. Vital aspects of this are the conference, which having attended the first ever conference we are amazed how much this has grown; the newsletter which not only disseminates useful information but also can raise the sense of family in that we are not alone in many of the situations we have to face; to provide more useful information and means of communication via the web site.

ASSERT is all about communication. Please let us know how we can help you more. If you have any questions or just want to tell someone your good news we would love to hear from you. Also if you would like to get more involved with ASSERT please get in touch. None of us are professionals at this, just people who from our experiences have a passion to help others similarly affected.

Question and Answer Tips

Question:

I work as a behavioural consultant with an 11 year old AS boy. The most problematic behaviour we face is a combination of elopement and "sit down strikes" (i.e. flopping, total physical refusal). Rewards including his most preferred activities or foods are only occasionally successful. There are times when he will engage in this behaviour when faced with a preferred activity (e.g. flopping in the school doorway when given the opportunity to go outside for recess). Overcorrecting does not apply here, timeouts only elicit tantrums with the behaviour repeating again and his body weight (around 100 pounds) and increased strength make it difficult to respond as well as creating a risk of injury for both the adult and my client when trying to prevent him from falling to the floor.

We have committed to a strict behavioural approach and including ignoring his negative behaviour (the sit down strikes) whenever possible while rewarding the desired behaviour. I welcome suggestions from anyone who has had experience and success in modifying this type of behaviour in any AS child.

Answer 1:

Sit down strikes are not unusual for children with AS, as you already know they are a means of communication. To you, you are thinking "reward going outside" or another activity, but the child with AS is telling something totally different. Look at what this young man is telling you before he goes into the behaviour. For example: My son, AS, Del + does a sit down when we are taking him away from what he really wants to do.

Yet there are times when a sit down isn't appropriate or can cause harm in some way, such as crossing a street. So you have to come up with ways to address the behaviour in ways they can relate to. We use a three-count rule, making the response to the number three fun. Let me explain. You have to make the count fun. When the child is sitting down, begin with one, two and on three sound off the number three with real excitement! THREEEEEEEEEEE!!! At the same time you, Note: may take two people to do this at first, but on three physically help the child to a standing position, then once up, CHEER, CLAP, create a party, say "Yea, you did it!" It takes some time, but after awhile the child gets a reward simply by doing what you are asking them to do, stand up.

My son Joshua still does his sit-downs when he has another agenda in mind. Example: When he does his errands, say going to the grocery store, he can get side tracked at the grapes...HIS FAVORITE THING TO EAT! He is at the store to get the items on his list of deliveries, but once he sees the grapes, he thinks his job is to eat all he can! OK, so we have to distract him, but ye ol Joshua is clever and knows where those grapes are, so he does a sit down in the middle of aisle three! Now a 22 year old, lying on the floor of a grocery store is a real site to see! Yet Joshua's staff knows the trick to getting him up and moving again, they simply begin the count "One, Two, Threeee!" Joshua jumps up, knowing this is something really cool to do. Sometimes he still needs a hand to get him up, but for the most part it works.

I haven't found time outs to really be successful, until Joshua was much older. For example: When Joshua gets really tired his behaviour goes along with the tiredness. So

he may be really grabby etc. During these times we let Joshua go into his family room. Note: This room has his TV, lots of fun things to do toys etc and other activities. Now you are thinking wow this would encourage the negative behaviour, him getting to do fun things, well just the opposite, you see he wants to be with people, he wants this more than anything in the world, be with the people he cares about. Joshua understands that while his family room is fun, sitting in the living room with his favourite people is much better, so he settles down and comes back into the living room with a better approach. He gets it.

When Joshua was younger we did use simple time outs, but this wasn't anything like sitting in a chair, or even going into another room, it was much simpler than that, you see we knew Joshua's secret, he loves attention!!!!!! So if he was doing an in-appropriate behaviour we simply turned around and didn't face him! He wanted us to pay attention to him. He would grab us while we ignored him, then once he sat back and was sitting nicely, we then turned around and gave him a positive word, like "Wow, I like the way you are sitting".

I know that I am preaching to the choir, but behaviours are our children's way of communication, since usually their verbal skills are off, so they find other ways to communicate, through gestures. Sit-downs, grabbing, biting and even hair pulling are all ways of them telling you something isn't right. Let me tell you that it is really important to listen to those behaviours and work with them. Teach others how to listen to their forms of communication. I often wanted to write a behaviour plan for educators, not for Joshua, but for the educators, in ways to train them in how to listen to Joshua's communication. Behaviours work two ways.

I can tell you that Joshua's behaviours has let us know when something is really wrong, like illness, that he is angry, upset or something else is going on. Yes, you have to work out ways that work when the behaviour can lead to danger, like the crossing the street example I gave, but also you have to learn to listen to what the child is telling you.

I have to share one example that really brings this home to me. When Joshua was about 10 years old, he was in a paediatric hospital and a Registered Nurse beat Joshua over two thirds of his body. While the hospital never told us which nurse did this, Joshua did through his behaviours. It took us

a long time to get Joshua to trust people again, but I thank God for his behaviours that Joshua could tell us in his way who did this to him.

I also will tell you that if Joshua does a sit down in a store and it isn't in the way of anyone, or if he just needs to vent his frustration, so be it!!! Everyone needs his or her ways to say, "this stinks!" If Joshua decides to sit down, so be it, we can wait until he is ready to move on.

Answer 2:

I get in trouble at work because the 17 year old will often do a sit down strike in the car. My job is supposed to be to wait her out, but that lasted an hour once. In a hot parking lot. It's just not safe and not fun and afterwards I'm still hot and irritated.

Now, if I see the signs of a strike coming on, I tickle her and chase her out of the car. :) My boss says I'm rewarding behaviour, but 1) I do it before I see the behaviour 2) It gets her out of the car, laughing :) I think we get so caught up in the "I'm the grown up, you must comply" thing that we forget the best way to win a power struggle with an angel to prevent it from happening. I 100% believe this isn't "giving in", but simply saying, "Yes, you have made your point and I understand that you don't want to go. Let's move on."

If I have trouble getting her out of the car even with a tickle-chase, I understand then that this is really really not something she likes. A visual schedule is always with us, and I pull off the picture of the fun thing that is next and let her hold it, saying "first we go here to the doctor, and then we can go to McDonalds. This usually helps.

I worked with a four year old (not AS) this weekend who had no language. No pointing, no signs, no gestures, etc. His communication is to cut and run toward what he wanted. So someone always had to hold him by the hand. He is so used to this that he doesn't walk on his own, or when he is let go, he runs swiftly and hysterically away. He also has the sit down strike, but still is young enough to be portable. Almost all of his "problem behaviour" (running) is a function of not being able to ask or choose anything in his life. I am reminded again why I am slaving away at school in hopes to be a speech teacher. :)

Dads' Zone for 'Out of Loop' Fathers

Dads'Zone www.cafamily.org.uk/dads.html is a new part of the Contact A Family website, developed with funding from the Department for Education and Skills. Dads' Zone provides both information that's specific to dads, and highlights how dads can use existing services in a way that suits them. For instance, dads can dismiss support groups as talking shops for mums, but one set of dads started a football team for children in their group, and as a result made valuable friends who had "been there too".

As well as information on support groups, Dads' Zone has material on fathers' rights, employment rights, benefits and

money matters, relationships and family life. Contact a Family's revised Fathers fact sheet www.cafamily.org.uk/fathers.html is also now available on CD and audio cassette, ideal for busy dads who don't like wading through detailed text, dads with low literacy skills or those where English is their second language and who can understand speech easier than writing. Contact a Family Help line: 0808 808 3555.

Email: <mailto:helpline@cafamily.org.uk> for a free copy of the Fathers fact sheet on CD, tape or paper.

Extracts from Epilepsy Action News

Europe's First Professor of Childhood Epilepsy Appointed

The first professor of childhood epilepsy in Europe has been appointed by Great Ormond Street Hospital, the Institute of Child Health and the National Centre for Young People with Epilepsy.

Professor Brian Neville has taken up the position, which will be known as The Prince of Wales's Chair of Childhood Epilepsy, which will be based at University College London.

Professor Neville will lead Europe's largest group of clinical scientists devoted to childhood epilepsy, providing an international centre for research and teaching to develop and improve new treatments and care for children with epilepsy. In particular, the team will work to develop their understanding of why young children with epilepsy often develop learning and behavioural problems, including autistic spectrum disorder.

Commenting on the appointment, Professor Neville said:

"I am absolutely delighted and honoured to receive this appointment and feel confident that the team will be able to make a major contribution towards the treatment of these debilitating conditions.

"A major part of my work will involve trying to develop integrated multidisciplinary community management for children with epilepsy whose personal, family and educational lives are currently so disrupted. I am looking forward to bringing together as many resources as possible to try to solve problems which have so far proved intractable."

The appeal to fund the post was launched three years ago with support from HRH The Prince of Wales, who has supported the organisations involved, visiting their centres and talking to young people with epilepsy and their families about the problems they experience.

Solving Sleep Problems Helps Children With Epilepsy – Study

Problems with their sleeping habits may explain why children with epilepsy are often hyperactive, according to a study undertaken at the University of Florida's Evelyn F and William L McKnight Brain Institute.

Epilepsy has long been thought to cause excitability and contrariness in children, the researchers said, writing in the journal *Epilepsy & Behavior*. However, they now think that the real reason some of these children cannot sit still or pay attention is because of a lack of sleep.

The study monitored the brain and muscular activity of 30 children with epilepsy between the ages of seven and 14 during single overnight stays. None of the children had seizures, but some awoke hundreds of times because of breathing problems.

Seventy-three per cent of the children studied (22 of the 30) met clinical criteria for inattention or hyperactivity. Of these 22 children, each had a sleep disorder, 14 had problems paying attention during the day and eight had hyperactive symptoms, supporting the idea that a poor night's sleep is associated with children's daytime attention problems.

In all, 24 of the children (80 per cent) breathed shallowly or had breathing disruptions caused by apneas (a temporary stopping of breathing), which usually happens when the soft tissue in the rear of the throat relaxes during sleep and blocks a person's airway.

As the breathing disruptions increased in duration, the children spent less time in rapid eye movement (REM) sleep, a period in the sleep cycle when brain activity is highest and people dream intensely. The children in the study spent 17 per cent of total sleep time in the REM stage, whilst the normal for young adults is 25 per cent.

Dr Paul Carney, chief of paediatric neurology at the university's college of medicine, said:

"When we treated kids with sleep disturbances, not only did their epilepsy get better, their daytime behaviour, concentration and capacity to learn increased. Many kids with epilepsy aren't being adequately assessed for underlying sleep disorders. We can significantly have an impact over their cognition, learning and maybe even improve their epilepsy by improving their sleep."

"Removing the sleep problem does seem to improve the behaviour problem significantly, because it changes the child's level of alertness, commonly, adults are just not as awake if they have a sleep disorder. But children who haven't taken their nap are wound up instead. Treating their sleep disorder, we think, can enable their brain to have some control over unwanted behaviour."

The researchers found no correlation between seizure frequency and behavioural problems. Epilepsy alone did not appear to predispose them to behavioural problems.

Research with different groups of children is now under way to determine whether treatment of sleep disorders will reduce seizure frequency and severity, and to more fully understand the effects of sleep disorders on children's behavior and cognitive abilities. A tonsillectomy is a common treatment for sleep apneas in children.

Sally Walburn wrote to Professor Carney about the article: this is her email followed by his reply:

"I read a short article in Epilepsy Action News here in the UK and wanted to ask some questions: Did any of the children have a learning disability/diagnosed syndrome?"

What did you use to treat the sleep disorder?

I would be interested in printing something in our newsletter about this as it is very relevant to children/adults with Angelman Syndrome – sleep, hyperactivity and epilepsy are all rolled into this – and as a parent without any study can really see a link – many of our children take Melatonin to help with the sleep.

I would be grateful for any further information which may help parents, our website is www.angelmanuk.org
Ms. Walburn,

Thank you for your interest in this work. I am pleased to know that you found it helpful.

With regard to your questions, many of the children studies did in fact have learning disabilities. At present, we are

conducting a larger study to both assess for the specific cognitive and learning disorder. We are also conducting studies on the effect of treatment of sleep disordered breathing, behavior and cognition. If you like, I can forward you the articles that were published by my group regarding this topic. Finally, you may be interested to know that children with Angelman syndrome also have notable sleep problems, disordered sleep architecture, which has been ill defined to date. These children also often have seizures and the relation between sleep, behavior, cognition, and epilepsy would be worthy of further inquiry.
Best,
Paul R. Carney, MD

Sally has contacted Paul Carney again and will bring further information if this is helpful.

Disability on the Radio:

You may have heard the recent broadcast on Radio 2 on the Jeremy Vine show about a father and the way he came to terms with his son's disability (Down's Syndrome). We thought it would be useful to share a précis of this show. Rich Williams kindly sat, listened and did this for us. We are sure there will be parts of the interviews that strike a cord in many of your minds and that you can identify with the parents, who contributed,

A slightly abridged/edited transcript of the Jeremy Vine show on BBC Radio 2 06/06/05 by Rich Williams.

JV Today in our health and well being hour, we are talking about how people cope when they learn that their new born baby has a disability. When Danny Mardell's son was born in 1995, he was over the moon. But his elation soon turned to shock, anger and grief when he and his wife were told that their little boy had Downs Syndrome. In this hour, we are going to talk about some of the issues arising from that, and we would love to hear from you if you are a parent who is either struggling to cope or just realising how wonderful it can be. Danny Mardell joins me now. Afternoon to you. So, we know that you struggled when you found out that your little boy had DS, but let's go back to before his arrival. You were expecting a first child, you had a tough upbringing yourself...

DM Well, just like any other parent really. You want the best for your child, and expect that you are going to have a normal healthy child. You don't expect that there are going to be any disabilities there. The scan that my wife had didn't show any abnormalities. In actual fact, she was 1 in 800 of having a child with DS. And so, when he was born, for the first 24 hours, we thought that we had a perfectly normal healthy child.

JV And tell us about the first day, and when it began to dawn on you.

DM It was actually the next day, when a paediatrician came into the room and looked at him, and turned around and said, quite callously actually, "I think your child has got DS", looked at him and then walked out of the room.

JV Just like that?

DM Yes, he just left me and my wife there. He said that he'd bring another paediatrician around later to confirm it.

JV And you couldn't tell that by looking at Danny Jr., that there was any problem?

DM We had no experience of DS. If we looked at child now, we probably would be able to see it. There are a couple of tell tale signs. Dan's ears are slightly low, and his eyes are slightly different. And also the line going along the back of his hand, which is the tell tale sign of DS. But with a first child, and having no experience of DS, no, we didn't have any idea at all.

JV And your reaction in those first days?

DM Obviously, we were very cut up about it, but really we coped well with it whilst we were in the hospital. It was more when we came out of the hospital, that I had problems with it. Because I was quite ashamed of him really. I was expecting this Danny Mardell being the same as myself and I wanted to build up an empire for him, so that he could be my son and heir, and here I was with my boy who I thought was going to be the silly kid in the corner. So I err rejected him.

JV Did you even have a question mark as to whether you wanted to give him your name?

DM I never told Carol this, but yes I did. How could I let him walk round with my name? I thought he'd be a silly kid walking around with my name, and I didn't want that.

JV And that carried on for several weeks?

DM It carried on for several months. Almost a year actually.

JV And you felt that you couldn't take a part in it?

DM I didn't want to. I rejected him. I just thought how could this be happening to me? This always happens to someone else. It should be happening to someone else. I didn't want to know the boy, or admit that he was mine. I carried on trying to be the brave guy and to wet the baby's head and calling him my son, but when it came to putting him into a pram and taking him up the road, I didn't want to be with him. And seeing peoples' reactions, when they could quite clearly see that he had a disability, such as shock, I felt ashamed of him.

JV And they of course didn't know what to say?

DM Well people were actually quite good. Friends and family rallied around very well. Even I looked good on the outside. It was tearing me up on the inside. It is a hard thing to cope with. I know a lot of other parents go through a similar reaction, as they have told me so when I have been talking about the subject.

JV Well, we are going to talk about it today. How people come to terms with it. Is that the right phrase?

DM Well, there are some people out there who never come to terms with it, and they end up putting their children up for adoption.

JV And you. In the first 6 months – you used to spend more time away from home?

DM It was actually more like 9 months to a year. I had quite a successful business anyway, and so was never at home that much. I just found more excuses not to be there. I'd work a little bit harder, and then say I needed a couple of pints, whether I wanted them or not, hoping that by the time that I returned, Dan would be in bed, and so I wouldn't have to wash, feed or change him. I left it all to my wife really.

JV In all that time, she was struggling alone with him?

DM She struggled immensely, but she never showed it. She did a very good job, and had the initial instant maternal instinct. I remember her words to me once were "if his father can't love him who can?" Basically, she handled it really well. I felt like I had been a failure. My failure was my son.

JV And after a year something began to change?

DM It was when Dan started to change. Plus having more children afterwards. He wasn't that much different. They all sat there, gurgled and made funny noises. Even Dan. It was when he tried doing the things that other children do, such as trying to learn to walk or talk, that I realised that I had a son there who was trying to get on with life. I suddenly realized that it was my problem, not his. And looking at him trying to progress made me see that he was a winner and that he had all of the love along with the other attributes that a child needs, and that I was being immature, and that I should be looking out for him.

JV Can you remember any particular moment when you began to feel that he was a proper person?

DM Quite a few actually. Although he didn't see a lot of his Dad, his first word was "Dad". And when he was learning to walk, he was actually watching the Tele Tubbies, dancing like them. The next thing was him walking towards the TV, and I remember crying my eyes out. I remember thinking, this boy is trying to achieve, why am I being so negative all of the time?

JV And you have a good relationship now?

DM Yes, very good. He's 10, a very loving boy.

JV How do you see him now? How do you see his disability?

DM I see him now as a child. Same as any other child, but with a different understanding of life. If you spent time with him, you would see that he is just as intelligent as any other child, but just that he doesn't understand the world in quite the same way. And he's trying to get on in life. He doesn't require as much help as some children with DS require, but he won't lead the same life as my other children. He may live in sheltered accommodation in the future, but he will lead a semi independent life.

JV And you have written a book called Danny's Challenge, talking about your life and experiences with your son. You've been raising money for charity as well. Where has that been going?

DM A number of projects such as an outward bounds project for people with learning disabilities, the special Olympics, a lady in Manchester who has adopted 7 seven children with DS and needed a lift in her house for some of the children who use wheelchairs.

JV And you didn't have the test for DS with the subsequent children?

DM No. My wife and I discussed it, but having had a negative test result with Dan, we felt that if we had chosen a termination following a positive result, it would have been like rejecting Dan. We didn't want to do that. Even though there was an increased risk.

JV And how do you stand on the idea of the tests?

DM I think each set of parents has the right to discuss the subject and to reach their own conclusions. What I am a little uncomfortable about is that the NHS almost insists that parents have it to try and encourage termination of children with disabilities, and to take it a little further, I believe that they are trying to cut costs by the back door. They look at children with disabilities as second class citizens, which they are not. They have the same rights as anybody else. It costs money to look after a disabled child for life on the NHS, and the Government is trying to save money. It's a cynical ploy. I think every parent should make their own decision. I wouldn't like to judge anybody. If they don't feel like they can cope, and want a termination then that is entirely up to them.

JV Thank you Danny Mardell.. Rabbi Julia Neuberger joins us now to discuss the subject of having a baby or a young child with a disability. And you listened to Danny Mardell's story?

JN I certainly was. And very moving it was too. A father who has great difficulties accepting that his child has disabilities and then grows to realise that he is a child like any other.

JV Because a lot of people have had those feelings but not been as blunt as Danny was in saying them

JN It's extremely common to see rejection. If you talk to paediatricians and obstetricians when they deliver babies with disability, one of the things that they say is that they wonder if there is going to be rejection. It can come from the mother just as much as the father. Although everybody talks about the maternal instinct, some mothers are actually horrified at having a child with disabilities, particularly when severe. The extent of disability can have quite an effect.

JV And they say that you grieve for the healthy baby you never had?

JN You grieve for the healthy baby you never had, you grieve for the opportunities that your child is not going to have I think. You see it as whole series of possibilities whenever one has a baby, and then you see it as everything that could have happened is no longer going to happen. You grieve often in the same way as you would grieve for a child with a terminal illness. It's very similar.

JV Well, Emily Pearl Kingsley is a mother who is often asked to describe the experience of raising a child with a disability and we've got a little excerpt from it here. She starts by saying that you should imagine that planning a baby is like planning a marvellous holiday in Italy. You buy the guidebooks, you make your wonderful plans, seeing the Coliseum, Michael Angelo's David and so on and then she goes on:

"After months of anticipation, the day finally arrives. You pack your bags and off you go. Sometime later, the plane lands. The flight attendant comes in and says Welcome to Holland. Holland? What do you mean Holland? I'm supposed to be in Italy. There's been a change in flight plan. You've landed in Holland and there you must stay. They've not taken you to a horrible place – it's just a different place. However, everyone you know is busy travelling to and from Italy. And they are all bragging about what a wonderful time that they have had there. And for the rest of your life you'll say – yes that's where I had planned to go. And the pain of that will never go away. But if you spend your life mourning the fact that you never managed to get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland."

JN Very moving, and certainly the experience that a lot of people have. You keep mourning for what might have been and so never get to enjoy what actually is. Indeed, children with disabilities give you other kinds of fulfilment. Some people never get over it. They can't come to terms with it. That's when the children are given up as Danny mentioned. It's unusual for both parents to feel like that.

JV Glenys Evans is on the line. You had the additional complication that your son was born healthy and at seven weeks he nearly died. It was as a result of that, a near cot death that he ended up being in quite a bad way.

GE Hi Jeremy. Yes that's right. He was fine until 7 weeks old, was a near cot death, and suffered quite a long period of time without oxygen getting to the brain and the resulting disability is that Tom has been left with cerebral palsy quite severely.

JV So you know all about having a child with a disability? Give us your thoughts...

GE Well, I think the previous speakers have spoken so well, and said so much of my feelings. I think that the initial thoughts that come to mind are, like the reading that you have just read, when you're pregnant, you do tend to plan ahead – map out your life. My life is going to go in this direction, this is what is going to happen. Then suddenly, one day, your life seems to come to a complete end. Total devastation and nothing is ever going to be the same again. But of course that isn't the case for me, and for many other families. It is a hard time and would never say that it isn't. It's been a long hard road, a hard slog, to push and encourage Thomas. To get all of the things that he has needed; medical needs, therapy needs, educational needs. Now as an adult, to go into adult life and meet the needs of all the other things that he needs around him.

JN But is there great joy in it? Have you had great joy from him?

GE I have. Absolutely. He is an absolutely wonderful son and I am very proud of him. When he was a young baby, they told

me to take him home and play with him because he was never going to do anything. The severity of the disability was so bad. As a young mum, I just couldn't accept that. I didn't know what was wrong with him, and I didn't know what I needed to do to help him. But I couldn't accept that. Now at 21, he's like any other 21 year old. He has a great sense of humour, he's tried many holidays and activities, and hopefully by the end of the year he will be living in a sheltered independent living complex with some carers. So in no way can anybody write Thomas off, and say that he hasn't enjoyed life to the maximum.

JV Thank you Glenys. That's very encouraging for lots of people. Another call. Kirsten Taylor is in Scotland. And how old is your daughter Kirsten?

KT She is 15 months.

JV And....I was going to say... what is the matter with her!? If that's an appropriate question.

KT (laughing) I would have taken offence to that quite a while ago.... She has a rare genetic disorder called Smith Magenis Syndrome. She is missing an arm from one of her chromosomes. When she was diagnosed, the hospital consultant had never heard of it. There is a big variety of things that could be wrong; developmental delay, learning difficulties, communication problems, some of the children have behavioural and sleep problems as well, so it's just a case of waiting and seeing I think.

JN That's very hard isn't it. Particularly when it so rare that consultants haven't seen it. They can't say this is what I have seen. It's much harder don't you think? Have you found other families?

KT We have a support worker who has found an older child of about 7 in the Glasgow area, but we haven't really gone down that route ourselves. We've been on the internet, but a lot of the information is so extreme, with topics such as behavioural problems and self injury that we found it too upsetting.....

JV The internet can be like that on lots of things

JN You kind of need a health warning on a lot of the content found on the internet, because so much of it is so extreme. So you're just waiting to see in a way.

KT Yes, but she is doing very well. She is 15 months old, and in the last couple of weeks, she has just started crawling. So she is following us around the house like a puppy.

JV Wonderful (laughing) and how is your relationship with your partner? Because people get under a lot of strain don't they?

KT We're a strong couple, so we're very lucky. But it has been very difficult. A very hard year. It was last May that she was diagnosed, and I have just gone back to work because I suffered from depression. I still do, so it's been a big strain. We've kind of got through it together.

JV I'm assuming that that is just the workload, the tiredness and then the shock of the diagnosis. All rolled up, it's, more than anybody can take.

KT Yes I think so. And the way in which services are set up, it's very much a case of go and have these tests done and then there is something wrong with your child and the effects are x, y and z. we're very sorry. Come back in 2 weeks. Then you're sent home.

JN They don't actually support you at the time that they tell you

the news, do they? It is quite extraordinary. It shouldn't be impossible for public services of all kinds to support you, but actually just when you need them the most, they are not that good.

JV Kirsten thanks you. It was the same for Danny, when the nurse came in and said "oh it looks like your baby has DS", and that turns their lives upside down.

JN Absolutely. They don't even stay there and say this is what it might mean or this is what you might need to think about.

JV But by definition I guess, a nurse is clinical. They work in a clinical way.

JN I think that there is something about the care of the whole person, and that if you are a nurse or a social worker or whatever and you are with parents who have had this enormous shock, you need to watch what the effect is upon the parents. People do get depressed, and they do get very miserable.

JV Julia, it's difficult for us to talk about it, because unless you are directly involved, it can sound a little pious to say, well, get on with life.

JN Yes, but I have a sister in law who had DS. Quite severely and she died when she was 27. She was the youngest of my husband's brothers and sisters. This is a while ago now, but I think my father in law found it really difficult to deal with. He couldn't believe that this child was his and he couldn't believe that his child was not normal.

JV Is that because men are more mechanical with life and that they think that 1+1=2?

JN There are lots of men who do find it harder. And who blame themselves in some curious kind of way. You certainly find women finding it difficult as well. It's not only men. It used to be said that men didn't bother with children, but we know now that men do bother with them, and lots of men bond perfectly happily with children with disabilities. I think he just found it hard, even when she was an adult as she couldn't talk very well, and they were quite a verbal family. She didn't behave as everyone else did. So lots of people do encounter it. It is quite common to come across children with disabilities, often quite minor, who go on to live very normal lives despite the small disability.

JV We have just had an email with a photograph of a lovely little girl with DS who is described as the centre of the family. Jane Carver is on the line form Chesterfield. Your daughter was born with learning difficulties....

JC That's right. She was born with learning difficulties and her bowels were outside of her body. It was a very shocking experience. I echo a lot of things that have been said. I was absolutely horrified. I felt like a failure. I couldn't bond with her. I found it very difficult to love her. The thing that changed that for me was that I had counselling when she was 4 years old. It changed my life. I was able to say to the counsellor many things that I had said to others lots of times but without feeling. In saying them I was able to purge myself of the feelings of failure. I love her so much now; I could run down the street telling people of it.

JN Do you think that was because the counsellor was actually listening to what you were saying?

JC I think that that was part of it. The other part of it was that

when you tell your experiences to other people, it becomes like a story with the emotions detached from it. There is also a part of you that wants to spare the other person from knowing how upset you really are.

JN And they want to spare you from you seeing them recognising your pain. It's all quite complicated because it keeps reinforcing. And you feel a failure because it gets worse and worse.

JC That's right. I went through that cycle for 4 years. Until I was able to have the counselling which completely changed me as a person. I think that it's a shame that it took 4 years for it to happen. It ought to be available to people who have a child with a disability right from the word go, even though they may not be ready for it at that point.

JV That's a recurring theme this afternoon. At the moment that you are told, there has to be some back up there.

JN Yes, the support needs to be there to allow people to go through the emotions. And if people can't do that, and sometimes they can't because of shock, they're angry like at the first stage of grief, you've got to be offered that support, really as an ongoing thing. Until you have, in a sense, come to terms and learned to live with and love the child, albeit maybe differently from other children.

JV What is your daughter's name?

JC She is called Megan.

JV And when you showed Megan to others, to friends and family, what was the scale of reaction?

JC I think the discomfort in reaction was mine I think. Because she looked a little bit different from other children as well, I was very conscious of that. I felt embarrassed really. I'd produced this baby that didn't really look like anyone else's baby. I felt envious of people with normal children. All these strange things that I used to think. I do find now that others look at her, because she is a little bit different, but it doesn't bother me. I can cope with it if people might want to look at twice at someone who looks a little bit different. That's OK for me now. In the early stages, it did bother me. But it was my reaction to other people rather than their reaction to Megan that was awkward. She can't talk, and they used to talk to her, saying hello, and things like that, and I used to make excuses for her such as she's tired. I simply didn't know how to tell people that she had a disability and wasn't able to talk.

JV We are both nodding our heads here, as we can see exactly what was going through your head. Thank you for coming on and talking about it. Our last caller is Paul Cox, in Southampton. Your child had learning difficulties...and epilepsy as well.

PC My daughter was born by emergency caesarean after complications. She needed some sort of revival at birth. But was shortly afterwards given back to my wife and myself to care for normally. When they ran initial tests before returning them to the ward, they had reason to take her to the ICU. After a couple of hours we were told that our daughter had started to have convulsions, and that they had needed to strongly sedate her. It was touch and go for the first few days, and they weren't sure if she would ever make it out of hospital. She now has epilepsy as a result of

oxygen starvation, which at good times is under drug control, but at bad times is out of control.

JV How are you with it Paul?

PC To be honest, I was the opposite of Danny, I think. Because of it, it made me feel a very strong bond towards her. From the moment she was born, I had a bond there. As soon as I found out that she had problems, the bond became even stronger.

JN And has remained so?

PC Yes. My wife gave birth to our second child, who was born with no difficulties whatsoever, and I am possibly ashamed

to admit that for the first few weeks, I actually did say to me wife at one point, that I found it very hard to bond with him. I don't know why. Perhaps it was because I had such a big bond with my daughter. It was hard to share my love with my son. Having now seen him to look around, to start to make noises, and to start to look like the spitting image of my daughter as a baby I'm now beginning to feel a bond but.....still not as strong as that which I have with my daughter. Its not that I have a favourite, it's just that I have a bond which will never be broken.

JV Thank you Paul. Thank you Rabbi Julia Neuberger.

Contact a Family – Ministerial changes

Contact a Family have been making contact with new MPs and Ministers since the General Election. The main ministers responsible for disabled children in the Department of Education and Skills are Beverley Hughes, Minister for Children and Lord Adonis. The new children's health minister within the Department of Health is Liam Byrne. In Scotland, the Minister responsible for education and young people is Peter Peacock and Andrew Kerr is the Minister for Health and Community Care. In Wales, the person responsible for health and social services including disabled children is Dr Brian Gibbons. Unfortunately, as the Northern Ireland Assembly is suspended, all policy issues relating to disabled children are currently dealt with by civil servants.

They plan to meet with all these ministers and their officials shortly to ask them to prioritise disabled children and their families over the forthcoming parliament.



If you enjoy these articles please think about writing one about your family, we really find this the most interesting part of the report.

The address to write to on this or any other subject is:

**ASSERT, PO Box 13694,
Musselburgh, EH21 6XZ**

Contact a Family and the Lady Hoare Trust

These two organisations have merged under the umbrella of Contact a Family. The Lady Hoare Trust brought to Contact a Family a team of experienced social workers who worked across the UK, supporting families of children with juvenile arthritis and physical disabilities.

From 1st July this team of social workers will be piloting a new face to face Contact a Family "Family Support Service" in some parts of the UK, excluding London. They will be called Family Workers and will aim to provide help on a short-term basis to families of children with any disability aged from 0-19. The family and the staff member together will decide on what the worker can do to help in each individual situation. The tasks that are agreed could include:

- Information on local services;
- Negotiating with other agencies such as the school or social services;
- Helping the family access benefits;
- Emotional support through a crisis or times of stress – such as receiving a diagnosis, or moving to a new school.

The service is for families who have a child with a diagnosed or undiagnosed disability or long-term health condition. It aims to help parent and carers with issues that arise in caring for their child and that no one else is helping with. In order to help as many families as possible it will be short term, but families will be able to ask for help from Contact a Family again if they experience further difficulties. The service is entirely confidential. The Family Workers will ask for anonymous feedback from parents on what they thought of the service and we will use these views to develop the service in the future. If you think that you would like help from one of CAFs new Family Workers, and you would like to know if there is one in your area, please do get in touch with Contact a Family. You can telephone the Contact a Family free helpline, Tel: 0808 808 3555.

Access to Dentistry

Contact a Family is working with the British Dental Association to find out if there is a problem in accessing dentistry for disabled children. They will use the results of this research to try and improve services for families. They will be carrying out a survey at Web: www.cafamily.org.uk/quizz.html during June and July.

If you have a chance to complete it, that would be helpful. However, what they really need is to hear from families about their own experiences, good and bad, of finding NHS dentistry, finding a dentist who is sympathetic to the needs of families, struggling to pay for private care, getting physical access to a surgery – anything you like, connected to your experience of dental care for your child. If you have a moment to e-mail: helpline@cafamily.org.uk or drop them a line at Helpline (Dentistry Survey), Contact a Family, 209-211 City Road, London EC1V 1JN. They would love to hear from you by the end of July with your own experiences.

News

Are you claiming a disability reduction to your council tax? If not, it might be worthwhile investigating whether you are eligible. To qualify for the reduction, households must include a child or an adult who is substantially or permanently disabled. They must also either:

- Use a wheelchair indoors;
- Need a second bathroom, toilet or kitchen;
- or Be the main user of one room, as a living space, for treatment or to store equipment.

The disability reduction moves council tax bills down by one band, regardless of income or savings, and claims can be backdated indefinitely if applicants can prove they met the criteria in the past. Many families are unaware of that the disability reduction exists. In some circumstances, families with disabled children will also be eligible for council tax discounts; and for families on low incomes, to council tax benefit. To check whether you are eligible for a council tax reduction, or for other benefits advice, telephone Contact a Family's helpline, Tel: 0808 808 3555, or visit www.cafamily.org.uk



HELPLINE

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

01268 415940

The Lone Parents' Guide to Caring for a Child with Additional Needs

With assistance from Contact a Family, One Parent Families have recently published this guide. Thanks to a grant from the Parenting Fund, One Parent Families are improving and developing their services to meet the needs of one-parent families caring for a child living with a disability. Until April 2006, One Parent Families are funded to provide a specialist advice service for lone parents who are caring for a child who has a disability or a long-term health problem. Call 0800 018 5026, Mon-Fri, 9am-5pm. Individual copies of the guide are free to lone parents calling that number. One Parent Families, 255 Kentish Town Road, London NW5 2LX

Tel: 020 7428 5400 Fax: 020 7482 4851

e-mail: info@oneparentfamilies.org.uk Web: www.oneparentfamilies.org.uk

Improving the life chances of disabled people

The Prime Minister's Strategy Unit has published this report which sets out the Government's vision. By 2025 they hope that disabled people will have full opportunities and choices to improve their quality of life and be respected and included as equal members of society. It can be downloaded from the web: www.strategy.gov.uk/work_areas/disability/index.asp

Direct Payments and Parents of Disabled Children

Scope has produced an easy guide to direct payments for parents of disabled children. A direct payments scheme recognises that families have different schedules and a range of needs which can be met by a more flexible approach to social care. Families receive money instead of social care services so they can employ a personal assistant or nanny, use the payments to enjoy a respite holiday or meet their needs in the way that is best for them. Funded by the Department for Education and Skills, Scope is letting more families know about direct payments. In the driving seat provides guidance on getting started, how to employ someone directly, and where to go for help. The jargon-busting section of the pack gives simple explanations of the terminology. Carrie Johnson, mother of 12 year old Carl, was one of the parents involved in creating the pack. She has used direct payments to regain independence by receiving crucial respite services:

"I had decided I needed flexibility – a babysitter at night so I could go to the cinema, after school care so I could work longer hours, help during the school holidays etc. I also wanted someone to come to my home so that Carl was in his own environment. The perfect solution was a local agency who had an excellent reputation from other families that used them and could offer exactly what I wanted. Each month Social Services pay our pre-agreed money into a separate bank account and the agency sends me an invoice which I pay by cheque. Direct Payments for me is to get in from work and find my son fed, bathed, in his pyjamas and happily playing his favourite games. Bliss!"

Scope has also published 'My money, my way: A young person's guide to direct payments'. Both packs can be downloaded from the web: www.scope.org.uk/issues/directpayments An audio version is also available on request.

Contact: Scope, PO Box 833, Milton Keynes MK12 5NY

Tel: 020 7619 7342

e-mail: publications@scope.org.uk