Changes to JAT working patterns to improve service
Frank O’Friel, JAT Manager explains

Spring 2007 Issue 12

Whilst shivering in the middle of the cold snap we are currently in, thoughts do turn optimistically to spring and new beginnings! The Joint Agency Service is about to restructure following an extensive look at how we can best deploy our resources. Since starting just over a year ago I have spoken to a number of you about the complexity and amount of time and effort it takes to get into our service.

By Easter we will have begun the process of addressing these areas by focusing a few of our workers on ensuring that families get a quick initial response from us on referral, and the integrated assessment takes place within a 6-7 week timescale. Currently as I am sure a number of you will realise it takes significantly longer than this to be fully assessed and receiving services.

The first three months of this new way of working will be spent catching up with the backlog of assessments but I am confident that, by the time your summer newsletter hits your doormat, the new referrals will be being dealt with in the same timescale.

Once we have caught up with the backlog this team will also provide the resources for a step down keyworking service for those of you with stable packages who are currently on care co-ordination. This will guarantee you an annual review and regular support throughout the year. Currently families held on care co-ordination only receive a patchy service based more on responding to crisis rather than proactive support. This service will also be fully operational in the summer.

Finally apologies for the delay in having our second parents consultation. We have been quite busy sorting this reorganisation out which was the subject of our first consultation last year. I plan to organise another consultation over the next few months around some of the areas that you highlighted for looking at including carers breaks and transport.
The Exeter Beacon Cluster AXS Pathway

The Exeter Pathway is one of nine schemes being established in different areas of the County to improve the links between the many different agencies who work with children and families. The Pathways will ensure children and young people who have additional needs will have improved access to services before their difficulties become more substantial.

They may already be known to some of the agencies and may require additional support over and above that which is available to everybody and/or more than one agency’s involvement may be required. At the heart of the process, parents and young people will be able to choose whether they wish to be involved in the pathway.

The Exeter Beacon AXS Pathway is centred on the Beacon Heath area of the city. The pathway area is in the North of the city covering the schools – Stoke Hill Infants and Junior, Willowbrook, Pinhoe, Whipton Infants and Junior and St James’ Secondary School. The pathway is now firmly in its development phase and initially of over 30 staff from all agencies will be taking part in the first training group to be held on March 20th/21st. This training will assist in:

- developing working relationships between the different agencies
- helping the different agencies to complete an assessment process which can be used by all agencies
- training agencies on the guidelines about sharing information between agencies, and the requirements for the consent of young people and their parents.

- The Pathway Co-ordinator for the Exeter AXS Pathway is Charles Sumner, who is based at Willowbrook School, Summer Lane, Exeter EX4 8NN. 01392 64274 or charles.sumner@devon.gov.uk

Face 2 Face

All is going well with the local Face 2 Face Scheme being set up to serve Exeter, Mid and East Devon. Twelve volunteers began training in January, and the service will be officially launched on Tuesday 24th April 2007.

The service will provide a trained volunteer “befriender” who themselves has experience of parenting a child with special needs, to listen and talk with any parents who may have recently found out their child has special needs, or be in need of such support generally. Anyone interested in the scheme, or who would like to find out more, is welcome to come to the launch; please ring me on 01392 219952 or 07799 403435, or email me at patriciajoliver@hotmail.com for more information. Referrals can be phoned through to me on the above numbers, from April. Parents can phone me themselves if they would like a befriender to talk to, or they can ask a professional they know to refer them to the scheme.

Trish Oliver, Face 2 Face Co-ordinator, Exeter, Mid and East Devon.

The Pathways will ensure children and young people who have additional needs will have improved access to services before their difficulties become more substantial.

Charles Sumner
Exeter AXS Pathways Co-ordinator

Face 2 Face

All is going well with the local Face 2 Face Scheme being set up to serve Exeter, Mid and East Devon. Twelve volunteers began training in January, and the service will be officially launched on Tuesday 24th April 2007.

The service will provide a trained volunteer “befriender” who themselves has experience of parenting a child with special needs, to listen and talk with any parents who may have recently found out their child has special needs, or be in need of such support generally. Anyone interested in the scheme, or who would like to find out more, is welcome to come to the launch; please ring me on 01392 219952 or 07799 403435, or email me at patriciajoliver@hotmail.com for more information. Referrals can be phoned through to me on the above numbers, from April. Parents can phone me themselves if they would like a befriender to talk to, or they can ask a professional they know to refer them to the scheme.

Trish Oliver, Face 2 Face Co-ordinator, Exeter, Mid and East Devon.
Play Initiatives In Exeter

Have a say for play in Exeter

Young people in Exeter put safe play in their top three greatest concerns, so Exeter City Council’s Museums and Leisure service, with funds from the Community Safety Partnership and Early Years and Childcare, set up a four week play rangers project in Belmont Park summer 2006.

Three play rangers were assisted by a volunteer. The scheme aimed to promote children’s play, develop a safe play environment and raise awareness of the importance of outdoor play. On most days they worked with up to thirty children aged from two to sixteen, some accompanied by parents - core age range was two to eight. Activities were creative, imaginative, arts and crafts, drama and storytelling, and active games and sports. They carried a mobile phone and had a direct line to the local Community Police and used Belmont Park as their base. There was a positive response from children and families, some of whom travelled from other areas in the city especially to visit the project and the project provided an ideal opportunity for informal consultation about play.

With Early Years and Childcare, children’s centres and other organisations, Exeter City Council has re-started the Exeter Play Association which will be instrumental in putting in a bid to the Big Lottery to develop Exeter as a Free Play City and continue the work of the play rangers. The draft Exeter Play Strategy is on the ECC website. For copies contact your local Information Co-ordinator.

Please join with us if you want to have a say for play in Exeter. contact: perry.evans@exeter.gov.uk or gay.smith@exeter.gov.uk 01392 665947 or 01392 665966.

Inclusive Play Update from Miriam

Many thanks to everyone who attended the various consultation meetings. These proved to be very useful meetings and I collected a lot of data about your wishes for the play park. I am currently working with two firms who make/provide play park equipment and in order to be truly inclusive the play park will need to cater for all, including those with physical and/or learning disabilities. In order for this to happen the play park will need to be surrounded by a 1.8m fence and have gates that fasten. The equipment will need to be large and robust enough to cater across the age ranges from young child to adult and as it is so innovative the companies are needing to design new specialist equipment. Also it will need to be multi-sensory and wheelchair accessible.

This all takes time and the project is currently not going forward as quickly as I would like but I am hoping that within the next couple of months I will have two possible designs. There will then be more consultation meetings with opportunities for your comments. When a final design is agreed a Lottery bid can be submitted. Please let me know if you have any questions, comments or suggestions you may have e-mail guard@eclipse.co.uk

Watch this space

Thank you to everyone who contacted us following our appeal in the last newsletter.

A project in Africa set up by a local Occupational Therapist was looking for unwanted Pedro boots and educational toys. We had a wonderful response and the items collected are on their way to Zambia. If you have any other items to donate, do get in touch with your Information Co-ordinator. Our contact details are the bottom of the page.

Your Local Information Co-ordinator is Ann Owens, Exeter Joint Agency for children with special needs, George.
All the families on the Joint Agency Record have now been sent the letter inviting them to contact Devon Welfare Rights Unit (DWRU) for advice, and many have successfully appealed for, or claimed the benefits they are entitled to.

The most exiting news is that advisers for Exeter have now identified 210 people in Devon of which 135 live in Exeter, who could be entitled to an increase in benefit. They have successfully claimed over £110,000 for these families since the campaign started - that’s an average increase to families of over £4,000 per year.

To give families an idea of the service provided, Vince Willson from DWRU has kindly sent an example of the help given to one family. He explains the family’s circumstance, how DWRU went about making the claim and how it was possible to make changes for this family by obtaining Disability Living Allowance (DLA) for their son.

This case concerned a married couple, one of whom is retired, who have a child aged 7 who has Asperser's syndrome. Although they had heard of Disability Living Allowance, the couple had never particularly thought that it might apply to their child. Only when they received the information about the project from the Joint Agency Team did they wonder whether their son might be entitled.

They contacted the project and we went out and helped to fill in the form. We prepared a statement and legal submission to go with the claim and an award of the middle rate of the care component was made.

The parents are going to use the money to pay for someone to accompany the child so that he can have piano lessons – he has always had a wish to learn the piano, but this had not been possible because the parents could not go with him and they could not afford to pay a carer.

The mother was extremely grateful for the support and said she would not and could not have made the claim without support – would not have known that there might be an entitlement and would not have known how to provide the relevant information in relation to the law.

This is what DLA is about – enabling people to do the things that they would not otherwise be able to do without support - to narrow the 'quality of life gap' between someone with a disability and someone who does not have a disability. The middle rate component of DLA is is £41.65 per week - £2165 per year.

Vince Willson Devon Welfare Rights Unit

If you have not yet had your benefits check and would like further information contact your Local Information Co-ordinator.

---

Your Local Information Co-ordinator is Ann Owens, Exeter Joint Agency for children with special needs, George
**Contact a Family**

We have published a new factsheet on Education Maintenance Allowance, [www.cafamily.org.uk/ema](http://www.cafamily.org.uk/ema) which looks at how to get a weekly payment for your son or daughter if they stay on at school, college or training after compulsory schooling.

Several factsheets have been updated:
- Working [www.cafamily.org.uk/employment](http://www.cafamily.org.uk/employment)
- Fathers [www.cafamily.org.uk/fathers](http://www.cafamily.org.uk/fathers)
- Transition in England and Wales [www.cafamily.org.uk/transition](http://www.cafamily.org.uk/transition)

Benefits, Tax Credits and other financial help [www.cafamily.org.uk/benefits](http://www.cafamily.org.uk/benefits)

Tax Credits Overpayments - a guide for parents [www.cafamily.org.uk/taxcreditsoverfact](http://www.cafamily.org.uk/taxcreditsoverfact)

If you do not have access to the internet, contact your Local Information Co-ordinator for a printed copy.

**Transition in health settings - your views needed**

We have been invited by the Department of Health to develop a presentation for their next national conference around transition. There are significant problems which affect some disabled young people and those with long term medical conditions as they move from children to adult services. This can have a serious impact on their health and for some conditions there is a high incidence of unexpected deaths occurring within 36 months of transfer to adult services. These problems need resolving urgently. We are very keen to hear from parents about their experiences of transition, both good and bad as well as their thoughts on how the transition experience could be improved.

To help us with this we would be very interested to hear from any group which has already consulted with parents on this topic. We are also interested in hearing from individuals what key messages they would like us to deliver to health professionals around transition.

If you can help please contact sheila.davies@cafamily.org.uk 020 7608 8773.

---

**General Benefits Helpline**

The General Benefits Helpline which people can use to claim benefits such as DLA and AA are now offering to complete the forms with the claimant over the telephone. They will take details and an advisor will call the claimant back within 2 weeks and go through the form with them taking down the details, this will then be sent to the claimant for signing and faxed through to the main benefits office.

The claimant must be ‘mentally competent’ and be able to answer questions over the telephone.

The General Benefits Helpline number is 0800 88 22 00.

**You Can Benefit DVD**

This DVD outlines the benefit criteria for Disability Living Allowance, Attendance Allowance, Carer’s Allowance and Vaccine Damage Payments. Colleagues from the Customer and External Relations Directorate worked closely with RNID to create the DVD. To order a copy of the DVD free of charge e-mail: customer.relationsteam@dwp.gsi.gov.uk or fax: 01253 338723

or write to: DCS Outreach Team, Room 111, Block 1 Government Buildings, Norcross Lane, Norcross Blackpool FY5 3TA.

Please make sure that you give full details of your postal address. The DVD should arrive within five working days.

There is also a series of short films online about the four disability benefits. Although the films are created primarily for British Sign Language users, there is a spoken commentary and subtitles for all viewers. [www.direct.gov.uk/en/DisabledPeople/FinancialSupport/DG_10038239](http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/DG_10038239)

---

Your Local Information Co-ordinator is Ann Owens, Exeter Joint Agency for children with special needs, George
It's Not Too Much to Ask

The system for providing vital equipment to sick, disabled and terminally ill children in the UK is 'ready to collapse' because of a 'scandalous' lack of funding and failing systems, according to Britain's leading birth defect charity, BDF Newlife. The charity has launched a campaign called "It's Not Too Much to Ask" to bring the problem to the attention of the Government and is calling for the establishment of a disabled children's tsar to oversee the establishment of a new disabled child equipment provision regime. The campaign aims to attract 250,000 signatures/names to a petition calling for change - one name for every deprived child. An electronic version of the petition is on the BDF Newlife website, Web:

www.bdfnewlife.co.uk and members of the public can also text their support to make it easier to get their voices heard. Text BDF (space) first name (space) surname (space) county to 87202.

Askability

Look at www.askability.org.uk

Awards for Young Musicians

This Scheme helps gifted young musicians realise their potential, where financial hardship is threatening to stifle their gift. The charity has granted nearly £360,000 in awards to over 700 talented young musicians since its inception in 1998. About £55,000 is given each year to between 100 and 120 young people. Publicity for the awards has meant that interest and numbers of applications have risen steadily over the years.

Individual awards of up to £2,000 are made, based on talent and financial need. Need is assessed not only on household income but also by means testing. Talent is assessed by reference to Grading from a recognised musical examining body; in the absence of examination grades, other references may be considered.

Application forms need to be accompanied by letters of recommendation from music teachers plus proof of financial need. For further information, please see the Awards for Young Musicians website.

Application forms will be available from the website from mid-December 2006. In order to register your interest in an application form, please send an email to:

info@a-y-m.org.uk by 30th April.

Awards for Young Musicians, PO Box 2097, Wickford, SS12 0ZQ
01268 571887
www.a-y-m.org.uk
Support for Grandparents

The trauma of a parent who has been given a diagnosis that their child has a special need, disability or life threatening condition, is probably the hardest thing they will ever have to survive.

There can be no greater need for those parents trying to adjust to this reality than to have family and friends to support them. Someone to share their tears and reassure them, or pick them back up when they feel unable to stand is vital. The family and friends of the parents have to suppress their feelings and remain positive for those parents, as well as deal with their own grief.

We have arranged a grandparent’s morning for people in this position to have the opportunity to meet and have a chat over coffee with other people in the same situation.

There will be a talk given by a clinical psychologist on the trauma, and ways of dealing with the situation. We will have displays on autism, benefit form filling, toy adaptation and any other areas people would like covered. If popular other events will be organised.

The get together will be on Saturday 24\textsuperscript{th} March from 10am to 12.30pm at Honeylands Child Development Centre, Pinhoe Road, Exeter.

Space is limited, so please contact Doug or Deb Barnes on 07799 142134 or 01395 276381 to reserve a place.

Douglas Barnes, chair of A Brighter Tomorrow

Sibs – for brothers and sisters of people with special needs

This organisation produces two factsheets which are full of information about the issues a sibling of a child with special needs may face.

Information for parents on supporting young siblings

Information for young siblings.

You can get a copy of these factsheets by calling 01535 645453, www.sib.org.uk

Recognising Fathers Booklet

New research by the Foundation for People with Learning Disabilities has found that health and social care professionals, family support services and employers largely ignore the needs of fathers who have a child with a learning disability. The charity has published Recognising Fathers, a booklet to help staff, service commissioners, policy makers and employers better understand the issues faced by fathers. More information: uk/page.cfm?pageurl=press_2006_11-21.cfm

Headway Devon

In the last newsletter we told you about a new service from Headway Devon for children and young people aged 11 - 16 right across Devon who have an acquired brain injury.

Headway Devon still has spaces. If you think this service would be helpful to you talk to your key worker or care manager, or you can contact Lucy Hooper at Headway Devon direct:

01392 211822
lucy@headwaydevon.org.uk

ICT Disability and Leisure - This course is for anyone, including parents/carers, with an interest in making computer leisure and internet activities available to people with disabilities.

COSMIC, Ottery St Mary, 26 March.
£99 + vat per person
£39 + vat per person voluntary and community sector organisations

Contact:
Course Administrator, AbilityNet, PO Box 94, Warwick, CV34 5WS
01926 312847
courses@abilitynet.org.uk

Your Local Information Co-ordinator is Ann Owens, Exeter Joint Agency for children with special needs, George
Make School Make Sense launches in England

Find out about the England launch of the make school make sense education campaign and see photos of the events that took place.

ww.nas.org.uk/nas/jsp/polopoly.jsp?d=1085&a=10230

Asperger achievers - your stories

2006 was International Asperger Year and the NAS was marking the event by celebrating the achievements of people with Asperger syndrome. We're inviting people with Asperger syndrome or autism to tell us their success stories. You can read some of these inspiring stories here.

www.nas.org.uk/nas/jsp/polopoly.jsp?d=1152&a=9089

ASD book project

Julie Morris from Surrey is compiling an anthology of stories, poems and artwork from people on the autistic spectrum and parents. Find out how you can be part of this project.

www.nas.org.uk/nas/jsp/polopoly.jsp?d=253&a=11431

Drinking survey

A study of problems of unusually high intake of fluids (water, fruit juice, fizzy drinks, tea, coffee, etc) among children and adults with autistic spectrum disorders, currently or in the past. Parents, carers or people with autism may like to complete an online questionnaire which will help to inform the research.

www.nas.org.uk/nas/jsp/polopoly.jsp?d=714&a=11190
Plymouth Eczema Support Group

A support group has been set up in Plymouth for families anywhere in Devon with young children suffering from psoriasis and eczema, but every one who suffers from any skin condition is also welcome.

The support group will be held on the last Wednesday of every month between 6pm and 8pm at Southway Community Centre, Hendwell Close, Southway, Plymouth, PL6 6TB

There will be a charge of £1.00 per person (except children under 14) which will cover the cost of the room and unlimited tea, coffee and biscuits. Any surplus money will be donated to the National Eczema Society and the Psoriasis Association at the end of every year.

Advice and talks from professionals will be given at the beginning of the meeting and then there will be time for people to get together in an informal and relaxed atmosphere! The support group is supported by the Dermatology Clinic at Derriford Hospital, the Plymouth health professionals who specialise in skin conditions, the National Eczema Society and the Psoriasis Association.

For advice & information about the support group;
Eczema group contact Amanda Gough 07810 641635. amandagough@blueyonder.co.uk
Psoriasis group contact Gemma Burns 07940 740784.

A new Study of Osteopathy for Children with Cerebral Palsy

A team of researchers at the Peninsula Medical School in Exeter, the Institute of Child Health at Great Ormond Street Hospital and the Osteopathic Centre for Children in London are carrying out a study to examine whether cranial osteopathy is helpful for children with cerebral palsy. Cranial osteopathy has become a popular form of treatment for many disorders over recent years but there is little available evidence about its effectiveness, particularly in children. Cerebra have provided funding for researchers to carry out a trial to establish whether it is effective or not.

The team would like to recruit children with cerebral palsy aged between five and 12 years who live in Devon around the areas of Exeter, Plymouth and Torbay to take part in the study. Each child will be asked to stay in the study for six months. Children will be divided into two groups: the treatment group will receive osteopathy straightaway, the control group will also have osteopathy, but after a wait of six months. This means the researchers can compare both groups of children to help find out whether osteopathy works for children with cerebral palsy.

If you would like to hear more about the study, without any obligation to take part, contact Vanessa Edwards 01392 262978.

Diabetes support group

Lorna, a parent from Totnes, has started up a diabetes support group as she wanted to meet up with other families who were in a similar situation to her. They had their 1st meeting at the beginning of December which was well attended. The group are planning to meet on the first Sunday of each month at the Daisy Play Centre in Totnes. They are hoping to arrange trips and outings during the holidays.

If you would like to find out more please call Lorna on 01803 868754.
RISEsw (soon to be CEDA - Community Equality Disability Action)

Kidz at Rise SW continues to go from strength to strength. Currently an inclusive play-scheme that operates during all the school holidays, in Exeter and Tiverton. Each year our aim is to offer fun and excitement for children aged 8 and over. Last year a fun packed time with over 22 trips in the summer alone, these included trips to Devon and Cornwall Police Headquarters, Exeter Fire station and we even had a go at archery at Exmouth Archery Club. The children grasped the principles really quickly, unlike the staff who struggled.

At Christmas Jon-Paul, the new leader, organised some very interesting outings, the most popular was to the ice skating rink in Exeter. Unfortunately he only lasted 3 seconds on the ice, unlike the children who couldn’t get enough of it! The wheelchair users were able to enjoy an interesting experience, so thank you to Exeter City Council for the opportunity, we hope to visit again next year.

Jon-Paul has some wild and wacky ideas for the club in 2007, camping experience, accessing some adventure style activities and creating interesting unusual sessions within the club in our fun filled days.

As part of our continuing development we hope to offer an Afterschool Club for children after the Easter holidays, which will operate out of the Clare Milne Centre every weekday during term time. Last year we had a small grant that allowed us to pilot a ‘Buddy Scheme,’ we are now looking to expand this for new groups of children in 2007. We will be looking at creating small groups of likeminded children who would normally find it difficult to access playschemes. These children will be community based and will have opportunities to access fun as a group, according their needs and wishes, this could be anything from swimming to skateboarding, shopping to pampering, the key to its success is the group’s ability to discuss and decide on activities collectively.

Watch out for the many new and exciting activities, including a name change from April 2007. Jon Paul Statton Risesw

If you are interested in any of these activities, please contact Jon-Paul Stratton on 01392 360645. kidz@risesw.org

www.risesw.org.uk

3D TV – helping people with learning disabilities get more from the telly.

TV is a central feature of many people’s leisure time. There are aspects of TV viewing which can be problematic for people with learning disabilities and Autistic Spectrum Disorder (ASD). MEdia is the charity, helping people with learning difficulties make better use of the media. They produce an excellent 46 page booklet called 3D TV – helping people with learning disabilities get more from the telly. It is packed full of ideas of ways to make TV viewing more interactive, and activities to turn viewing into a learning opportunity.

The leaflet is produced in conjunction with MENCAP

They also produce a smaller leaflet called TV and films in the lives of people with autism which deals with some of the issues faced by families of children with ASD.

Again it has some great ideas for making viewing a learning experience. In it parents tell how they made home videos to show their son how to draw, after watching it a few times he copied what he saw. They then used this method for other tasks which he was finding difficult.

If you would like a copy of either of these visit www.ldmedia.org.uk or call your local information co-ordinator.
Impartial, Confidential - and Free for all Parents/Carers
By Joan Tremblett, Parent Partnership Liaison Officer

The service is restructuring to ensure that we can deliver support to all parents/carers across the county.

Our small team of Parent Partnership Officers will also be working with Learning Communities to highlight the importance of working in partnership with parents and carers.

We will be using a central telephone contact number with a guarantee that all calls will be responded to within 48 hours (2 working days). In addition, our website will contain a range of useful information with copies of our leaflets available to download.

So what can we offer?
Do you have any concerns about your child’s education?
Would you like to talk to someone confidentially who can give you impartial information about your child's special educational needs?

Then this free service is for you. We can:

- Explain all about special educational needs
- Support you at meetings with schools and other agencies
- Help you to write letters and fill out forms related to special needs
- Listen to your concerns and worries and answer your questions
- Signpost you to other services if and when appropriate
- Help you become a valued partner with the school in your child’s education
- Explain school action, school action plus and statutory assessment
- Discuss your child’s exclusion

We can also provide a range of sessions about SEN procedures and good communication skills for parents/carers, school based staff and governors

If you would like further information please contact:-
Devon Parent Partnership Service on 01392 383080 - this is a confidential answerphone service, so please leave a message if we are not available to answer your call - we will get back to you!

parentpartnershipservice-mailbox@devon.gov.uk
www.parentpartnershipdevon.org.uk
**Gilley the Giraffe who changed - By Nimmi Channa**

This delightful children’s book tells the story of Gilley; a young giraffe who suddenly develops encephalitis. It explores feelings and confusion that face a young child coming to terms and dealing with a new condition and how they may change. The story begins with Gilley feeling unwell and after waking up after a long fever he suddenly feels different. He has a seizure, is forgetful, he feels tired all the time and school becomes harder. This book outlines most of the symptoms associated with the condition but in a way that children can relate to in a non negative way. After Gilley is diagnosed, life becomes easier as he finds a way to deal with his condition. Gilley and his family meet with professionals like Dr Harry Hippo and Wise Owl (Gilley’s teacher) to explain Gilley’s illness and symptoms which correspond as handy tips for children and parents on how to manage. It can be read with children or be read on their own. With beautiful watercolour illustrations using fantastic colours that fill each page and really set the mood. I believe this book would be really helpful to any parent of a child with this condition or younger children with this condition and anyone who wants children to understand what it’s like to be ill. It has a really positive outcome with his classmates coming up with the motto ‘Be Brill 2 Kids Who’ve Been Ill’.

**Emma McGahren  emma.mcgahren@cafamily.org.uk**

Published by the Encephalitis Society  Price: £8.50 to professionals and organisations, no charge to parents of a child affected by encephalitis (a donation of £1.50 to cover post and package is however requested).

ISBN: 0955218004

www.encephalitis.info

---

The Transporters DVD aims to help children with autism to look at the human face and to learn about emotions. The DVD is aimed at children from two to eight years, and the series of 15 five-minute episodes features the adventures of eight lovable toys with human faces, each focusing on a different human emotion: happy, sad, angry, afraid, excited, disgusted, surprised, tired, unfriendly, kind, sorry, proud, jealous, joking and ashamed. Stephen Fry is the narrator and each episode has an associated interactive quiz to help children learn about the featured emotion. The DVD also includes an information booklet for parents and carers.

Free copies of the DVD will be available to UK residents from The National Autistic Society. To find out more about the series go to www.transporters where you can view the first episode and order your DVD. Please note that DVDs will be supplied in March 2007.

---

Your Local Information Co-ordinator is Ann Owens, Exeter Joint Agency for children with special needs, George
Changes to the process for issuing Blue Badges
Devon County Council (DCC) has decided to make several changes to the way it issues Blue Badges. These include:

- Badges will be issued by the MyDevon Customer Service Centre (CSC).
- Discretionary applications will no longer require GP involvement, and health professionals will be consulted only in exceptional cases.
- You will be able to fill in applications over the telephone by contacting MyDevon.
- DCC will no longer charge customers £2 for issuing a Blue Badge.
- The eligibility criteria will be confirmed in the CSC using DWP systems.

You can apply for a Blue Badge or make enquiries by calling 0845 155 1007. If you are unable to complete a telephone application, you can request an application form on the above number or download one at www.devon.gov.uk/blue-badges.

These changes will help you because:

- You will no longer need to provide a letter of proof of eligibility.
- An instant assessment of eligibility will be given in most cases.
- You will no longer be charged for the badge.
- The processing time for badges will be significantly reduced.
- You will be guided through the application process by a Customer Service Advisor.

For more information on Blue Badges and how they are issued, go to www.devon.gov.uk/blue-badges, or talk to your local information co-ordinator. A leaflet is also available from your Local Information Co-ordinator.

Direct Payments

We are now producing a separate ‘direct payments’ newsletter, full of advice and information. It should be delivered to all families who are using direct payments within the next month.

If you are considering having Direct Payments and would like an informal chat please contact your local Direct Payment Support Worker:

Exeter  Clare Key  01392 383764
East Devon  Sarah Dixon  01392 384442
Mid Devon  Louise Smith  01392 381116 to be directed to your relevant worker
North Devon  Julia Forrester  01271 341538
South and West Devon, and Teignbridge  Jeanette Lee  01392 386006

Louise Smith County Children’s Services Direct Payments Co-ordinator - 01392 381116

Useful website
www.everychildmatters.gov.uk/_files/6A714A67FF1DFC93DCAB4BBDF9CFFF01.pdf
Every Disabled Child Matters
Find out about the new Every Disabled Child Matters campaign to ensure the right services and support for disabled children and their families.
www.nas.org.uk/nas/jsp/polopoly.jsp?d=824&a=11420

Patient Information Leaflets (PILs)
The website www.xpil.medicines.org.uk ensures that PILs supplied with medicines are accessible to everyone, including those with sight problems. All the PILs on the X-PIL web site can be viewed in different sizes and are designed for screen readers.
The Royal National Institute of the Blind (RNIB) Medicines Information Line can also provide PILs in a number of physical formats:
- Large / clear print
- Braille
- Audio CD
You can also listen to a PIL when you call the Medicines Information Line.
The RNIB Medicines Information Line is free to use and available 24 hours a day, 7 days a week. Please call them on 0800 198 5000.

British Sign Language (BSL)
If you would like to try learning BSL, Living Options Devon is offering a 6 week taster in March or May. Cost is £45 per person. For more information or to book a place please call Justine on 01392 459222.

Dual Diagnosis: ASD and Down’s Syndrome
Wednesday 2nd May - Pratts Hotel, Bath
This conference is geared towards parents of children with a dual diagnosis of ASD and Down’s syndrome as well as a range of education, health and social care professionals. There will be plenty of opportunities for networking.
More information: 0845 230 0372 lesley.alabaf@downs-syndrome.org.uk

Dyslexia – The Miracle Cure by Wynford Dore, Jon Blake Publishing £17.99
This seems like a huge claim! Has anyone any experience of the ideas put forward in this book? If so, please get in touch with your local information co-ordinator.

The Helping Relationship
Monday 18th June –Armada House, Bristol
This one day conference looks at the relationship between parents and professionals working with children with special needs. It is open to both parents and professionals.
More information: 01497 831550 p.limbrick@virgin.net

Carers UK has launched a year long investigation looking at the extra costs faced by carers. They are looking for people to complete an online survey:
www.carersuk.org/Newsandcampaigns/Fairdeal

Item for Sale
Kitten Tricycle by Quest 88 Ltd. With back support, foot plates, waist safety strap, push/pull parent handle and tools – suit child approx. 2 – 5/6 years of age.
Excellent condition £299.00, Contact on 01392 660725

Your Local Information Co-ordinator is Ann Owens, Exeter Joint Agency for children with special needs, George
Carers’ Week Service of Celebration, Exeter Cathedral

At this year’s celebration in June, Parent Carers’ Voice will be highlighting some of the trials and tribulations of bringing up a child who has special needs. I am looking for photos of children in a variety of situations which I can use in a rolling PowerPoint display, and for some amusing or touching highlights in your child’s life.

No child or family will be personally identified, and any photos lent will be returned.

If you have anything suitable that you are prepared to share, or would like to discuss this further, could you please contact me Nicky Ruane, Parent Carers’ Voice, Exeter CVS, King William Street, Exeter, EX4 6PD. 01392 201572. nicky.ruane@exetercvs.org.uk

Disability Information Service

This new service for adults with disabilities, their families and carers throughout Devon, is now up and running. There are three advisers within the Customer Service Centre dedicated to disability related issues, two of whom are disabled themselves and so have first hand experience of some of the difficulties that disabled people are faced with. The Disability Information Service is a holistic service providing information, help and support across a wide range of issues and services utilising the many agencies already in place in Devon.

You can contact them 8am to 8pm Monday to Friday or 9am to 1pm on Saturdays:
phone 0845 155 1005  textphone 0845 155 1020   SMS 07773 333231
disabilityinfo@devon.gov.uk

Besides providing general information, they are currently focusing on employment and have details of government and other schemes to help disabled people into work and to help them stay there.

Guides and Brownies

Do you have a young person who would like to join the Brownies or Guides but not sure they would be able to?

The Guides and Brownies Group in the Heavitree area have just moved into new wheelchair-friendly premises and the Group’s experienced leaders would be happy to discuss the possibility with potential new members.

You will need to bear in mind that, like so many Guides and Brownies groups, there may be a waiting list. If you would like to discuss the possibilities please contact Mrs Jo Ireland on 01392 431446.
DISCplus – DISCuss  You are invited to contact the newsletter with your questions. We will do our best to find the answers. Please send your letters to the address at the bottom of the page.

A parent has contacted me to say that she has a 9 person tent which is on offer to anyone who can make good use of it. Ideally she would like it to benefit children with special needs, but if any one is interested please contact Cathy Hill on 01392 386066. This tent is free to a good home.

A parent has asked where they can purchase continence aids for their child who is not known to the Joint Agency Team.

Boots hold a catalogue of products which can be purchased in store, the products are not always on show but they are available. If your child has an ongoing problem then the alternative route could be a referral to the Joint Agency team which would be followed up by a nursing assessment and a referral to the continence service with a view to free provision.

For more information on incontinence see www.eric.org.uk

Top Tips from you

In the last edition we told you about the launch of the new online blue badge parking bay map. A number of parents have contacted us to say that they were unsure how to navigate around the map.

The easiest way to view the area of interest is to enter the postcode, click and hold on the map then drag the mouse in the direction you would like to view. The map shows Blue Badge parking bays, Red Route parking bays, petrol stations, and public toilets.

A parent from the South Hams area wrote in with this top tip: When playing a board game with pieces that are moved around, place a piece of Blu Tack on the bottom of each piece. This will mean that if the board is accidentally knocked the pieces won’t go flying!
Insider information - Can you help?
questions from you

We have been asked by a parent of a child with ADHD who hates the taste of his medicine if we have any suggestions on ways to encourage children to take their medication? If you have any ideas or suggestions please do let us know, we will print the answers in the next newsletter.

We’ve had a request for some top tips for when your child is required to stay in hospital overnight. If you would like to share your experiences and any good ideas and advice that you have then please contact your local information co-ordinator.

If you can help in any way with answering these questions get in touch. If you have any questions please let me know and I will put them in the next newsletter. My contact details are at the bottom of the page.

answers from you responses to the questions in the last newsletter

We asked for any information about music teachers with experience of teaching children with special needs either on a 1:1 basis or in small groups.
So far no one has contacted us with any information, If you do know of any please get in touch.

Laura from South Hams contacted us to say that she is the parent of a child with a visual impairment and is interested in meeting up with other parents/guardians of children of any age with similar problems.

Rachel in Tavistock also contacted us to say she has a pre school child with physical disabilities and was hoping to meet up with others in a similar situation.

We have had a few people pass on their details but would welcome more. If you would be interested in meeting up please get in touch with your Local Information Co-ordinator.
Balloons. Bereavement and Loss Looking Onwards

Balloons is a new charity that provides community based support for children, young people and their families from Exeter, Mid or East Devon following the death, or before an expected death of a parent, significant carer or sibling. The service can offer:

- a dedicated phone line
- support and advice for families
- support and advice for professionals who are helping families
- individual help through home visits and group activities
- resources for borrowing by young people, families and professionals.

Referrals can be taken from children, young people and their families, as well as from statutory and voluntary organisations.

Balloons, C/O Franklyn House, Franklyn Drive, Exeter, EX2 9HS. 01392 208429. info@lookingonwards.org
www.lookingforwards.org

In the last newsletter we mentioned that if you were applying to the Family Fund for a grant for a holiday you could also apply for money to help with other items such as a washing machine etc.

Well the same goes if you need to apply for money to help with the cost of hospital visits – you can also apply for other items.

For more information on the Family Fund call 0845 658085 or visit www.familyfund.org.uk

Family Fund application forms are available from your Local Information Co-ordinator.
### County Forum

At the last meeting held on 22\textsuperscript{nd} November Ernie Lloyd, Assistant Education Officer for Exclusions and Re-Integration spoke about the new Schools and Inspection Bill coming into effect from September. The emphasis is very much on **inclusion** of children in education and reducing fixed term exclusion. Two new Inclusion Support Officers will be working with schools, parents and children to achieve this and new parenting classes may be introduced for some. People attending the meeting felt that many parents did not require ‘parenting classes’ but to instead learn strategies for helping a child with special needs.

All children’s services in Devon have recently been inspected and this report was discussed. Many services were given an adequate score but improvements were needed in others. An Action Plan has now been drawn up by Children and Young People’s Services. Nine areas are recommended for immediate action, including Therapy Services. PCV will endeavour to monitor this Action Plan. We still need to hear anecdotal evidence when outcomes are not being delivered so do feel free to contact your local PCV Development Worker. A parent’s voice does have power and PCV is seen as the **forum** through which issues affecting children with special needs are heard. Lobbying through elected representatives is also a powerful means of support and PCV will be doing some work on this in the New Year.

Tim Tod, Chief Executive of Devon Youth Association (DYA), spoke about the work DYA is doing looking at transition of young people to adult services. Tim will be talking with and listening to young people and their parents/carers.

The issue of transport for children to/from education will be reviewed by Parent Carers’ Voice in the New Year. Anecdotal evidence is welcomed so that a report can be made to Devon Children’s Trust Board.

The next County PCV meetings will be held on 7 March and 2 May. The are open to the nominated representatives of each of the 6 local groups.

### Exeter Forum

In recent months parents have attended both informal ‘Air and Share’ meetings and the slightly more formal type meetings to discuss their issues and concerns, as well as having the opportunity to voice their opinions on the topics being discussed at County Level. At the November meeting concerns were raised over inclusion in schools. There followed a lively discussion about how many schools seem to embrace the challenge of inclusion and work well with parents to provide the supportive atmosphere that enables children to thrive, whereas others appear not to want to work with families to ensure that the needs of children are met. Jenny Rankin, school nurse, gave an interesting talk on puberty, adolescence and sexual health matters for children with special needs and the problems that parents may encounter at this time. Jenny answered many questions, explained how this subject is dealt with in both mainstream and special schools, and showed us some of the resources that are available for use by parents.

In early December a group of parents met up for lunch at the Imperial in Exeter. Everyone had a great time and felt that it was definitely worth repeating.

The January meeting again proved lively, with topics of discussion including the training of enablers and the Joint Area Review Action Plan. Joan Tremblett, Parent Partnership Liaison Officer, spoke about developments and future plans within the Parent Partnership Service, and the help and support that is available to parents, and answered questions from individual parents.

Any issues that are raised in meetings are addressed locally, and taken forward to the County Forum for further discussion and action..

**Formal meeting** - Friday 27\textsuperscript{th} April, 10.00 – 12.30 Exeter CVS, King William Street, Exeter.

**‘Air and Share’ informal meeting** - Thursday 29\textsuperscript{th} March, 12.00 – 1.30 Whipton Children’s Centre. All parents/carers are welcome at any of the meetings.

For further details please contact:Nicky Ruane, PCV, Exeter CVS, King William Street, Exeter, EX4 6PD 01392 201572. nicky.ruane@exetercvs.org.uk

---

Your Local Information Co-ordinator is Ann Owens, Exeter Joint Agency for children with special needs, George
Outward Bound Courses
Absolutely Free
Do you enjoy outdoor activities, meeting new people, seeing new places and having fun?

The Sir Francis Chichester Trust offers young people aged 16-24 the opportunity to attend either a one or three week course at one of the Outward Bound Centres based in Wales, Scotland and the Lake District.

If you are interested the closing date for applications is 26 February so you need to act quickly!

For more details and an application form contact:
Anthea Parkyn, YFC Centre, Retail Park Close, Marsh Barton Road, Exeter EX2 8LG.
01392 250976. info@chichestertrust.org.uk
www.chichestertrust.org.uk

CandLE in collaboration with the University of Bolton (Communication and Learning Enterprises)
Three courses designed to inform and help parents, carers and anyone working with young people with communication difficulties and/or physical disabilities are going to be held in Exeter during March. They are available to parents or carers at a discounted cost of £50 per day.

Supporting Learning and Education.
Understanding movement and communication difficulty.
Making it work for the individual
If you are interested contact Mick Millward. 07904 693302.
contactcandle@btinternet.com
www.contactcandle.co.uk

Do you have any information you would like to see in the next newsletter? Would you like to write an article for it?
Get in touch with me by the end of April-
Contact details below.

DISCplus
Exeter JAT,
George St,
Exeter,
EX1 1DA

Phone: 01392 383732
ann.owens@devon.gov.uk

This newsletter, along with the newsletters of all the other localities and all the back copies, can be seen on the DISCplus website – www.devon.gov.uk/newsletter

This supplement is available on request in a range of languages and formats including large print, Braille and on audio tape. Get in touch with your Local Information Co-ordinator for details.