

Parent Voice

News

A Parent Link project



Hazel Court pupils win 'Top Takeover Day' Award

May 2011

Hazel Court School staff involved all school pupils and teaching staff in Takeover Day on the 12th November 2010, a national event organised by the Office of the Children's Commissioner, where children and young people 'take over' the roles or work alongside adults for the day.

Children and young people got involved all over the county in the 'East Sussex Takeover Day Award'. Following a judging process which was 'taken over' by the young people from the Youth Cabinet, Hazel Court School won the 'Top Takeover Day Award' for the secondary school category.

Pupils have won £250 for a project in their school and all pupils involved were given individual certificates to recognise their achievements on 'Takeover Day'.

Pupils from Hazel Court School had many roles on the day from working alongside the head teacher, to planning and running lessons and even a keep-fit class. Some pupils also worked behind the scenes with the caretaker to understand more about his job in making sure pupils are safe and the school building is well looked after.

Bev Carter, Participation Manager for Children's Services said: *"The pupils at Hazel Court School really took the responsibility of being 'members of staff' on 12th November seriously and they thoroughly enjoyed their experience of being in a leading role. The pupils even made their own identification badges for the staff roles they took on so everyone knew who they were, and teachers were dressed up as pupils too!"*



Takeover Day was so successful that teachers now want to involve pupils more in decision-making and definitely want to take part in this year's national Takeover Day on Friday 11th November 2011.

We hope you put this date in your diary too.

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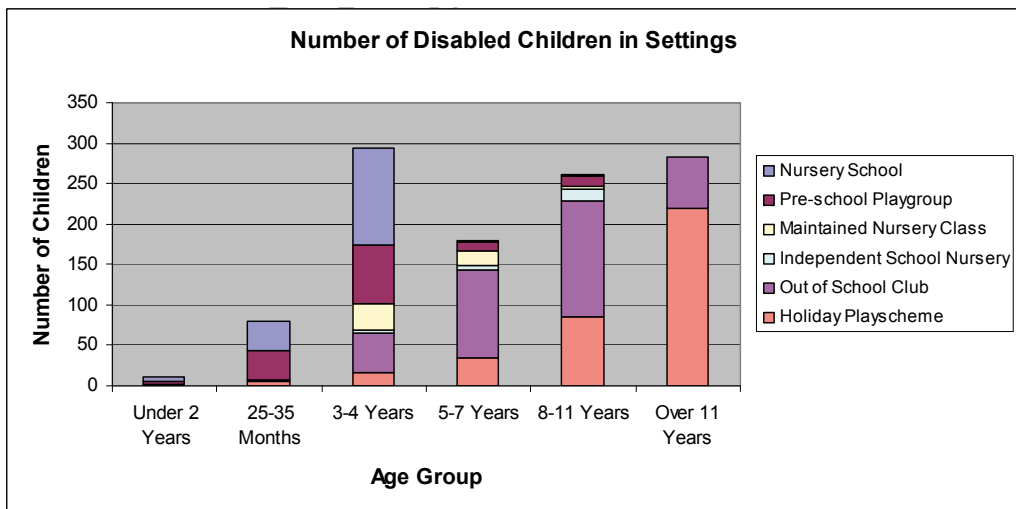
Disabled Children’s Access to Childcare (DCATCH)

A project was carried out to learn what support providers can offer for disabled children and how many disabled children are currently accessing childcare in East Sussex. Providers were asked:

- Have you had any experience with disabilities?
- How many disabled children are currently in your setting?
- Parents have told us that they lack confidence in childcare settings. How do you approach this attitude?
- How can you be best supported to include more disabled children?

A total 302 out of 456 providers replied to the survey. The following graph shows the result of these questions.

If you want to find out more about specialist childminders call the Family Information Service on 01323 463850.



Disability Awareness and Safe Handling of Medicines courses have been offered and been well attended.

“Disability Awareness training.”

“An opportunity to discuss and explore issues.”

“It challenged our practice.”

Specialised equipment was purchased to help severely disabled children with complex needs access services. For example a ceiling track hoist to help children and young people access pools at leisure centres. A more detailed report will be published during April on the East Sussex County Council website.



There is a guide to childcare for disabled children. If you would like a copy you can get one free from Parent Link on 01273 481172.

Early Support

The Early Support Key Worker service is available to the families of preschool age children (0-5) with complex disabilities or special needs. It offers support by bringing practitioners (eg teachers, nurseries, therapists) together alongside families to co-ordinate and plan services.

When planning the child’s transition into school, support is offered, not just in terms of educational issues but anything else that is significant to the child and their family.

For example, if the child has health or therapy needs we can work with school staff and other agencies to identify ways in which

these can be best addressed. Needs of other family members, such as health issues or sibling support can also be shared with their permission, so that the school is aware of the child’s wider environment.

Many families report that having an Early Support Key Worker as the child settles into school provides a familiar and supportive contact at a time when preschool services end and support becomes more school based.

For further information go to eastsussex.gov.uk and search ‘keyworkers’.

Contact: 01323 747470

Email: keyworker@eastsussex.gov.uk

Autism Support Network, Lewes (ASNL)

Autism Support Network Lewes (ASNL) is a non-profit support group for parents, carers and practitioners working with anyone with an Autistic Spectrum Disorder (ASD), or similar conditions such as ADHD, Dyspraxia, Pathological Demand Avoidance etc, in the area around Lewes, East Sussex.

People on the Autistic Spectrum often find daily life and communicating with others difficult. For parents and carers, this can lead to isolation as the person they care for may not be able to join in with 'normal' activities – e.g. children's birthday parties. The specialist support needs of many people with ASD can also make family life very costly.

ASNL was established in 2010 by a parent who had identified a significant gap in support locally, particularly for parents of children with ASD. The group formally established a Committee in February 2011.

ASNL holds monthly open meetings at the Phoenix Centre, Lewes and hosts a website and



Autism Support Network Lewes

Facebook networking forum. All are welcome to attend!

This network provides opportunities for parents, carers and practitioners to meet, discuss, share and learn about all aspects of caring for a person with ASD. Most months the network invites a professional, such as Speech and Language Therapists, Occupational Therapists or Autism Behaviour Consultants to bring up-to-date and relevant expert advice to parents. Parents say they value local, high quality support and advice.

For more information and to contact email: info@asnl.co.uk or go to www.asnl.co.uk.

ASNL – Autism Making Sense

We welcome Parents, Carers, Professionals in the ASD field and ASD Support Practitioners.

Venue: Phoenix Centre, Lewes

Time: Thursdays 7.30-9.30pm

Meeting Dates Summer 2011

- 19th May
- 16th June
- 14th July

Contact: Jeanni

Email: jdw77@live.de

Tel: 07725 810455



New Transition Service

East Sussex County Council has decided to set up a new transition service to help young people with a disability and their families make the move into adulthood in a more planned and personalised way. The service will support young people aged 16 to 25 who have a disability and who are eligible to receive support from adult social care. The service aims to provide families with up to date information at this time and to help young people to think about the things they want in life as they become adults and make plans for how this can happen.

The service will be working closely with schools, connections services and health workers to co-ordinate all the assessments and support young people may need and to make sure that young people with a disability are able to make choices about where they live, who supports them and what they might want to do in the future.

Watch this space for further information.

**HOT TOPIC!**

In this edition of Parent Voice we are trying out a new idea. We want parents to tell us about their HOT TOPIC. Claire is our first parent to contribute!

Claire, mother to three children, 1 with special needs, lives in Hastings. She has written into Parent Voice about provision for under 8's. Claire says *'My family had been receiving respite care on a regular basis. It had become a lifeline, allowing us to spend quality time with our other two daughters and also to allow E a degree of independence which her condition restricts'*

Claire then explains: *'In the summer of 2010 families in East Sussex with children with Special Needs under the age of 8 years received a letter from the council informing them of the withdrawal of their respite and short break services. I didn't understand this decision it seemed entirely arbitrary and I decided to appeal'*.

Claire tells us that the service for her daughter has now been reinstated, but she has some questions...

Question: What happened in 2010 when some services seemed to stop?

Response: Beverley Moore, Children's disability team: *Contracts with independent and voluntary organisations are continuously re-tendered to ensure better value for money and increase the numbers of children able to access services. Each provider of services is different in what they can offer and the regulations that guide them. Whilst this allows a great deal of flexibility it is recognised that there can sometimes remain gaps in the service. Where gaps do exist children's needs can be met on an individual basis e.g. through the 'spot purchase' of services.*

Question: The Children Act 1989 says councils must assess needs on behalf of children and carers. The Carers Act 2004 says councils must tell carers that they have a right to ask to have their own needs assessed. But even if an assessment shows there is a need for support, there is no law that says that the type of support must include a short break or respite care. What's your view?

Response: From April 2011, there will be a duty on local authorities to prepare a statement for carers on what services will be available in local areas and what criteria they will be accessed by.

By 1st October 2011 local authorities must publish a statement for carers in their area setting out:

- details of the range of short breaks services provided;
- any criteria against which eligibility services will be assessed;
- how the range of services is designed to meet the needs of carers in their area.

You can find details of the assessment process by:

- going to www.eastsussex.gov.uk
- searching children and family assessment.

For details of short breaks, activities and respite care:

- go to www.eastsussex.gov.uk
- search short breaks and respite care.

Question: It seems to me that the onus is on families to chase down the funding that they are entitled to and to find out what services are out there for children with SEND especially the under 8s. What help is there?

Response: Viv Oliver, Parent Link: Our service (which provides information support and advice to parents of children with special needs/disabilities) is being merged with the family information service. The new 'one stop shop' will hold information about services and entitlement. We will work with partners to make sure this information is available on the ESCC website and that people who work with families know about it.

Julie Morehead, Early Years Support: We have a range of services available to families of preschool age disabled children. These include Early Support for the children with the most complex needs (*see page 2*), the specialist Early Years and Teaching Support Services who provide preschool educational support to children with special educational needs and Children's Centres staff who can offer a range of universal

and specialised services. All can signpost to appropriate services for further support.

We appreciate any feedback which enables us to reflect on and hopefully improve what we can offer. We do recognise however, the need to share more information about services for the under 8's and find any gaps and are planning an under 8's event in July. *See page 12.*

Question: I have heard about Individual Budgets (IB) how will this influence services for the under 8s?

Response: Bernadette Dawes, Short Breaks Commissioning Manager: Individual budgets will give more choice and control for all ages. We must make sure parents have the information and support they need. The information on the INCONTROL website helps to understand what difference they can make.

Go to: www.in-control.org.uk

Search: Debi and Ryan

For more information about Individual Budgets see the Parent Voice News insert.

Question: The government is allocating LA funds for short breaks, how are parents involved in deciding how the money is spent and how effective the services are? What's happening now with short breaks?

Response: please see Bernadette Dawes full response on the insert.

Question: Claire asks what plans are there to consult parents now and in the future?

Response: Viv Oliver: Please look out for participation and consultation opportunities in this newsletter. Join the PARENT VOICE contact list and you will be told about opportunities that might interest you. Look at the insert to find out about the recently formed parent carer Forum, an independent forum able to represent the views and wishes of parents and carers.



Finally Claire says that: *'I urge parents to work together to inform the council that the provision of short break services for under 8s is a priority and it is only through parent power this will change locally'*

If you want to contact Claire please email her at: claire.shanahan@talk21.com

Do you have a HOT TOPIC?

Do you have questions you want answered? If you do contact Yvonne Kneller on

01273 481172.  It's over to you.

Skiing is for everyone

Freedom and exhilaration, isn't that what brings skiers back to the slopes year after year?

The Southern Ski Club for the Disabled meets on the first Saturday of the month, 6pm to 8pm, at Knockhatch Ski Centre, Hailsham and enables all people with disabilities to learn and enjoy skiing. It's an opportunity to develop self confidence, learn a new sport and also to make new friends. Whether the skier has sensory, physical or mental impairment our trained guides and specialist equipment ensures everyone has time on the slope.

Our taster session currently costs just 50 pence

but we are open to visitors to come and just have a look, this often helps those on the Autistic spectrum.



Each skier is assessed by an experienced guide and is then paired up with appropriate equipment, guide or helper (who we desperately need more of) and then it's off to the slope.

For those who really catch the bug there are holidays abroad organised which are open to the whole family to experience the mountains and snow.

For more information please contact Ian Edwards (Chairman) on 07775 687648.



Family Fund Grants



The Family Fund gives grants to families raising a

disabled or seriously ill child aged 17 and under. We help with items that make life easier and more fun for families.

Can the Family Fund help me?

The Family Fund can consider an application if:

- You are a permanent resident in the UK;
- You are the parent or carer of a severely disabled child or young person aged 17 and under who lives at home;
- You are eligible for, and can send us evidence of one of the following tax credits or benefits; Child Tax Credit, Working Tax Credit, Income based Job Seekers Allowance, Income Support, Incapacity Benefit,

Employment Support Allowance, Housing Benefit, Pension Credit;

- You have permanent legal residency in the UK and have lived in the UK for 6 months and are eligible to work and apply for public funds.

What can the Family Fund help with?

Last year we supported 55,000 families. Some of the most popular grant requests are for holidays, days out, washing machines, driving lessons and computers. The Fund helps with grants that relate to the care of the child, so we are able to help with standard items and sometimes more unusual requests – anything from a goldfish to a dog, a trumpet to a greenhouse!

How we have helped one family

Ten year old Lucy has cerebral palsy. Her family have been helped with traditional grant items such as clothing and bedding. But it is the Fund's latest award – a Wii which the family received

earlier this year – that has added a new dimension to family life. It means that Lucy can now play with her sister Chloe and brother Cain and have fun family nights together as a family.



Lucy's mum says "We get the popcorn out and have a party with the Wii in the front room two or three nights a week. Lucy's always the winner in the bowling game, which makes her very pleased."

If you think the Family Fund can help please get in touch via email info@familyfund.org.uk, telephone 0845 130 45 42 or visit our website www.familyfund.org.uk

If you would like someone to come and talk to a support group or team about the work the Family Fund does please contact Clare Kassa, Network Development Manager at the Family Fund email clk@familyfund.org.uk Tel: 01273 748362

Update of the Disability Images Project

After two successful photoshoots last year, work by equality consultant Sarah Playforth and a lot of consultation with parents, teachers and young people, East Sussex County Council's Equality and Engagement Team have a final



draft of the disability images pack! It is due to be printed by end of March 2011 and will be sent out to all East Sussex schools and children's services teams and children's centres.

Schools and children's services teams will receive a folder with a CD-Rom enclosed which contains a selection of the positive images, posters and a teaching resource.

For more information contact Charlotte Papworth from the Equality and Engagement Team:
charlotte.papworth@eastsussex.gov.uk

A leaflet is now available about the Children's Integrated Therapy Service

and can be downloaded from the East Sussex County Council website www.eastsussex.gov.uk

Look out for the article in the next edition of Parent Voice News.



Face 2 Face: the one-to-one befriending service for parents of disabled children

Learning your child has a disability may come as a massive shock or it may simply confirm something you've suspected for a long time. Either way, the news often leaves parents feeling shattered, lonely and needing support.

That's where Face 2 Face can help.

Their free and confidential online and telephone befriending service is available to parents in East Sussex. They support parents of children with any type of disability or special need.

Every Face 2 Face befriender is a parent too – someone whose own child has a disability. They know what it's like to cope with a new diagnosis and can offer support parent-to-parent. Each befriender is carefully trained and supervised by a professional Face 2 Face coordinator.

To apply for online and/or telephone befriending contact 0844 8009189 or email face2facenetwork@scope.org.uk www.face2facenetwork.org.uk

WHIZZ-KIDS

The Whizz-Kidz, Kidz Unlimited project supported by the Big Lottery, is proud to offer a range of services for young disabled people in your area.

Ambassador clubs

Our Brighton Ambassador Club is one of our new fun and friendship groups for young disabled people aged 10-18. We meet every 6 weeks and as well as a chance to meet other young people, we provide media training, life skills, drama, music, campaigning, leadership training, sports and much, much more. These are action packed and dynamic groups designed to increase confidence and independence and equip young people with the skills to move into adulthood.

Work Placements

Our work placements programme offers 15-25 year olds a range of exciting opportunities to learn new skills and prepare for the world of work. Placements run throughout the year. Work experience is fully supported with an introductory meeting and a work place buddy. We also provide transport, personal assistants and equipment, where needed.

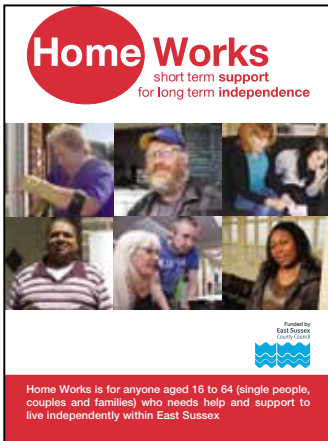
Find out more

If you are interested in finding out more about our services or applying to become part of our Ambassador network, please contact us on 0800 151 3350.





Struggling with housing? Heard of Home Works?



Home Works is a short-term housing related support service funded by East Sussex County Council.

It's aim is to help people who are having difficulties with managing their housing – this could be due to things like financial difficulties,

relationship breakdown, problems with neighbours, health issues or anything else that might impact on someone's housing.

Home Works covers the whole of East Sussex. Support workers visit people in their own homes or out in the community ensuring that even those in the most isolated rural areas can still receive the service.

Home Works is available to people who:

- live in East Sussex, in any tenure (this could be private rented, social housing, temporary accommodation, or their own property);
- are aged between 16 and 64 on referral;
- would benefit from a short term housing related support service;
- and have support needs.

To find out more, please call:

**Emily or Liz on 01424 858341
(Hastings and Rother)**

**Jonathan or Gina on 01273 898700
(Eastbourne, Wealden and Lewes)**

You can also find us at

www.southdownhousing.org

Families for Autism

Families for Autism



Families for Autism is a new venture founded by parents and individuals who all have a connection to children or young people on the autistic spectrum.

We are a passionate, caring group of people who experience autism on a daily basis and our mission is to provide support, encouragement and understanding to children and young people on the autistic spectrum and their families. Our Patron is Stephen Lloyd, Member of Parliament for Eastbourne and Willingdon who has a personal link to autism himself and who has been very supportive.

In the last seven months we have raised over £17,000 through grants and fundraising activities such as sponsored events, an autumn fayre and two chocolate parties. The money we have raised has enabled us to open a

Saturday club based at Hazel Court School and a Youth Club based at The Eastbourne Academy. Both clubs provide a range of activities such as cookery, art and craft, sensory play and outdoor activities in an autism friendly environment with well trained staff. We also offer outings such as swimming and bowling.

To find out more, visit our website at www.familiesforautism.com or contact Julie Jones on 07908 314102 or email julie.jones@familiesforautism.com

Aiming High – Activity Day for Young People with Autism Spectrum Disorder

ASD, what comes to mind: young people alone and unable to join in social activities? This was not the scene on Saturday March 12th at the Brighton University Sports Centre in Eastbourne. 60 young people (and their parents/carers) aged from 11 upwards attended a day organised by East Sussex ASD Monitoring & Support Groups and funded by Aiming High.

The aim of the day? To have fun, meet others with ASD and try new activities like: sports, art and crafts, nail art, music, and climbing.

Dean Beadle, a young man with Asperger's Syndrome, ended the day by speaking movingly and with humour about his school life. Parents and young people alike were inspired by his positive message and one young man wrote:

"I am better able to understand about my Asperger's and how I can do well in life because of what Dean said."

Dean's view of the day? *"I didn't see a roomful of children with ASD but one full of straightforward young people chatting, laughing and being kids. Who says having ASD has to be a disability?"*



Down's Syndrome Training Day: 22nd June 2011



The Down's Syndrome Training Day is an essential training programme designed to support education and speech and language professionals in meeting the needs of pupils with Down's syndrome in primary schools. The programme will strengthen your confidence and expertise in the understanding of the following key areas:

- **Speech, Language and Literacy;**
- **Evidence for the learning profile associated with Down's Syndrome;**
- **Behaviour;**
- **Differentiation of education delivery.**

Key Speaker: Julie Hughes – Director. Down Syndrome Education Int.

Organised by: Seaford Down's Syndrome and Special Needs Support Group. (Registered Charity No. 1139897)

Cost: £55 per professional delegate. Parent donations.

Timings: Registration from 8:45am. Start: 9:15am and Close 4.15pm

Venue: Sutton Hall, Downs Leisure Centre, Seaford, BN25 4QW.

Availability: Only 50 seats available, 10 of which are for parents.

To secure your place, please contact: Sally Hipkiss (Secretary) phone: 07946-549744 or email: thenyes@talktalk.net

Seaford Downs Syndrome and
Special Needs Support Group

down syndrome
education international
discovering potential • transforming lives





ChoicES Employment Services



ChoicES is an East Sussex County Council Supported Employment Service, based within Adult Social Care. It is a county-wide service for adults with

learning disabilities who are seeking support into work.

We support both job-seekers and employers at every stage of the employment process. This includes:

- Arranging full-time, part-time, voluntary and work placements;
- Carrying-out detailed profiling to match candidates with jobs;
- Ongoing training and support, ensuring all employees can perform their duties to the highest standard;
- A dedicated Employment Advisor to support businesses to make sure they get the best from their employees;
- Comprehensive Health & Safety, and risk assessments to ensure employees are happy and safe.

To access this service, clients must be aged 18 or over, have an Adult Social Care assessment, and a diagnosis of a learning disability recorded on our Care First system.

The ChoicES ‘pathway’ remains a person-centred process where the client’s wants, ideas and skills are at the heart of all that we do. Throughout this work, we can offer a range of experiences including: skills assessment (including other professionals), Key Moves, travel training, Job Club, training/colleges, individual budgets, job searching, etc. This work can help us to find a suitable employment setting to suit the individual.

A recent example of our service is an adaptable young man, who came to live in St Leonards, with some experience of employment. Given the information he was able to provide us, we were able to marry his skills with an opportunity as a kitchen porter at the Conquest Hospital. We supported him for a number of weeks, until he ‘found his feet’, and he is now looking to develop his skills and tasks within this setting, and ideally work towards part-time paid employment. He has personally developed so well over this time and now loves going to work, independently, three days a week!

For more information on how ChoicES may be able to help, please contact: Liz Mellor ChoicES Co-ordinator on 01273 336655.

A NEW INFORMATION SERVICE

Parent Link* and Family Information Service (FIS) are joining together.

The new team will be providing information, advice and guidance, both general and specialist, across the range currently being provided individually by the services.

- Childcare
- Positive activities for young people
- Special Educational Needs and disability
- Educational matters

The new combined service will be available to all families throughout East Sussex and will continue to take calls about all children’s services.

Many of our current projects such as Parent Information Contacts, the ‘Parent Voice’ consultations and newsletter and the disability register will be continuing.

We would like your help to shape the new service!

You can either:

- Join our steering group. It meets three times a year and helps guide and monitor the service; or
- Send your ideas comments to parentlink@eastsussex.gov.uk 01273 481172



Looking forward to working with you to deliver the service you need!

**(Parent Link is the East Sussex Parent Partnership Service)*

PARENT RESEARCHERS

Turning Point's Connected Education project in East Sussex trained parents and students to be researchers, to find out what other parents and students think about schools. Interviews were carried out to explore perceptions and aspirations within five secondary school communities in Hastings and Eastbourne.

This research is helping to change things for the better by shaping policy and practice within each school community. Parents have given lots of ideas for improving communication and relationships. They have also made suggestions about how schools could help them to better support their children with learning.

The experiences of parents with special needs and disabilities have also been looked at separately.

The research shows that parents with a child with SEND:

- Worry more than other parents about their child growing up to be independent and responsible.
- Want their child to 'do well' at school but are more unsure than other parents about what their child is able to achieve.
- Tend to have either a very good or a very poor relationship with school. This often depends on how well they think the school is meeting their child's needs and how well the school communicates with them.
- Would like schools to listen more to their views about the best ways to support their child.
- Would like to have closer relationships with schools.

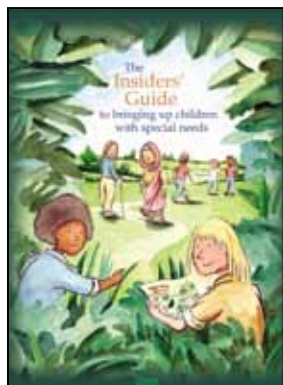
The next stage is to work with schools to help them use the final report to plan for making changes that will make a difference to all parents and young people. Watch this space!



Becky Surman
Head of Connected Education

INSIDER'S GUIDE

After the successful completion of our pilot Insider's Guide courses we facilitated the training of 8 parents and 8 professionals to run the courses across the county.



Those who took part in the facilitator training reported their experience as 'Insightful and Inspiring'. The experience was so inspiring to the parents that they have decided to set up a Parent Carer Forum to represent the voice of parents in East Sussex (*see insert*) and to ensure that the delivery of Insider's Guide courses continue to flourish.

Details of courses local to you can be found advertised in Children's Centres, Schools, through Parent Support Adviser's and The Excellence Cluster.

Parent Link will be advertising the Insider's Guide Courses on their website in due course.

If you would like further information please contact Kerry on 01273 481172.





My Rights, Your Responsibility – your child's right to be included

My Rights, Your Responsibility is a set of information written primarily for parents of disabled children. It provides information to parents on their child's rights to access activities, community facilities and other services.

So often disabled children and young people are told they cannot join in for reasons relating to health and safety and their impairment. This information tries to address those issues and details what needs to be done to ensure that children and young people can safely join in and that the organisation providing the activity meets its responsibilities in terms of health and safety.

Health and safety should not be used as an excuse to prevent services becoming more inclusive but should be used to ensure that risks are minimised and that we move towards a situation where all children and young people are given the opportunities to join in activities that they would like to do.

To find out more about this project visit www.ncb.org.uk or call 020 7843 6082. There are also a number of printed leaflets e.g *The Disability Discrimination Act, What can parents expect from services?* etc. You can download these leaflets or order hard copies by emailing data@mdsltd.uk.com or calling 020 8676 9989.



Event for parents and partners about services for disabled children under 8



Who is this for?

- Parents and people working with under 8s

When?

- Thursday 7th July 9.30–2pm
Lunch included

Where?

Congress Suite, Compton Street
Eastbourne BN21 4BP

What's it for?

- To increase knowledge of existing and new services;
- To promote partnership working amongst parents and services for children with additional needs;
- To identify what's working well, gaps in services or which services aren't working so well.

There will be presentations and a chance to have your say.

To book a place call Val Hay on 01825 769578 or email valerie.hay@eastsussex.gov.uk

Why not contact Parent Voice...

We welcome your ideas for future articles, contact:

Parent Voice

Tel: 01273 481279

Text: 07797 830320

Email: parentlink@eastsussex.gov.uk

www.parentlinksussex.org.uk