

Parent Voice

News

A Parent Link project



New Youth Cabinet elected!



December 2011

8,933 local young people took to the polls between 14th November and 5th December to elect their new East Sussex Youth Cabinet.

The Youth Cabinet consists of 20 elected members and plays a key and high profile role in campaigning on issues that young people have identified as a concern during the **Big Vote** election.

Each area of the county is represented and six members of the Cabinet also represent the county nationally through the UK Youth Parliament.

This year the top three concerns for East Sussex young people were to tackle and prevent bullying (16% of the vote), lowering education/tuition fees (14%) and better access and affordability of public transport (12%).

Cllr Colin Belsey, the County Council's Lead Member for Children and Families, welcomed the new Youth Cabinet into Office at the results evening on 12th December and said:

"The Youth Cabinet is an amazing group of young people who really do make sure the voice of young people in this county is heard. They have been hugely successful in making sure decision makers know what matters to young people. Their on-going campaign on transport and environmental issues is a great example."

New Youth Cabinet Member, Holly Tadman, a pupil from Saxon Mount School said of the evening: "I look forward to meeting new people and listening to other young people in my school, so they are involved in the Youth Cabinet's



Holly and Kyle from the new Youth Cabinet

campaigns. If you believe in yourself you can achieve your dreams!"

On looking to the future, new Youth Cabinet Member Kyle Wells, from St Mary's School Horam said: "It was daunting meeting everyone, but I'm really looking forward to working with the Youth Cabinet."

For more information on the Youth Cabinet and on the Big Vote 2011 call 01273 335250 or visit: www.connexions360.org.uk/youthcabinet

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The newsletter for parents and carers of children with Special Educational Needs and/or a disability
parentlink@eastsussex.gov.uk





The East Sussex Parent Carer Council page

Since the last Parent Voice newsletter East Sussex Parent Carers' Council has been working hard to establish the **organisation** and recruit **membership**.

Developments planned by the Steering Group are:

- **an official launch of PaCC during February or March 2012 involving interested parents and groups, the voluntary sector and representatives from the health, social care and education services;**
- **a dedicated PaCC website;**
- **close links with Parent Link/Family Information Service to involve parents in the planning and delivery of information events, training workshops and the many consultations taking place; and**
- **training for parents interested in participating and making a contribution.**

In order to ensure that the parent voice is represented, **PaCC** members have been attending meetings locally and nationally about the creation of the **“Local Pathfinder Change Boards”** (see article on page 9) **but there is a lot more work to be done.**

Hi, my name is Michelle. I am the co-Chair of the ESPaCC and this is the first instalment of our “Getting to know your PaCC”.

I live in Eastbourne and have two children. My 16 year old daughter has complex needs and goes to Ingfield Manor School in West Sussex, a Scope school for children with complex physical and associated difficulties. I am a Parent Governor there and have recently taken responsibility for setting up a website and newsletter for the school.

In my “spare” time I am a mentor with the Prince’s Trust working one to one in East

We continue to receive expressions of interest & support but we still need more people to become actively involved in the PaCC Steering Group. This is a really exciting opportunity to make a difference. Remember it is...

OUR CHILDREN – THEIR VOICE – THEIR FUTURE

If you would like to be involved in any way or just kept informed then please email us at: eastsussexparentcarercouncil@hotmail.co.uk



or visit us on Facebook: **East Sussex Parent and Carer Council**

or contact Parent Link on 01273 481172 and they can put you in touch.

Our next scheduled meetings are:
4th January, 1st March, 30th April and 12th June (at venues to be confirmed).

ALL WELCOME



Our Children Their Voice Their Future



Sussex with young people aged 16-25, helping them to explore and plan their next steps towards employment, education, or training.

I believe passionately in the voice of parents and families and I’m really excited about the changes that are happening at the moment thanks to the Green Paper. This is all about giving parents control and choice.

Finally, this is our chance to really make a positive difference for our children.

Boccia in Sussex

Looking for something new and fun? Why not try Boccia?

Boccia is a non contact Paralympic sport and is extremely easy to pick up: it is similar to lawn bowls where the closest to the white jack ball wins!

Boccia (*pronounced Botcha*) has many benefits such as aiding concentration, patience building, teamwork and forward planning. Played from a seated position (either on chairs or from a wheelchair) turns are taken by teams or individuals to get their ball closest to the white jack ball – the nearest ones score – it really is as simple as that!



As well as skill training, we play different games and hold regular competitions. We are also looking to joining the Pan Disability League in the future.



Lewes Boccia was set up in March 2011 by Dave Capper-Sandon for his son who has Cerebral Palsy. Dave is fully trained by Boccia England (NGB), holds the Community Leader Award and is a Boccia England Regional Referee.

We play on alternate Sundays, usually 2pm - 4pm, throughout the year (including holidays!) and cater for all disabilities and ages.

To find out more contact Dave on 07729 447913 or email info@lewesboccia.co.uk

Or you can visit our website www.lewesboccia.co.uk or find us on Facebook www.facebook.com/lewesboccia

Who does what?

Pari Rueb works as a Children's Disability Nurse Advisor for the Child Development Team at the Conquest Hospital.

Her role is to visit children and families in their homes across the county to undertake assessments for special needs following referral from professionals. This includes children who need assessing for social communication disorders, developmental issues, continence problems and families who require support following a new diagnosis.

She has worked for the Child Development team for 12 months and brings a wealth of experience in working with children and families with additional needs.

She previously worked at the Evelina children's hospital in London for six years and prior to that the Royal Alexander children's hospital and Brighton and East Sussex hospitals NHS Trust.

If you would like any further information on the services she provides you can contact Pari at the Conquest Hospital on 01424 755255.

Correction

The article in the September edition about the improved facilities at Sorrel Drive incorrectly gave the impression that Rockinghorse Children's Charity funded the refurbishments. This is not the case and the £900,000 project was largely funded by the Aiming High for Disabled Children programme.

The Rockinghorse appeal is completely separate and is for outdoor gym and sensory equipment for the Bungalow garden.

Our apologies for any confusion caused.



Bookstart in East Sussex



Bookstart
Est. 1992 by BOOKTRUST

Bookstart is the national programme that provides babies and young children with free packs of books and ideas for parents on how to enjoy sharing books together. All babies and pre-school children are entitled to a Bookstart Baby Pack and a Bookstart Treasure Bag.

Bookstart also provide two special needs packs and two useful booklets for parents of children with additional needs.

Bookshine packs are available for children aged 0-5 years that are deaf and includes a touch and feel book and a book featuring simple British Sign Language (BSL) signs.

Booktouch packs are available for children who are blind or partially sighted. This pack includes two touch and feel books, ideal for stimulating children's sense of touch as well as information and advice for parents.

Finding books to suit different needs leaflet will help you to identify books that might be particularly relevant to your child's specific needs.

Finding inclusive books has a list of early year's books showing positive images of disability, as well as titles that may prove useful in discussing disability and diversity.

You can download the leaflets from the Bookstart website www.bookstart.org.uk

For further information on how to obtain any of the Bookstart packs or copies of the leaflets, please contact Sue Stevens, Bookstart Project Manager on 01323 416324 or email sue.stevens@eastsussex.gov.uk



In the Picture books

Positive storybooks featuring disabled characters

Scope's *In the Picture* campaign raises awareness of the need to include disabled children in the books they read. If you are looking for picture books that feature disabled characters, why not check out their list. You can find it by going to their website www.scope.org.uk and searching 'In the Picture books'.

Hazel Court School win Top Takeover Day Award for the second year!

Huge congratulations to the pupils and staff of Hazel Court School who have won the Secondary School category of the **Top Takeover Day Award** for the second year running. The Award, organised by the Equality and Participation Team in Children's Services, was judged by young people from the Children in Care Council. They were very impressed with all the efforts Hazel Court, who topped all other entries, put into their day.



The Children's Commissioner's national Takeover Day gives children and young people the chance to work with adults for the day and be

involved in decision-making. Young people benefit from the opportunity to experience the world of work and make their voices heard, while adults and organisations gain a fresh perspective on what they do.

HOT TOPIC!

Dyslexia

We put parent Jacqueline Temple's questions to Qualified Dyslexia Teacher Jean Judson from Tideway School, Newhaven.

Why is there no confirmed diagnosis of 'dyslexia' at school, only "at risk"?

Many children have difficulties learning to read and spell but they may not be dyslexic. Their difficulties could be due to other reasons such as poor attendance – and therefore lack of consistent teaching – eyesight problems, illness, lack of confidence, poor concentration skills or family background and culture. There is no definite diagnosis because it is difficult to estimate the impact any of these other factors have had on their literacy skills. If a child scores an 'at risk quotient' (ARQ) of 1.0 and above on the Dyslexia Screening Test (DST) they are said to be 'strongly at risk' of dyslexia. Also, the child's performance in the test itself may be affected by lack of concentration, anxiety or illness and the result may not be an accurate measure of their ability, they may well perform differently at another time. However, the test is a useful tool for highlighting areas of relative strength and difficulty and enabling appropriate support to be put in place.

Why does it take so long to make a diagnosis of "at risk" of having dyslexia?

Children starting school in Reception will have had very different experiences at home. Many will have been enjoying books and 'reading' while others will not. As well as starting at different levels, children also develop at different rates. Primary teachers are anxious not to label children as being dyslexic until they have had the opportunity to catch up. However, if a child experiences literacy difficulties then they need to be supported appropriately. Even if they are not dyslexic, dyslexia-friendly teaching methods such as having a range of multi sensory

activities, using a simple font like Arial or Comic Sans of at least 14pt size on the Smart board, wide spacing between lines and a different coloured background such as buff or pale pink can be very helpful for all children.

Why are children with learning disabilities often in a class full of children with challenging behaviour?

Challenging behaviour can be a way of disguising other problems including learning disabilities. Children often behave badly to avoid having to do the work and risk feeling embarrassed that they don't understand. Children who are dyslexic sometimes fall into this category. They are relatively bright in other areas but find reading, writing and spelling very difficult. As they are expected to read and write every day at school they can quickly start to feel they are failing which in turn erodes their self esteem and causes a lot of distress. Their behaviour becomes more challenging when confronted with literacy based tasks because this is the area they have problems with. Children with particular learning difficulties will have work set an appropriate level in class and may also have opportunities to work in a small group or even 1:1 with a teacher or teaching assistant for part of the week.

Are there any help groups for children or parents with poor short term memory and dyslexia?

The British Dyslexia Association (BDA) has a very useful website www.bdadyslexia.org.uk which is packed with information for parents, for adults with dyslexia and for schools.





Happy holidays!

Are you in need of a holiday but put off by the cost or challenge of finding one suitable for your disabled child?

Help is available. A good place to start is www.direct.gov.uk (search for 'Holidays in the UK for disabled people'). You will find organisations that provide advice and information to disabled people about travel and holidays, financial help and a link to Visit England's National Accessible Scheme.



Help with funding

Some charities help towards holiday costs and some own their own properties.

Here are some we have found in addition to those at Direct.gov.uk Apply early for the best chance of success.

- **The Family Fund** work with Butlins, Haven and Thomas Cook and can provide grants towards the cost of a holiday www.familyfund.org.uk
- **Blitz** raise funds to subsidise short breaks to Blackpool and St Anne's for those living with a disability. Visit www.bondhotel.co.uk and click on Blitz.
- **Trewan Sands Children's Trust** raise money to provide holidays for families who are referred to them by the child's special school or local authority disability team. Visit www.tsctrust.org, look in 'downloads' for an application form.

You may be interested in...

Headstart School in Ninfield is currently looking for volunteers for their organization and also able to offer work experience for mature students. They offer training and an induction and the experience of supporting groups of students with EBSD and also students on the autistic spectrum between the ages of 10 to 18 years. Please contact Julia for further information: admin@headstartschool.co.uk or 01424 893803.



A new report commissioned by the Early Years Support Service to seek parents views about

Booking a holiday

Explaining your particular requirements clearly when booking accommodation or dealing with a travel company is important. You can use a company that offers holiday accommodation designed for people with disabilities, their families and carers. Here are a couple we heard about:



www.ellwoodcottages.co.uk Parent Kerry told us Ellwood Cottages are "...set in the heart of the Dorset Countryside with the most helpful and welcoming owners who go that extra mile to meet your individual needs".

www.thelinberwicktrust.org.uk



"Just in case" Insurance

It is advisable to take out travel insurance even if you are travelling in the UK. This is especially important if:

- you have a wheelchair;
- you're taking special equipment; or
- you're likely to need medical attention which may cut short the holiday.

For more advice visit www.direct.gov.uk and search for 'Travel Insurance for disabled people'.

Let us know if you have had a good holiday experience. We are keen to learn about services that we can share with other families. Call Parent Link on 01273 481172.

the development of a shared ASD pathway for the benefit of children families and practitioners has been published. The report is called **Parent and Carers' Views of Autism Spectrum Disorder (ASD) Assessment and Diagnosis**. If you would like to receive a copy call 01323 747470 or email keyworker@eastsussex.gov.uk

Time Out respite play scheme for children. The group meets one Saturday a month at The Welcome Church, Heathfield from 10am until 3pm. **For more information contact Janice on 01435 868583.**

Plane failing

My name is Hayleigh Barclay and I am a 24 year old wheelchair user. I have a condition called Spinal Muscular Atrophy which means that I have weak muscles and a curvature of the spine. This requires that any time that I have to sit I have to be supported in a specific way.

Up until the age of 13 I could sit comfortably in an airline seat but as my condition changed this became impossible meaning that I have not been able to travel by plane for ten years.

Having discovered that others have the same problem, that many disabled passengers feel undignified and in pain whilst sitting in a standard airline seat and that wheelchair users have had equipment damaged or broken whilst being transported, I decided that something must be done to resolve the situation.

I have started a campaign to encourage the aviation industry to research ways which would allow a wheelchair to be securely fitted on board a plane so that wheelchair users could remain in their own seats while flying. The campaign also encourages airlines to have a better understanding of specific needs and to create better services for disabled passengers.

Please join my campaign by signing my online petition at www.surveymonkey.com/s/airlinecampaign and searching for me on Facebook to keep updated.

Please show the world that this issue matters because it's the only way that people will listen.

Hayleigh Barclay



Having fun? Pass it on!

Have you enjoyed a group or activity you think others should know about? Or are you thinking about setting up your own group?

Spread the word!

The Family Information Service holds lists of fun things to do for young people of all ages countywide. Here are some activities we heard about...

- **Special Olympics** groups in Eastbourne and Hastings and Rother run activities for children aged 8 years and over and adults with a learning disability. Try athletics, boccia and much more www.specialolympicsgb.org.uk
- **Freedom Leisure** in Rye, funded by East Sussex County Council, has improved access to the swimming pool and gym



facilities. There is now a hoist, pool chair, changing table, disabled toilet and shower. For more information or group bookings please contact Natasha Burch on 07717 776788.

- **Active 4 All** at Freedom Leisure in Uckfield are offering fun games and activities for young people with learning and physical disabilities, every Tuesday 4.30-6pm. It costs £3 per session, which includes a free refill when you buy a Costa coffee. For more information please contact Natasha Burch on 07717 776788.

To find out more or share your discoveries, call the Family Information Service on 0345 60 80 192 or email familyinformationsevice@eastsussex.gov.uk

We can also help you find childcare, show you where to go for more advice and support and help with the costs of family life. Our service is free, friendly and independent.





My time – a place to talk

Loss, in any form, has a direct impact on young peoples' lives and in some cases can result in mental health issues.



Set up with funding from Comic Relief, My Time, is a service provided by the Fellowship of St Nicholas and based in the Hastings and St Leonards area. It has two main aims; to support young people who have mental health needs resulting from loss, and to de-stigmatise mental health amongst professionals working with young people.

Group sessions, based on the peer support model, are aimed at helping young people understand their feelings and then gain coping strategies to deal with what can be very frightening emotions.

All sessions include creative activities such as an Anxiety Thermometer and the Circle of Trust.

My Time is easy to access as anyone can make a referral. Young people can refer themselves. Places are available for young people outside of the area who are able to travel.

Of the young people who have attended My Time, 86% reported an improvement in their well-being after 10 weeks, a great indication that talking helps.

For more information contact Natalie Trowell on 01424 423683 ext 34, email ntrowell@fellowshipofstnicholas.org.uk or visit our website www.fsncharity.co.uk

TRAINING DVD LAUNCHED FOR PROFESSIONALS WORKING WITH DISABLED YOUNG PEOPLE

A DVD that tackles issues around sexuality for young people who are disabled or have a life-limiting condition has been produced by a local NHS employee.

The Whole Picture: exploring disability and sexuality is the first resource of its kind in this country and was the idea of Corine Koppenol-Lyndon, Lead Nurse for Disabled Children & Young People for East Sussex Healthcare NHS Trust.

Funding for the production of the DVD was provided by the Department of Health. It was produced by Triangle, an independent organisation which works with children and families across the UK, and East Sussex Downs and Weald and Hastings and Rother NHS. It is distributed nationally by the Association for Children's Palliative Care (ACT).

The DVD aims to break the taboo surrounding sex, sexuality and relationships with young people with a disability or life-limiting condition. It offers practical advice for professionals working in the field and explores the need for training, understanding and empathy, as well as the need to develop appropriate policies and procedures in the workplace.

Anyone who would like more information on the DVD or about ACT can contact them at info@act.org.uk or call 0117 916 6422.



New Services for Disabled children: Have Your Say

Major innovations in the way services are provided for children with special needs and disabilities are to be put to the test by a group of councils across the South East, including East Sussex.

Come along and find out more!

Have your say. Help find and test better ways to meet the needs of children with special needs and disabilities and their families.

Come and join us on:

2nd February 2011

At Uckfield Civic Centre

There will also be lots of information stalls, refreshments and a light lunch.

There will be an introduction from Jenny Clench who is leading on this work in East Sussex, followed by short informative presentations and consultation sessions on:

- assessment and planning
- transition and support for employment
- individual budgets; and
- participation and information needs.

Throughout you will be able to have your voice heard and influence what happens next.

Be a 'pass it on parent' and let other know about this event...



To find out more contact Sarah Lindfield on 01273 481230 or email sarah.lindfield@eastsussex.gov.uk

Booking is essential

Disabled Dance Festival comes to Eastbourne

The International Dance Federation (IDF) Disabled Dance Festival 2012 will take place in Eastbourne as part of the World Dance Championships. Disabled dancers will perform in front of an international audience in different dance disciplines, including street dance (hip hop), tap dance, belly dance, Caribbean (salsa), boogie woogie, freestyle and lots more.



This is the first time that the event has been staged in the UK and it is an opportunity for residents in East Sussex to see a spectacular dance event. There will be competitors from more than 22 countries.

The championships will open on 24 May 2012 with the disabled dance festival taking place on Sunday 27 May from 2pm-6pm at the Devonshire Park Centre, a fully accessible venue.

For more details, tickets, or if you would like to take part, email the organisers on info@idfdanceuk.org or telephone Helen on 07883 084774.

See the website www.idfdance.com and look for Disabled Dance Sector on the left hand menu.

Short Breaks and Individual Budgets Update

Hello, I'm back with a quick update on Short Breaks and Individual Budgets.

In the first quarter of 2011/12 (April to June) the figures we have show that we provided short breaks to 447 children over 25,231 hours.

In the second quarter (July to Sep), this rose to 596 children over 29,306 hours, a significant increase on the first quarter.

East Sussex has also published its Short Breaks Services Statement, a document which shows what services are available, the eligibility criteria for these services and how the range of short breaks is designed to meet the local needs of families with disabled children.



This and the Short Breaks brochure, which lists the current services in East Sussex, can be found on the East Sussex County Council website by searching Short Breaks Services Statement.

The Individual Budget pilot is also right on track, with all places filled and things moving along swiftly. A meeting was held in Eastbourne on 21 November with speakers from East Sussex and In-Control explaining to service providers how the scheme and pilot will work.

That's all for now, any questions please contact me using the details provided.

Simon

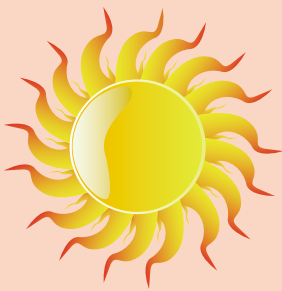
Telephone: 01273 336543

Email: simon.waters@eastsussex.gov.uk

Website: www.eastsussex.gov.uk/shortbreaks



Holiday childcare for parents of disabled children



A recent article by KIDS on a parental survey run in partnership with **Mencap** reported that two-thirds of all parents of disabled children received no holiday care during summer 2011.

Local authorities do not have to provide a childcare place for every disabled child, but rather to take reasonable steps to do so.

East Sussex County Council is very pleased to support parents with disabled children to access suitable holiday childcare. In times of cuts to local budgets ESCC is committed to continuing support.

ESCC does this by:

1. providing subsidised holiday play projects on special school sites;
2. providing an Inclusion bursary grant to help parents and childcare providers remove barriers to inclusion within local community play projects;
3. giving access to short breaks; and
4. co-ordinating a specialist SEN childminding network for all year round childcare opportunities.

Ruth Szulecki

Early Years Development Manager



Winning the Lottery!

A local group was the grateful recipient of a £9,900 award from the Big Lottery Fund Awards for All.

Seaford Downs Syndrome and Special Needs Support Group received the award to buy specialist play equipment for use at their monthly family drop-in at Seaford Downs Leisure Centre.

The group's Chairperson, Senay Smallwood said: "The new equipment will make a big difference to the children in our group. As well as helping develop their motor, cognitive and social skills it will help them build confidence and let them join in activities they might not otherwise be able to."

Does your group need funding?

For further information call 0345 60 80 192 and ask for Emma.

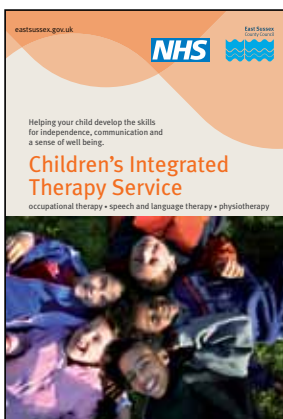
Useful links

www.seaford-dssnsg.co.uk

www.awardsforall.org.uk



Children's Integrated Therapy Service: Post 16 project



In April 2011 children's occupational therapy, physiotherapy and speech and language

therapy staff from Health, Education and Social Care came together under one service; the newly formed Children's Integrated Therapy Service (CITS).

CITS, an exciting initiative, provides an integrated and equitable therapy service for children and young people in East Sussex.

There is recognition both locally and nationally that therapy services for young people aged 16-19 years are inconsistent with a need to improve support during times of transition.



As a result I have been asked to look at current services in East Sussex and draw up a proposal to develop Therapy Services for this age group.

I am keen to hear from any parents and young people



who would like to contribute to this piece of work. My contact details are below. I look forward to hearing from you!

Sandra Tomlinson

Children's Integrated Therapy Service Project Development Manager

Work Mobile: 077920 028356

sandra.tomlinson@esht.nhs.uk

COMING SOON!

Workshops for Parents and Workers

Would you find the following workshops useful?

- toileting and continence;
- sleep;
- challenging behaviour; and
- sexuality and learning difficulties?

We are running the workshops in spring 2012.

Call us for more information and to book your FREE place 01273 481172.

We also want to know about your ideas for workshops and if you would like to be involved in developing workshops in East Sussex. Having parents involved from the start makes a real difference!

You would be working with partners from services including: the Family Intensive Support Service (FISS), Early Support Key Worker Service, Parent Link and Care for the Carers to develop the workshops.

Experience has shown us how useful support of this type can be. We have run some general support sessions for parents called *The Insiders' Guide*. Parents have told us they have been very helpful. We want to build on this if it would be of value to you.

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

Specialist training day

Friday January 20th
2012



St Thomas More
Church Hall Highlands Road Seaford

Morning speaker: Dr Warren Matofsky

Behaviour as a communication: promoting emotional development at school.

Afternoon speaker: Rebecca Baxter MSc, BSc (Hons), Cert MRCSLT

Developing speech language and literacy skills across the curriculum for children with Down's syndrome.

For further details or to book a place contact Jackie Macdonnell 07985 113794 or email Jac.mac91@hotmail.co.uk

Remember the Information Day

2nd February 2012

Uckfield Civic Centre

See page 9 for more details

Insiders' Guide

Insiders' Guide courses coming soon



Transition and moving towards teenage years

Starting Monday 9 January at Peacehaven Library,
Delivered by Jane Hawkes (Parent Link) Michelle Nice (Parent) Kerry Fox (Parent)

Challenging Behaviour

Starting Feb 2012 at Stone Cross, Eastbourne
Delivered by Cleo Kitcher (Parent Support Advisor) and Kerry Fox (Parent)

Both courses will run for six weeks

If you would like to attend either of these course contact Parent Link on 01273 481172.