

Participation, Advocacy and Rights

**WELLSPRING
WEST SUSSEX**
- A regular newsletter
for children and
young people with
disabilities, and their
parents and carers
across West Sussex

Hello! I hope everybody had a brilliant summer and the first half of the new term and school year has got off to a good start. Changes can bring useful experiences, so if you or someone you know has moved school, changed job or even moved house, why not write to Wellspring and tell us about it - your participation could be really helpful!

This edition is all about finding your voice and making it heard! Find out about the work of the Impact Advocacy Service and how they can support you on page 2 - pages 8 to 10 have details of lots of other organisations who can help you to speak up! On page 4 there are details of local groups for parents and on page 15 find out about the South East Coast Muscle Group, set up by the Muscular Dystrophy Campaign.

If you are a young disabled reader, turn to page 7 to read about the work of the West Sussex Youth Cabinet and on page 11 find out what Takeover Day is all about and how to join the Youth e-Panel.

If you have any equipment lying unused that may be of use to another family, see page 14 for details AskDES Kids, a new service.

On page 6 there are details of some sports and leisure opportunities for the autumn and winter. If you're wondering where I am in this photo, turn to page 13 to read about my holidays.



The Wellspring Transition Guide will be available early next year, so keep an eye out for that!

Lizzie Baily
lizzie@wellspringwestsussex.org.uk



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Contact ICIS for information on services offering care, support or advice in West Sussex.
Telephone: **0800 859929**
e-mail: enquiries@icis-info4life.org.uk
www.icis-info4life.org.uk

Impact Advocacy Service

As a reader you might not be aware that Impact Initiatives have been providing an advocacy service for adults with a learning difficulty for over 10 years within the county.

This service has been funded by West Sussex County Council and seeks to provide issues based advocacy support to individuals across the county, this includes parents with a learning difficulty going through child care proceedings and support to three self advocacy groups to assist them to speak up for themselves.

During the early the part of 2010, the advocacy team and Impact initiatives were involved in tendering for various advocacy contracts that West Sussex County Council required in order to ensure that they put People First as part of their strategy for ensuring that customers living in the county received the necessary support to ensure that their views and voices are heard within a variety of situations and that their experience of accessing statutory services is a positive one.

Since April 2010 not only have we been awarded advocacy contracts to continue to provide advocacy support to adults with a learning difficulty and parents going through child care proceedings and the self advocacy groups but in addition to facilitate a Quality checking project to assist adults with learning difficulty to access transport and leisure facilities across the county and to help staff employed within these two industries to understand the needs of people with a learning difficulty.

We have also since April been contracted to provide advocacy support to adults with an acquired brain injury and with sensory and physical impairment aged 18 to 65 years old living in West Sussex.

This is an exciting time for both the advocacy team and for people living within the county, who require the support of an advocate, as access to advocacy is now greatly enhanced.

What is advocacy?

Advocacy is when someone speaks up for a person with the intention of making sure that person's views and wishes are listened to with the respect and attention that they deserve; this is the essence of advocacy. Advocacy describes a natural activity which is often present in any community whose members are concerned to look after one another. Most people's first experience of advocacy come from within the family, where family members support and promote each other's rights and interests, for example a parent may advocate on behalf of their child to their class teacher, or a sibling speak up on behalf of their brother or sister dealing with the mental health system.

Most people advocate for themselves without thinking about it, for example when querying a bill or complaining about a poor service, someone is being a self advocate in defending their own interests. Some people find it very difficult if not impossible to speak up for themselves in this way, illness, age, disability, cultural background – these are some of the factors that make it very hard for some people to get their voices heard and which leave them at risk of being excluded from the services and entitlements that most of us take for granted. This, together with the fact that for many, families no longer provide the support and cohesion that they once did, had led to the development of dedicated advocacy services/organisations offering advocacy support in their communities.

A whistle stop tour of what an advocate does

An advocate will undertake the following:

- Stand alongside the person to safeguard their rights and promote their interests.
- Is committed to seeing that things get better for that person.
- Is always interested but does not let his/her own views interfere with what needs to be done.

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- Is non-judgemental but never neutral.
- Does not give advice but aims to help the person gather the information that they need to make informed decisions and choices.
- Is active but does not 'take over', always following the person's lead and working at their pace.
- Has his/her loyalty focused primarily on the person they are working with and as such, the advocate is separate and independent from other supports and services that the person may be receiving, which means there should be no conflicts of interest.
- Is motivated above all by goals of social justice, community inclusion and citizenship.

If you would like to know more about our advocacy services in West Sussex, are interested in becoming a volunteer advocate or would like to know more about the work undertaken by Impact Initiatives, please contact the Advocacy Team at Dove Lodge, Littlehampton on **01903 730044**.



Image from www.advocacyforinclusion.org

Childcare Sufficiency Assessment

We want to hear from you...

- Are your childcare needs being met in West Sussex?
- If not, is this because there is no suitable childcare to meet your needs?
- Does your child/children have a specific childcare requirement?
- Are you able to find childcare so that you can work or access training?

What is the Childcare Sufficiency Assessment?

The Childcare Act 2006 places a duty on local authorities to undertake a Childcare Sufficiency Assessment every three years. Our first Assessment was completed and published in March 2008 and is available to view on the West Sussex Grid for Learning (WSGfL).

What is the Assessment for?

The Assessment helps us to identify gaps in childcare provision and enables us to make plans to secure sufficient provision to meet the needs of parents.

How can you help and have your say?

In order to complete the assessment we have to conduct a parental demand for childcare exercise. It is really important for us to hear

from you and know about your childcare needs in order that we can make plans to secure sufficient childcare.

Our questionnaire will be available on-line from 17th September until 20th October 2010 at **www.westsussex.gov.uk**

It is on the 'Have Your Say' pages under 'consultations'.

Alternatively, you can access a copy at your local Children and Family Centre.

The questionnaire will ask about the childcare you are currently using, if any, and about what your future needs might be.

Who else is involved?

We have to review the current supply of childcare and we do this by working with all childcare providers, including childminders, across the County.

Also, we will talk to employers, children and other organisations to help us find out about the childcare in West Sussex and what childcare is needed.

What happens then?

A draft assessment will be produced and made available on the 'Have Your Say' page on the West Sussex County Council website for comments. The final assessment will be published in March 2011.

Parent Participation

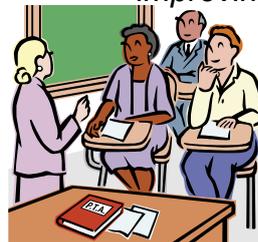
Many parents invest time and effort trying to influence services and they sometimes wonder, 'Is it worth it?'. If you're making your views known to service providers at any level, then yes, your input is invaluable, even though it may be difficult to see the results. Change takes time. You are also part of a growing movement of parents who realise that services will never fully meet families' needs if families are not at the heart of planning and developing them.

- making an impact by asking the questions no one else asks
- putting forward parents' views
- practising old skills and learning new ones
- making new contacts among like-minded parents and supportive professionals
- gaining respect, as your unique contribution and all the skills and knowledge you bring to the process are recognised
- seeing services change, as a result of your input.

The rewards for parents

Getting involved in working or planning groups can be a positive experience. Some of the things parents say they get from being on working groups are:

- the opportunity to learn more about how services work and how decisions are made



Information taken from 'Parent Participation improving services for disabled children', published by Contact a Family www.cafamily.org.uk

Local Parent Groups

West Sussex Parents Forum was originally formed by a group of hard working parents/ carers who volunteered their time to help the County Council in planning services for disabled children and young people aged 0-25 living in West Sussex.

We started out, 3 years ago with 40 parents on our database. Since then we have evolved rapidly, and although we still call ourselves West Sussex Parents Forum, we are actually a campaigning organisation that is totally independent of West Sussex County Council. We aim to represent the views of all parents with disabled children and young people in West Sussex

Email:

parents@westsussexparentsforum.co.uk

www.westsussexparentsforum.co.uk

Tel: **07528 418149**

You can also follow us on Facebook and Twitter.

Parent Carers' Planning Group

The PCPG aims to

- Identify needs and gaps in current services
- Comment on plans for implementation of new services
- Provide feedback on how services are performing
- Provide a route for officers to respond to issues raised by parent-carers and to report back on progress
- Inform parent-carers and their representatives of developments in relevant services

Meetings are held quarterly at venues in the County and are chaired by an Elected Member. There is open membership of the PCPG for parent-carers.

Officers attend from a variety of services including Special Needs & Child Disability, the Primary Care Trust, Connexions, Learning Disability Services and Parent Partnership. Key local voluntary organisations supporting parent-carers also attend.

The next meeting is on Wed 20 Oct 10.30am to 12.30pm in the Arundel Room, Brinsbury Campus.

Email : Gemma.North@westsussex.gov.uk for more details.



West Sussex
Parents Forum

Free Benefits Advice

Do you have a child with a disability or additional needs and feel that you need some help and support to access the right DWP benefits?

Aiming High and West Sussex County Council are funding a Benefits Advisor to offer help with DLA, Income Support, Incapacity Benefit, Housing Benefit, Employment Support Allowance, Tax Credits etc.

Write to: David Harper, WSCC, 6 Southey Road, Worthing BN11 3HT

or email: david.harper@westsussex.gov.uk

Give these details :

Name of Child:

Age:

Name of person to contact:

Tel:

Address:

Postcode:



We will contact you to make an appointment or invite you to a group event.

Family Fund changes

The Family Fund, the largest charitable grant-maker for families with disabled children, has changed the way it looks at income to help more families on the lowest of incomes.

From 1 April 2010, the Family Fund will consider a grant application where a family's total income from all sources, including net income and benefits, is below £25,000 in England and £27,000 in Northern Ireland, Scotland and Wales.

Previously a limit was imposed on working families, as families in receipt of benefits were automatically eligible.

Derek Walpole, Chief Executive of the Family Fund, said:

"In these tough times, it is our duty to ensure that we are helping families on the lowest of incomes and we are being fair to working and non-working families alike.

Our previous criteria was created with the best of intentions but effectively penalised working families in favour of those on benefit and prevented the Family Fund from helping many

families with disabled children who were in greater need.

Working families have long complained to us that they feel treated unfairly. For many parents or carers with disabled children, work creates positive mental health and provides a break from caring. It also encourages disabled children's own aspirations for work in the future, which improves their life chances.

"We have not reached this decision lightly. Our first preference would simply have been to increase our earned income limit without changing the rules for families on benefit. However, that would have required a further increase in our government grant. In the absence of this, the Family Fund's trustees have chosen this efficient way of making matters fairer."

Clare Kassa
Network Development Manager - Family Fund

Tel: 01273 748362

E-mail: clk@familyfund.org.uk

Circles Network

Circles Network is a national voluntary organisation formed in 1994. Our aims are to build inclusive communities where everyone, regardless of ability and background, can belong and contribute with appropriate support for children, young people and adults across cultures and diverse settings to flourish and contribute meaningfully.

Since 2000, Circles Network has been building Circles of Support in West Sussex as funded by West Sussex County Council to provide support and advocacy for disabled people. All of our work is based around the Values of Inclusion, which highlights that 'All means All.' In every one of our forms of support, we make use of Person Centred Planning, so ensuring that the focus person is in control of every aspect of the planning of their lives and becomes more confident and able to self advocate. This year, we have been working in collaboration with West Sussex Child and Adolescent Mental Health Services, West Sussex Community Team for People with Learning Disabilities, and Impact Advocacy to name just a few.



Circles Network
building inclusive communities

We are currently facilitating over ten Circles of Support such as The Clifton Road Friendship Group, which meets once a month and organises events and trips out to bring people together and works towards building inclusive communities. Our circles of support with young people have led to work experience

opportunities within the local community, art exhibitions displaying marginalised artists' work and the setting up of a young person's own cake business! 'Parents with a Difference,' a Circle of Support for disabled parents in Crawley, is

setting up a time banking scheme and a website with information for other disabled parents.

If you would like to hear more about West Sussex Circles of Support please email Ally Collier -

alexandra.collier@circlesnetwork.org.uk
or phone **01444 236 593**.

Leisure Opportunities

Introducing **Discovery Open Days at Broadbridge Heath Leisure Centre near Horsham**. These free multi activity days are for children with disabilities ages 0 - 19 years and include a variety of inclusive activities such as trampolining, rebound therapy, fun with food, multisports, arts and crafts, boccia, new age kurling and bowling. Specialist coaches and experienced staff are on hand to help the children, and parents/carers, with each activity. Family and friends are welcome to join in the fun - you can try as many different activities as you like with no cost - we even throw in a buffet lunch too.

Next open days Sunday 7th November and Sunday 12th December

If you are interested in attending the day to promote your services, or just to look and see what we do, please email: **suzannetravers@dcleisure.co.uk** or call on **01403 219206**.

Chanctonbury Sports and Leisure Centre has recently been given funding for disability sports at their centre in Storrington. We have **Multisports, Trampolining, Gymnastics and Table Tennis**. For children aged 5 - 19 (different age groups for different activities).

The sessions are open to anyone in Sussex but we have to give priority to children who live in Storrington and the surrounding area. We also have some space for non disabled siblings, but these are limited to keep space for disabled children. For more information contact : **Scott Bacon, Sports Development Manager**
Tel: **01903 746070**
Email: **sportup@chanctonburysl.com**

West Sussex Youth Cabinet

Wellspring member Kyran was an elected member of the West Sussex Youth Cabinet until recently...

The West Sussex Youth Cabinet is a group of young locality representatives and the 4 UK Youth Parliament representatives, who are democratically elected by young people from all around West Sussex. The Youth Cabinet represents the views of the young people in their areas at county level. The project is currently in its 9th year and works closely alongside the County Council and the Youth Service.

What does the Youth Cabinet do?

Our job is to represent young people's interests, views and concerns at meetings and events with adults and other young people, locally, nationally and even internationally. As well as this, we work on projects which aim to improve situations and solve problems that affect young people.

Examples of some of the work that the Youth Cabinet has done include the 3-in-1 scheme, multiple awareness films, annual school councils' conference, promotion of the eco-schools scheme, and many more...

Who can be on the Youth Cabinet?

Any one between the ages of 11 and 19 can apply to be on the Youth Cabinet during election periods. The Youth Cabinet is for all young people with all different kinds of needs, passions, wants and aims to always be representative of all young people..

Get In Touch

If you have any questions whatsoever on:

- Attending a Youth Cabinet meeting
- How to get involved with the Youth Cabinet
- Receiving Youth Cabinet work or products
- Getting support as a young person with a project or problem
- Problems with the Youth Cabinet or the web pages

Please contact the following:

Pandora Ellis- Youth Cabinet Co-ordinator

Tel: **07764 793106**

Email: **pandora.ellis@westsussex.gov.uk**

www.yourspacewestsussex.co.uk

Or write to us at:

West Sussex Youth Cabinet

PO BOX 1

Lewes

BN8 6WB

Student Council

The student council at QE11 school, Horsham meets with the head teacher and deputy on a regular basis. Each class elects a representative, who will speak for all pupils in their class. They are able to bring any issue to the council for discussion and are taken seriously. The student council plays an important part in the decision making process at school, for example helping to choose colour schemes for the school, deciding on the theme for our playground project. They also bring requests for equipment. They also spent a great deal of time developing the student manifesto, which brings together the views of all pupils on what they would like to see at school.

Information taken from the School Prospectus

Student Manifesto:

www.queenelizabeth2.w-sussex.sch.uk/school%20information/School%20Manifesto.pdf

Advocacy contacts

Caburn Support Services Ltd

Seadown House, 1a Farncombe Road,
Worthing, West Sussex, BN11 2BE
Steve Alexander, Registered Manager
Tel: **01903 216164**

Email: info@caburnsupport.co.uk
www.caburnsupport.co.uk

Support to enable adults with physical or learning disabilities or mental health problems and people recently released from custody (16+) to live independently within the community. People living in Chichester to Brighton area. Enables them to access local services and acquire self help and independence skills. Also supports care leavers to live in independent accommodation using self help skills, advocacy and accessing specialist services. Can also provide domiciliary care. Works with occupational therapists, social workers, community liaison officers, education and Connexions services and Youth Offending services.

Circles Network (Circles of Support), West Sussex

Suite A, KBF House, 55 Victoria Road, Burgess Hill, West Sussex, RH15 9LH.

Angela Butcher, Lead Facilitator

Tel: **01444 236593**

Email: angela.butcher@circlesnetwork.org.uk

Email: info.southeast@circlesnetwork.org.uk

Project Manager West Sussex and Surrey.

Alexandra Collier. Tel: **07912 210350**.

Email: alexandra.collier@circlesnetwork.org.uk

www.circlesnetwork.org.uk

Project working with adults who are at risk of social isolation and have learning difficulties. Using circles of support, person centred planning tools and the values of inclusion, the project helps people to have control over and make changes in their lives. *(see page 5 for more information)*

IMPACT Advocacy Service (Part of Impact Initiatives)

Dove Lodge, 49 Beach Road, Littlehampton, West Sussex, BN17 5JG.

Mike Ashbee, Advocacy Services Manager

Tel: **01903 730044**

Email: mike.ashbee@impact-initiatives.org.uk

Email: advocacy@impact-initiatives.org.uk
www.impact-initiatives.org.uk

Provide an independent, crisis (short-term issues-based) advocacy service to adults with learning disabilities, physical impairments, sensory impairments, acquired brain injury by creating and supporting one to one partnerships between individuals and paid or volunteer advocates. Additional support for parents with learning difficulties who are going through childcare proceedings. Also piloting an advocacy service for vulnerable adults within the Horsham Locality who require advocacy support during a Safeguarding investigation being led by Horsham Locality Adult Services Team. Supports 3 self-advocacy groups (learning disabilities) within West Sussex (Worthing Speakabout, Bognor & Chichester Voice and Burgess Hill Speakup). Impact advocacy has an Easy Information service which makes information easier to understand using various methods and is available to organisations who want to reach people with learning difficulties. Impact Initiatives is a Registered Charity. *(more information on pages 2-3)*

People First (Self Advocacy)

Unit 3.46 Canterbury Court, Kennington Park Business Centre, 1-3 Brixton Road

London, SW9 6DE. Debra Schiman Disability LIB Tel: **020 7820 6655**

Email: debra@peoplefirstltd.com Email:

general@peoplefirstltd.com

www.peoplefirstltd.com

Organisation run by and for people with learning difficulties 14 years and over, who are standing up and speaking out for themselves. Gives training and support to self-advocacy groups and service providers. Provides Easy Read Services and Training on Accessible Information, Disability Equality and good support. Anyone with a learning difficulty can be a member wherever they live in the country. Disability Listen, Include Build (Disability LIB) project for self-advocacy groups to talk to for advice. Run a London Campaign Network campaigning on all issues relevant to people with learning difficulties. Members can communicate with all other members on

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issues that are important to them. Organises conferences and produces a quarterly newsletter and resource list of materials, including picture banks and publications.

Southdown Housing Association Supporting People Service User Network

2 Bell Lane, Lewes, East Sussex, BN7 1JU.

Paul Richards, Co-ordinator

Tel: **01273 405840**

Email: p.richards@southdownhousing.org

www.westsussexsun.org

The Service User Network, also known as SUN, is a consultation network open to all users of Supporting People's services in West Sussex. The group is consulted on the planning, review and development of Supporting People

Services across the County. It has a voice at key decision making meetings, the Commissioning Body and the Working Group. The intention is to give the group a real say in the way that Supporting People delivers its services. People who would like to be involved in the group are encouraged to get in touch.

Speak Up

The Old Post Office Resource Centre, 30-32 Station Road, Burgess Hill, West Sussex RH15 9DS.

Steven Murray, Chairman Tel: **07776 072 603**
Harriet Wilson, Supporter.

Email: midsussexspeakup@googlemail.com

A Self Advocacy Group for people in Mid Sussex who have a learning difficulty. The group meets once a month to talk about things which are important to the members, support each other, plan activities, and go to training events. The group meets with people who organise their services and other groups to tell them what they think. They also enjoy social events throughout the year.



Speaking Out Advocacy Service

Centurion Mental Health Centre, Graylingwell Drive, Chichester, West Sussex, PO19 6GS.

Sandra Trebble, Co-ordinator

Tel: **01243 791906** Mobile: **07973 330276**

Email: saundra@speakingoutadvocacy.freerve.co.uk

Advocacy scheme for adults with mental health problems in Chichester, Bognor, Midhurst and surrounding areas. Free, confidential and independent of all other service provision.

Trans-active

www.trans-active.org.uk

Transition is a "journey" into adulthood and teenagers with learning disabilities need to

make life choices about school, college, work, their social time and where they might live. Trans-active is a project in which teenagers with and without severe learning disabilities work together using multimedia to explore

and communicate choices they will have when they leave school. The project is about using and giving support, making plans, making friends and having fun and enables people with disabilities to work through their options. The website is for young people and their parents or carers and includes links to organisations that can provide information on all aspects of transition.

Voice Bognor and Chichester

Bognor Regis Methodist Church, Waterloo Square, Bognor Regis, West Sussex PO21 1ST.

Fred Rowland, Chair Person

Mobile: **07748 088427**

Email: bcvoice.chi@btinternet.com

Service encouraging self advocacy. Run by people with learning difficulties to offer mutual support, contact and help for people with learning difficulties to speak up for themselves.

Worthing SpeakAbout

West Worthing Baptist Church, 45 South Street, Tarring, Worthing, West Sussex BN14 7LU.

Moira Hall, Group Supporter.

Tel: **01903 824308** Chair Richard Dockett.

Email: **speakabout@btopenworld.com**

A group providing self-advocacy for people with learning difficulties in the Worthing, Littlehampton and Shoreham areas. Meet at St Charles Roman Catholic Church Meeting House, Chesswood Road, East Worthing. 4th Thursday of month, 7-9pm. £1 for coffee or tea.

Mind West Sussex Advocacy Services

2nd Floor, 45 Rowlands Road, Worthing, West Sussex, BN11 3JN.

Bill Turner, West Sussex Team Leader

Tel: **01903 216430** Mobile: **07721 099540**

Email: **bill.turner@mindcharity.co.uk**

Advocacy services for adults and young people (11-65) with mental health difficulties, who are in-patients or living in the community.

Adult Services The main aim of the advocacy service is to ensure that mental health service users are enabled to express their needs.

Provides advice, support, information and representation. The service is available to both in-patients and day hospital and community patients including home visits. Also has a service which gives access to an independent mental health advocate. The service is full time, independent and confidential.

Downs Advocacy Service Horsham and Crawley

Horsham Hospital, Hurst Road, Horsham, West Sussex, RH12 2DR.

Bill Turner, Advocacy Co-ordinator

Tel: **01403 270388** Mobile: **07721 099540**

Email: **bill.turner@mindcharity.co.uk**

Mid Downs Advocacy for Mid Sussex

Mental Health Unit, Downsmere, Princes Royal Hospital, Lewes Road, Haywards Heath, West Sussex, RH16 4EX.

Mo Davies, Advocacy Co-ordinator

Tel: **01444 417286** Mobile: **07919 892334**.

Email: **mo.davies@mindcharity.co.uk**

Pressure Point Advocacy for Adur, Arun, Worthing and Chanctonbury

2nd Floor, 45 Rowlands Road, Worthing, West Sussex, BN11 3JN.

Malcolm Bateup, Advocate Tel: **01903 213630**

Mobile: **07815 761531**

Email: **malcolmbateup@mindcharity.co.uk**

Speak your Mind Advocacy for young people

Has two workers covering the North and South areas of West Sussex. A confidential advocacy service for young people 11-19 years experiencing mental health difficulties or who are unhappy with the way they are being treated or the services they are getting.

The advocate will visit young people in the community, listen to them and see things from their point of view, talk through their options with them, make sure their opinions are heard at meetings and reviews, will give information about their rights and will support them if they want to make a complaint. Also supports young people who are detained at the unit.

Speak Your Mind Advocacy Services (North)

Lewes Road, Haywards Heath, West Sussex, RH16 4EX.

Alan Dazely, Young People's Advocate

Tel: **01444 443895** Mobile: **07918 746252**.

Email: **alan.dazely@mindcharity.co.uk**

Website: **www.mindcharity.co.uk**

Speak Your Mind Advocacy Services (South)

2nd Floor, 45 Rowlands Road, Worthing, West Sussex, BN11 3JN.

Claire Allwright, Young Person's Advocacy

Worker Tel: **01903 233145**

Mobile: **07733 222903**

Email: **claire.allwright@mindcharity.co.uk**



Takeover Day

11 MILLION Takeover Day takes place on 12th November 2010 and in West Sussex we are looking for organisations to take part.

What's it all about?

11 MILLION Takeover Day is a national event offering young people across the country the chance to work alongside adults and get involved in decision-making in a wide range of organisations.

In West Sussex on the 12th November we would like young people to take over a range of job roles in organisations, to give young people an insight into the processes and decisions that take place.

This could involve inviting young people to try out jobs, offer their perspective on key issues and being part of big decisions, job shadowing and taking charge of budgets. For example; what young people would do if they had a specific amount to spend on Children's Services or other young people took over the airwaves at a local radio station.

Many organisations took part in Takeover Day 2009 and agreed that it helped break down barriers, and can really encourage cohesion between generations and across communities.

How can your Organisation benefit?

- Improved links with customers or service users and the local community.
- Fresh ideas, insight and creativity.
- A better understanding of how children and young people experience issues involved in their work.
- The chance to demonstrate their commitment to listening to children and young people.

So how can YOU get involved?

To show your interest in being part of Takeover Day 2010 please email:

lara.pearce@westsussex.gov.uk

We hope you will get involved 11 MILLION Takeover Day and take advantage of this fantastic opportunity for adults to celebrate the importance of children and young people in our society.

I am also looking for young people to joining the **County Youth Panel in West Sussex** whereby young people can get involved in their community, have more of a voice and say about local issues, receive training that looks good on their C.Vs, meet new people and help develop and plan county wide events. In the past they have been involved in planning the South of England Show, BBC Radio station interviews, Countywide Celebration Events, 11 Million Take Over Day and many more... Why not get involved by contacting Lara Pearce via email at lara.pearce@westsussex.gov.uk or look at www.yourspacewestsussex.co.uk for more information.

Lara Pearce



Join up and be part of the **NEW Youth e-Panel**, where young people in West Sussex can have their voices heard even more!

It's easy just Google 'Youth e-Panel' & follow the West Sussex link or visit www.yourspacewestsussex.co.uk

For more information please contact:
lara.pearce@westsussex.gov.uk

Health Rights

Your rights

Working out what your rights are can be tricky. In this section, we've made it as easy as possible for you to find relevant, clear and useful information.

There are some important things for you to remember:

Confidentiality

The person seeing you should explain how any information you give them might be shared, and about your right to talk to someone on your own.

Consent

The person seeing you should check that you agree with the help they are suggesting and explain the possible choices if you do not agree.

Your needs

If you or your family need help from an interpreter or want information in a certain way, then the doctor or the person working with you should try and organise this.

Complaints

If you are not happy with the help you have received, all services should have complaints procedures.

Advocacy support

An advocate is someone independent who can offer you support in speaking about what help you want. Under the Health and Social Care Act 2001, you have a right to an advocate if you want to make a complaint about your care from a mental health service.

A note about the United Nations Convention Legally (according to United Nations Convention on the Rights of the Child) you have the right to say what you think should happen when adults are making decisions that affect you and to have your opinions taken into account.

And..

You have the right to get, and to share information as long as the information is not damaging to yourself or others.

*Information taken from
www.youngminds.org.uk/my-head-hurts*

My Head Hurts is a resource for parents and young people who want advice on mental health treatments, the evidence supporting them and where to get help.

physio4kids

Gina Farmer BSc.(Hons) in Physiotherapy

Private Physiotherapy - Treatment in your own home or at 'The Barn', Denvilles

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Lizzie's Summer Holidays

Whilst on holiday in Devon this August, I started making a list with my family of all the places we had stayed over the years. There were so many we decided we would have to make an album with a photo from each holiday!

I thought I would write about the most recent holidays I have been on over the summer as well as a day trip to London, as there were points to comment on.

In the middle of July, we went to my cousin's wedding in Oxford. In order to fully participate in the build up to the big day and enjoy family time afterwards, we rented a log cabin nearby. Luckily, my cousin had been to check out the site before we set off so we had seen photos of where we were spending the next few days.

The curb on to the path to the cabin was quite large but the owner had provided a ramp to overcome this hurdle. The cabin itself was raised with a decking surround and four large steps up to the front door! We took our extendable metal ramps and placed them against the steps to give an almost 45 degree slope! My sister and I then had to drive our chairs up the slope which was quite scary! Once we were on the decking there was level access into the main room of the cabin which was really lovely with a modern kitchen and dining area as well as huge leather sofas and a widescreen TV on the wall. The door to the bathroom and bedrooms was too narrow for our wheelchairs, but my sister and I can be carried short distances so this didn't bother us. Every time we left the cabin over the wedding weekend we had to go down the ramps which felt even steeper going downhill; it was like a rollercoaster experience! It became a smaller challenge each time we faced it and we had such a wonderful time overall that it was well worth a bit of an adrenaline rush!

In early August I went to London with my father and a couple of friends. We took the train from Havant to Waterloo which was very easy, especially as we had booked in advance; I found the station staff extremely helpful and they were ready with the ramps at both ends. From Waterloo station, we walked to County Hall and collected our pre-booked tickets for

the River Cruise and London Eye. We didn't have very long after waiting for the tickets (pre-booking did not make this any quicker), so we headed for the Millennium Pier just below the Eye. We were ushered past the queuing crowds and were welcomed aboard and shown straight to the on board lift which took me to the upper deck. There was plenty of space at the back of the fixed seating and I was able to turn and see all the attractions being commented on during the 45 minute round trip. Next we had to start queuing for the 'flight'. I was really glad we had our tickets for this as there were people waiting the whole length of the County Hall building; we went to the front of the queue at the bottom of Eye! Again the staff were really helpful and told us to move the barrier



anywhere we saw a space so soon we were climbing into our pod which had been stopped for the wheelchair to drive on. We had a wonderful clear view across the city and it was funny seeing tiny people in the boats below! After we came back to earth we walked along the South Bank to the Festival Hall where we found

there was a lift which took us back to pavement level a bit nearer to Waterloo. After a pit stop at the station we got back on the train and headed home feeling quite exhilarated. It was bizarre to be back in the countryside after being with huge crowds of tourists!

After a busy few weeks at home, we took two weeks in Devon at the end of August. This was just the most perfect rest for our family! We had two single storey converted pig sheds with decking that overlooked a beautiful valley of farmland. The main sitting rooms were spacious and there was a good sized wet room in both cottages. The best thing was the decking though; we lived outside most of the days, reading, talking and getting better at Sudoku! There was a tarmac footpath walk round the farm circuit so I was able to venture out and explore too. We came home refreshed and ready to face the new challenges of September!

If you would like any more details of where we stayed, don't hesitate to drop me a line!

Lizzie Baily

lizzie@wellspringwestsussex.org.uk

AskDES Kids

Are you looking for affordable second hand disability equipment for your child, or do you have an item you wish to sell? AskDES Kids is an extension of a very popular service run by the charity WSAD which allows you to do just this. AskDES provides people with the opportunity to buy and sell second hand disability equipment, through a dedicated website www.askdes.org.uk. People can also ring up the WSAD Information and Advice line at **01903 244457** to get up-to-date listings of items for sale.



through it. The more people who advertise on the website, the more useful and widely-used it becomes. This means more and more people will be able to buy items which can help make life that little bit easier for children with specialist requirements.

WSAD volunteer Denise, who runs AskDES says, "AskDES works so well because it is a niche service, linking up specialist equipment with people who will really benefit from it. It also saves useful items, like wheelchairs, from being disposed of in landfill. It is shocking how many people think this is the only option for used disability equipment

which could really make a difference to someone's quality of life."

The existing AskDES

Service enables people to buy and sell a wide range of specialist disability equipment at an affordable price. WSAD came to the conclusion that there is a definite need to provide a similar service for children, as items are frequently outgrown rather than outworn, and the cost of new items is often prohibitively expensive. WSAD is now working on developing AskDES so there is a widely-used specific section for children's and young people's equipment.

AskDES relies on people being aware of the service and advertising items for sale

If you have any items you wish to sell, or you want to find out more about what items are currently for sale via AskDES Kids, call **01903 244457**

or email: info@wsad.org.uk.

You can also visit the website www.askdes.org.uk or also pop into the offices at 7 St John's Parade, Alinora Crescent, Goring-by-Sea, BN12 4HJ.

Crossroads Care

Crossroads Care West Sussex covers the whole of the county and offers a full range of flexible services for adults and children with various disabilities or health conditions. This includes Day, Evening and Night services, Self Funding services and Social Clubs.

We also provide a tailored package of support for longer periods of care.

Please contact us to discuss your specific requirements.

Tel: **01243 830797**

Office Hours 9am - 4pm, Mon - Fri

www.westsxcrossroads.org

Tele Cottage,

Horsemere Green Lane

Climping,

Littlehampton

West Sussex BN17 5QZ

South East Coast Muscle Group

Joining forces to secure better services in the NHS South East Coast region
Patients, families and clinicians are joining forces from Eastbourne to Canterbury in the South East Coast Muscle Group to secure better services in the region. The Muscular Dystrophy Campaign looks forward to working with the South East Coast Specialised Commissioning Group (SCG) when a review of neuromuscular services in the region is undertaken.

Get involved even if you can't come to Muscle Groups meetings!

Gaps and Weaknesses - Problems Uncovered

The Muscle Group was launched in Eastbourne in May 2009 with families sharing their experiences of difficulties accessing services. Problems discussed included:

- a patchy physiotherapy service
- the lack of a Muscular Dystrophy Care Advisor in the region to provide advice and support for patients and families

- particularly poor transition service from paediatric to adult services
- long distances to travel to London to access specialist services

South East Coast Muscle Group Autumn Meeting

Monday 1 November 2010: 2pm - 4pm,
Premier Inn Crawley South, 45 Goffs Park Road, Crawley, West Sussex RH11 8AX



Come along to the next meeting of the South East Coast Muscle Group in Crawley for an update on the campaign for better services in the region, and to share

experiences and advice with other local families living with muscle disease.

The venue is wheelchair accessible and there is free parking.

New members are always welcome!

Join the fight - contact the Campaigns Team to join and find out more about the South East Coast Muscle Group: **020 7803 2865** or email: campaigns@muscular-dystrophy.org

Skills for Care Research

Volunteers needed in your area... Can you help?

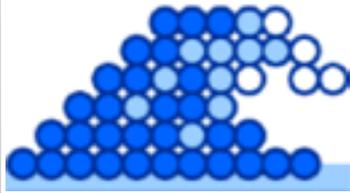
- Do you employ someone to help you because you have a **health condition** or a **disability**?
- Do you employ someone to **help you care** for a family member or friend?
- If the answer is **yes** to either of these questions then you could be eligible to help us...
- NatCen has been asked to conduct a survey with people who employ their own care and support workers (either directly or through an agency).
- Before this survey is carried out we are looking for a small number of people to try the new questions on.

- Taking part would involve completing an interview in a place of your choosing. Our interviewers are flexible and your individual needs will be considered when the interview is set up. All interviews will take place during October.

- Everyone who takes part will receive a £20 High Street Voucher

- If you would like to take part, or if you would like more information, please get in touch by:
Free Phone: **0808 168 1348**
Email: Curtis.Jessop@natcen.ac.uk

NatCen is an independent social research organisation and a registered charity. For more information about NatCen and how our research is used please see our website www.natcen.ac.uk



Wellspring
West Sussex

Please write to us at:

Wellspring West Sussex,
c/o 26 Goldsmith Road,
Worthing
West Sussex
BN14 8ER

info@wellspringwestsussex.org.uk



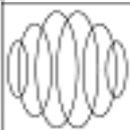
Next year's editions will be focusing on

Arts & Sports

If you would like to contribute any articles, letters or images to these editions, please send or e-mail to the above addresses.

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lizzie@wellspringwestsussex.org.uk



Contact ICIS for information on services offering care, support or advice in West Sussex.

Telephone: 0800 859929

e-mail: enquiries@icis-info4life.org.uk

www.icis-info4life.org.uk

Wellspring West Sussex acknowledges the support of:

- Child Disability Team
- ICIS: Information for Life

Wellspring West Sussex is a registered charity set up to provide information, dialogue and discussion with and for children and young people with disabilities, and their parents and carers across West Sussex.

It produces a regular newsletter—**Wellspring: West Sussex** which has a circulation of approximately 2500 copies. During the year it organises or supports a number of activities for young people with disabilities, and their families. The organisation is managed by a committee of volunteers, parents and carers, young people and representatives from the voluntary and statutory sectors.

It is funded by grants from various sources including statutory agencies.

WELLSPRING ONLINE!

Don't forget to check out the
Wellspring website!

www.wellspringwestsussex.org.uk

The information here is for your guidance and is not a recommendation by Wellspring West Sussex. Comments expressed within Wellspring West Sussex do not necessarily reflect those of the committee or the funding agencies.

Wellspring is supported by is supported by West Sussex County Council,
the voluntary sector and volunteers.

WELLSPRING—A newsletter for you?

If you wish to receive a regular copy of the newsletter but are not on our mailing list yet, please fill in your name and address below, cut out this portion of **Wellspring** and post to our address shown below (or e-mail details to the address above)

Your Name

Your Address

Send to: **The Editor, Wellspring, c/o 26 Goldsmith Road, Worthing, West Sussex BN14 8ER**
NB. The names of readers are kept on an electronic database. This database is used only for the newsletter 'Wellspring'

*Please let us know if you change your address or if you are receiving more than one copy of Wellspring