



**Annual Report  
2009-2010  
&  
Development Plan  
2010-2012**



## Our Mission

“West Sussex Parents Forum exists to improve the quality of and access to information and services by giving a voice to parents of children and young people in West Sussex who have learning difficulties and disabilities.”

# West Sussex Parents Forum – Annual Report 2009-2010 & Development Plan 2010-2012

## Introduction

The purpose of this Annual Report and Development Plan is to outline the achievements that the West Sussex Parents Forum has had during the last year as well as setting out what we want to do for the next two years.

This document is split into **two sections**, the first being a look back at our achievements as we look at **‘what we have done 2009 – 2010’**. The second section looks forward to the future as we look at **‘what we want to do 2010-2012’**.

As a group of parent volunteers it is our priority to ensure that we are making our voice, the voice of parents of children with disabilities and learning difficulties, heard. Our members, volunteers and other stakeholders have all been involved with shaping our plan.

## Message from the Chair – Kelly Willard

Wow what a year! I am overwhelmed with the support you have all shown in the last year. I just cannot express how I feel - we have made a really BIG difference in West Sussex and for the first time, I do not feel that we are banging our heads against a wall! The turnaround with the Aiming High for Disabled Children funding has shown that we have ACHIEVED being listened to and we need to be proud of this as it shows how, as a collective voice, we can make a difference. We still have a long way to go in campaigning for our children and young people’s futures. One parent sent me an e mail recently saying that she had told EDCM what is happening in West Sussex around the Aiming High funding, their advice was to keep up the pressure – this is what we intend to keep doing!



We are very excited about this report and the following pages not only tell you what we have been doing over the last year but more importantly, set out what we plan to do over the next two years as we continue in our quest of making our voice heard! Once again thank you all for your support and the time that you give up to attend meetings and for the many hours of volunteering. We could not do this without you,

**Kelly**

## Section 1: What we HAVE done 2009 – 2010...

### Campaigning

We have **lobbied** West Sussex County Council which led to a 'U-turn' in their decision to unfence the Aiming High for Disabled Children Funding in West Sussex.

We have **contacted** the **Prime Ministers'** office regarding the plans to re-divert capital funding for Aiming High.

We have **worked** with Every Disabled Child Matters, Contact a Family and Together for Disabled Children to ensure that the issues that families face in West Sussex are **voiced** at a **national level**.

### Meetings

We **represented** the voice of parents and carers at the **Parent Carers Planning Group**.

We provided feedback from parents into the **Children with Special Needs and Disabilities Work-stream** which directly reports into the Children's Trust.

We have played an active role in the **Aiming High for Disabled Children Project Group** as support parent representatives who sit on the Information, Capital Funding, Parent Participation and Commissioning Subgroups.

We have joined **CAMHS** at their disabilities meetings, looking at ways to best support disabled children and their families.

We have sat on the **Personal Health Budgets** meetings as lead by the NHS, providing the view of the carer.

We had various meetings with WSCC about **Self Directed Support** in the County.

We have ensured that the views of parents with children under five are not forgotten at the **Early Years Implementation Meeting**.

### Aiming High for Disabled Children

We worked with the Aiming High for Disabled Children team in West Sussex through their **commissioning process** to ensure that more **short-breaks** have been set up for disabled children and young people.

We supported five 'Aiming High for Disabled Children Family **Fun-day events**', which ensured that parents had the opportunity to talk to the Forum face to face.

We worked in partnership with WSCVYS, Aiming High for Disabled Children in **recruiting a Parent Participation Worker** for West Sussex.

### Events

We **hosted a Question & Answer** session for parents to ask questions about service that affect disabled children and young people in West Sussex.

We held an **information event** in Worthing for parents and carers about activities and services for disabled children, young people and their families.

We **organised** a visit from the **Department of Work & Pensions – Disability Living Allowance Team** to come and talk to our members about the changes in the new DLA forms.

We hosted a **Pamper Evening** to thank all our members for the hours of unpaid caring that they do every week.

## Projects

We have continued to work with Transport to continue to push through the **Transport – Parent Charter**.

We have worked with the **Transition** Team at WSCC to voice the concerns of parents and carers with regards to **information** around the time of transition.

We have worked with other areas in the South East in putting together the **PAT (Parent Action Team) Mark** and secured funding to support parents in becoming PAT Mark assessors.

We have **presented** at several **conferences**, informing professionals how best to work with parents. These conferences have included; **Early Years Conference, Children & Family Centre Conferences, Service Wide Conference for Disabilities**.

We have provided parental feedback to the **NHS West Sussex review of Children with Complex Health Needs** that was lead by Dame Philippa Russell.

We have been worked with WSCC in beginning the **review of Disability Services** in West Sussex.

We have been part of the **Special Educational Needs review** that is currently being undertaken by WSCC.

## Organisationally

We have **grown** as a **Management Committee** and adopted specific roles and responsibilities.

We are working towards becoming a **registered Charity** with the Charity commission.

We **redesigned** our logo, newsletter and website.

We have spent time as a team putting together a **development plan** for the next two years.

We have grown our membership to **335** parent / carers.

## And not forgetting...

We have been on the **interview panels** for various Social Workers and Occupational Therapists.

We have **presented** the work of the Parents Forum to the **WSCC Select Committee**, talking directly to elected members about the needs of disabled children, young people and their families.

## Lindsey's Story....

**My son was diagnosed as having Autism at the age of three, receiving this diagnosis made me feel very isolated and from that moment onwards my whole life changed.** Having a son who lives with Autism really opened my eyes to looking at things differently and it was this that made me want to get involved with the Parents Forum.

I got involved with the West Sussex Parents Forum about four years ago. At the time I had a gap in my life and thought that getting involved with the Forum would be a good way to fill it. I felt passionate, and still do, that other parents should not have to face the experiences that I did when my son was first diagnosed; no support, limited information and a lack of general understanding of what it is to be the parent of an Autistic child let alone what it means to be a child living with Autism.

Since being involved with the Forum I have been amazed at what little understanding many 'professionals' actually have. Before I got so involved I assumed that professionals were the experts and had all the answers, but I soon realised that they don't. As a parent I am the expert and it is part of my mission to help others, including professionals' understand. For me it is about raising awareness of Autism and other disabilities – at the end of the day the Forum represents all parents trying to cope and understand that their child is different and needs support in order to reach their full potential.

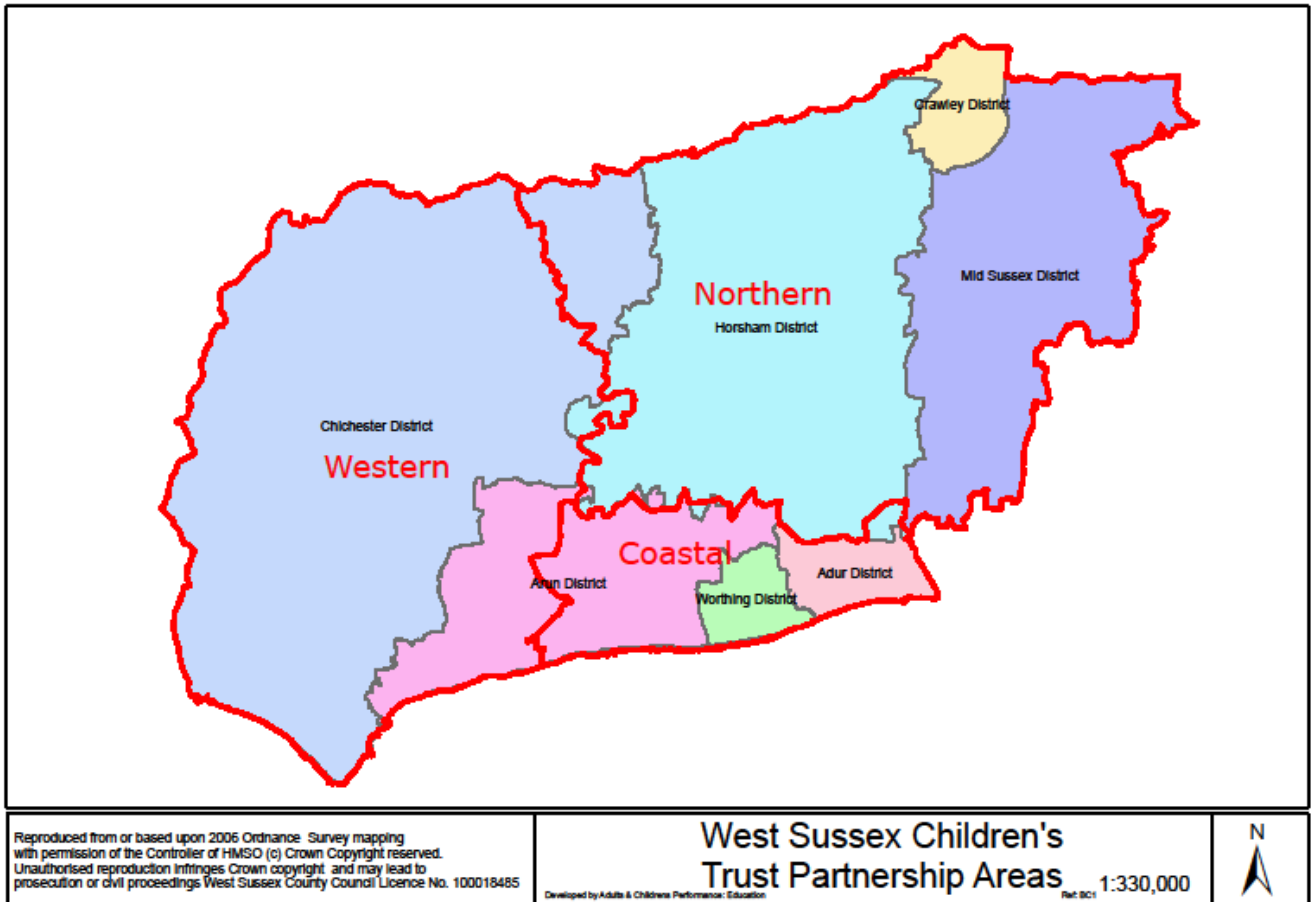


Personally getting involved with the Forum has helped me regain my confidence. I feel treated as an equal by the professional I work with at the meetings that I go to and I have seen the opinion of a parent challenge people's thinking about things. Being part of the Forum has also seen me make new friends with other parents who understand what it is like to be a parent of a child with a disability. There is a level of understanding that I am not sure I would find anywhere else.

**I see the work of the Parents Forum as essential and having our voices heard is so important, as I truly believe that parents have the power to shake things up for the better, if only they speak out. The more parents' are heard and understood the easier it will be to break down the barriers that stop children getting what they need.**

When I look back at my time with the Forum I think that we have come a long way, but there is still a lot that needs to be done. At the moment it is uncertain times with cuts being made everywhere, but as a parent I would say that it does not always need to be about money. It is about others having compassion and a willingness to 'go the extra mile'. I want others to think 'what can I do to make a difference for this family' with this approach we can work with others and ensure that our children get the support, understanding and services that they need.

## Our Membership



It is one of our aims over the next two years to focus the Forum into areas. Currently we focus our membership in terms of North and South of the County. We are likely to work in the different areas that the Children's Trust Partnership works in, as outlined in the map above. If you would be interested in getting involved on a more local basis, then please contact us.

Our current membership total is = **335**

Members in the North = **147**

Members in the South = **188**

## Kim's Story

*Kim is currently the Finance Administrator for the Forum. She has two sons who were both diagnosed with Cerebral Palsy when they were about a year old. Kim outlines why she got involved with the Forum*



### How long have you been involved with West Sussex Parents Forum?

Since the beginning in 2006 when we began having meetings regarding parents and carers in West Sussex having their voice heard. Initially 'Parents Make Yourselves Heard' was created as part of the Parent Partnership Service. But in 2008 we felt that it was important to be independent, so West Sussex Parents Forum was created.

### Why did you first get involved with the Forum?

Ultimately I am involved to try and improve services for disabled children, but I think that I first got involved by accident. I have been involved with various meetings, such as the Parents Carers Planning Group and Carers Support Service for about ten year's, it has been by being involved in these that I have become more and more involved.

### What difference has it made for you since being involved? Has it changed you as a person?

I have to be honest, sometimes I wonder if we are making any difference at all as it is a constant battle. It is a battle because that is

how it feels. Using my own experience for example it is one battle after another. It was a battle to get my son into the school that most suited him, then another battle to get the support in the move to secondary school and at the moment we are thinking about when he leaves school and we are wondering what happens next. It is a different set of professionals each time so, without meaning to be negative, it is a battle.

Being part of the Forum though, and going to meetings and being part of projects, I have received more information about things. I can also see that although it has taken a long time, the Forum now has got a line of communication into West Sussex and it feels like we are beginning to be listened to.

Personally being part of the Forum has made me more confident as a parent. I am more confident going to meetings and am not scared to speak up on the behalf of other parents. If I have a personal battle with a service I now feel more empowered.

### How important is it that parents are making their voices heard in West Sussex?

It is really important. **It is essential that we should have our views listened to. At the**

**end of the day, we are the professionals regarding our children.** I am lucky that in my experience over the years, I have had a good experience with most the professionals that I have worked with, but I have heard shocking stories from other parents, where they have not been listened to.

I have noticed in the last couple of years, people are taking notice of the Forum, as we becoming a force to be reckoned with – and that’s a good thing!

### **What are your thoughts about the future of services in West Sussex?**

There is a real worry at the moment – with all the budget cuts that are taking place. My youngest son is having a review at the moment and this will involve more assessments and it all goes back to funding. I can sense that we will have another fight on our hands to get the support that it needed. As parents we understand that cuts are needed, but there still needs to be services in place to support people who need additional support.

I strongly feel that in West Sussex money is not invested properly, I don’t think that enough money is spent to begin with in prevention and support. For example if my son had been offered more Physio when he was younger, he might not have needed surgery. It’s very short sighted to think that spending money in this way is not more cost effective. It is the same with short breaks for families; if more support was offered in the

beginning then families might not get to crisis point.

This way of working requires a different way of thinking and during my time working with West Sussex, there is a feeling that all the systems are very stuck in their ways. In order to move on I feel that the culture needs to change and their needs to be more investment in the long term – it’s not about short term fixes, but sadly funding dictates this.

### **If you could have one wish in West Sussex what would that be?**

Other than the change in thinking that I have already mentioned my one wish would be that parents are really listened to and treated as an equal. I am fortunate because I have been involved for a few years, that people do listen when I speak up – but what about those parents and families who cant speak up for themselves for what ever reason? This is why I am still doing this and still involved. I want to ensure that we are speaking on behalf of those parents by offering them a voice and independent support. So many parents think that professionals know everything, in reality though they don’t know everything, they can’t possibly – but if we work together and really listen to each other I believe that the outcomes for our children will be better.

## Section 2: What we WANT to do 2010-2012

### Campaigning

We will **campaign collectively** on behalf of our members about issues that are raised by Parents Forum members ensuring that the voices of parents and carers in West Sussex are clearly heard.

#### **We will do this by:**

- **Linking** in **nationally** with organisations like Together for Disabled Children, Every Disabled Child Matter and Contact a Family to ensure that our members are aware of policies being set by government that will have implications locally.
- **Lobbying** Counsellors and MPs to ensure that disability matters are firmly on the agenda locally.
- **Holding** Health, Education and Social Care **accountable** for the **decisions** that they are making regarding funding cutbacks and amendments to services and ensuring the parents are part of the making these decisions too.
- **Supporting** those parents who need help understanding and making their way through the various systems that exist in West Sussex.

### Support and Train Parents

We will **support** and **train** parent professionals, so that they are able to work with professionals who provide services for disabled children and young people.

#### **We will do this by:**

- Running '**Parents Participating Confidently**' Training across West Sussex throughout 2011.
- Training parents in becoming **PAT Mark Assessors**
- Offering a '**buddy**' system for those acting as Parent Representatives for the Forum.

### Represent our Members

We will ensure we are making our voice heard and **representing** the views of parents and carers to the Children's Trust and other appropriate bodies within health, education and Social Care in West Sussex.

#### **We will do this by:**

- Continuing to **send parent reps** to **appropriate meetings** that discuss services and matters affecting disabled children and their families.
- **Consulting** with our members on various issues affecting the future of services and provision for disabled children, young people and their families.

### Information to Members

We will continue provide our members with up to date **information** about services within health education and social care affecting families, ensuring that parents and carers have every opportunity to participate in decision making process.

***We will do this by:***

- Continuing to **provide newsletters** to all our members bi-monthly.
- Providing an **up-to-date website** that contains information on what is happening locally, as well as signposting parents to what is happening nationally.
- Providing more **Information Events** across West Sussex where parents can come together and find out more about the services on offer to families in the county.
- Hosting an annual **Question and Answer** session where parents and carers can speak to those Managers in Health, Education and Social Care who are responsible for making decisions and who hold budgets for services.



## West Sussex Parents Forum –

### Income & Expenditure Account for Year Ending 31 March 2010

	<u>2008/09</u>	<u>2009/10</u>
<b>INCOME</b>		
Initial Funding	330.00	0
Start Up	5,000.00	0
Transport Improvements	1,215.00	2,791.00
Aiming High	3,330.00	10,000.00
Interest	9.00	11.00
On-Going Costs	0.00	3,966.00
<b>Total Income</b>	<b>9884.00</b>	<b>16,768.00</b>
<b>EXPENDITURE</b>		
Initial Funding Expenses	287.00	0.00
Start Up Expenses	1,434.00	991.00
Transport Improvements Expenses	1,215.00	2,791.00
Aiming High Expenses	2,975.00	7,528.00
On-Going Costs	0.00	3,130.00
<b>Total Expenditure</b>	<b>5,911.00</b>	<b>14,440.00</b>
Surplus/ (Deficit)	3,973.00	2,328.00

**West Sussex Parents Forum -  
Balance Sheet as at 31<sup>st</sup> March 2010**

	<u>2008/09</u>	<u>2009/10</u>
Assets		
Funds		
Bank	3,973.00	<b>6,301.00</b>

Represented by:-

Accumulative Funds

General	52.00	63.00	
Start Up	3,566.00	2,575.00	
Aiming High	<u>355.00</u>	2,827.00	
Ongoing Costs	-3973.00	<u>836.00</u>	<b>-6301.00</b>
	0.0		0.00

**Independent Examiners Report:**

My examination includes a review of the accounting records kept by the Treasurer and a comparison of the accounts presented with these records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from the Treasurer concerning any matters. The procedures undertaken did not provide all the evidence that would be required in an audit, and consequently no opinion is given as to whether the accounts present a 'true and fair view' of the accounts as at the 31<sup>st</sup> March 2010.

Peter Cheesman – 14<sup>th</sup> August 2010

## **West Sussex Parents Forum Management Committee**

### **Chair**

Kelly Willard

### **Secretary**

Lindsey Butterfield

### **Treasurer**

Enid Doyle

### **Committee Members**

Carrie Phillips

Julie Higgs

Kim Paul

Lara Roberts

Lyn Aaron-Ferrigno

Ranti Fallowfield

Rod Brown

### **Observers**

Daniel Cheesman

Nik Demetriades

## **West Sussex Parents Forum 2009-2010 Supported By:**

ASD Support Group

Carers Support West Sussex

Contact a Family

Cool 2 Care

Enable Me Project

J B Eventus Ltd

Kangaroos

NHS West Sussex

PACSO

Parents for Autism

SNAP

Springboard Project

Starfish Websites

Together for Disabled Children

We Play Too

WSCC – Aiming High Team

WSCC – Child Disability Teams

WSCC – Children & Family Centre's

WSCVYS

You Can Do It

Thank you to all those organisations and individuals who have supported the work of the Forum

## **Special thanks to the following organisations that have kindly supported our Pampering Event:**

Spurgeons – Broadfield Children & Family Centre

Beales Worthing

Glaxo-Smith Klein

Bodyshop Littlehampton

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