

## From the Chair



It's been an exciting year for us at the Worster-Drought Syndrome Support Group. 2012 has been a great year for people with disabilities - because of the Paralympics, attitudes towards disabled people have certainly been much more positive. I for one have seen a much improved respect for people who have to face these challenges on a daily basis. Two events I have been to this year were Naidex at the ExCel in London, and the Learning Disability Today Exhibition at Olympia, London. There

were so many people there searching for answers regarding the future for disabled people. I have obtained some of the latest information about benefits and they feature on the back page.

Please do remember to join our facebook page [www.facebook.com/wdssg](http://www.facebook.com/wdssg), where I will post more information that I think you will find useful, from the conferences and exhibitions that I attend. I would also like to ask that if you have a story or find any useful information, could you pass this onto Nicki or myself so we can put it in future newsletters.

Merry Christmas,  
Mark Mayer

## Mark does Harry Potter

at Denby's Wine Estate in Dorking



## for his big 40!

Featured members:  
Mark Mayer  
Sarah Sugden  
Kathryn Marygold  
Callum Turley  
Rik Turley



## Congratulations to Tom Childs for being awarded Cub Scout of the year, for having a great attitude and always smiling.

"My Tom's achieved so much this year! Top of his list is that he was awarded Cub Scout of the Year for always smiling and having a great attitude towards everything and everybody. He was also nominated for the Deputy School Council this year! He's in his last year of primary school now and is preparing for secondary which is going to be a whole new journey of struggles but I'm sure he's going to be fine."

Jenny Childs

## Celebrations

# Money Matters

LATEST NEWS



## A quick guide to Personal Independence Payment (PIP)

(updated 25 September 2012)

Disability Living Allowance (DLA) will be replaced by Personal Independence Payment (PIP) for people of working age (16 to 64) from 8 April 2013, even if they have an indefinite or lifetime award. The introduction of PIP is part of a wider reform of the welfare system. The new benefit will better reflect today's understanding of disability which has changed significantly in the two decades since DLA was introduced.

PIP will include an assessment of individual needs and aims to ensure that financial support is targeted at those who face the greatest challenges to living independently.

### What is PIP?

PIP is to help towards some of the extra costs arising from ill-health or disability. It is based on how a person's condition affects them, not the condition they have.

### PIP is for people aged 16 to 64

- ▶ DLA will remain for children up to the age of 16. Once PIP has been introduced, the Department of Work and Pensions (DWP) will contact them as they approach 16 to explain what will happen
- ▶ DLA will remain available to those 65 or over on 8 April 2013 (the day that PIP is introduced)

In the same way as DLA, claimants can receive PIP whether they are in or out of work. The benefit is not means tested or taxed. There are two components to PIP - for daily living and mobility needs. Each component can be paid at standard rate, or enhanced rate for those with the greatest needs.

PIP will include an assessment of the individual's needs by a health professional. Most people will have a face to face consultation as part of their claim. Awards will be reviewed to ensure that the claimant is receiving the right support. Reviews will be at appropriate intervals depending on how likely it is for the claimant's condition or impairment to change.

### When is PIP being introduced?

**FEBRUARY 2013** DWP will send general information about PIP to all existing DLA claimants in their DLA uprating letters. DLA claimants don't need to take any action as a result of this letter.

**APRIL 2013** New claims for PIP start for people living in areas including Cheshire, Cumbria, Merseyside, North East England and North West England.

When a DLA claim is received from this area, it will be treated as a claim to PIP instead. DLA new claims continue in all other parts of the country and for existing DLA claimants.

**JUNE 2013** New claims for PIP will start for the remaining parts of the UK. There will be no new claims to DLA for people aged 16 - 64.

**OCTOBER 2013**

Reassessment for PIP starts for existing DLA claimants.

DWP will write to remaining DLA claimants at some point before Spring 2016. The letter will let them know that their DLA is due to end and explain how they can make a claim to PIP. The first letters will be received from August 2013.

From now on if an existing DLA claimant (aged 16 - 64 on 8 April 2013) reports a change in their condition, or their fixed term is due to expire they will be reassessed for PIP - unless they have already received a DLA renewal letter (which are sent well in advance of the review date).

**SPRING 2016**

All DLA claimants aged 16 - 64 will have been contacted about reassessment by this point.

### What about existing DLA claimants?

There are no automatic entitlements to PIP, even where an indefinite or lifetime DLA award has been made. Existing DLA recipients who are aged between 16 and 64 years old on 8 April 2013 (the day that PIP is introduced) will need to decide if they want to make a claim for PIP.

DWP will write to individuals at some point before Spring 2016 to let them know when their DLA is due to end, and explain how they can make a claim for PIP. Claimants will be randomly selected for reassessment.

Existing claimants do not need to take any action now

From October 2013, existing DLA claimants that report a change in their condition, or where their fixed term award is due to expire, will be reassessed for PIP, unless they have already received a DLA renewal letter (which are sent well in advance of the review date). If an existing DLA recipient makes a claim for PIP then their DLA would normally continue until a decision on their PIP claim is made. If PIP is not awarded or not claimed then DLA will stop.

### How are other benefits affected?

PIP does not affect benefits such as Employment and Support Allowance or Jobseeker's Allowance. People receiving Attendance Allowance will not be affected by the introduction of PIP. Like DLA, receiving PIP may provide access to other help. This can include Blue Badges, concessionary travel passes or Motability. These arrangements are being finalised and we'll update this guide once confirmed.

Carers may also receive Carers Allowance because the person they are caring for is receiving DLA or PIP.

If claimants are subsequently not eligible for PIP then these benefits and services may also be affected.

There is a range of more information about PIP online at

[www.dwp.gov.uk/pip](http://www.dwp.gov.uk/pip)

Affiliated to Contact a Family and Rare Diseases UK

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Registered Charity: 1095290

IR Charities Charity Ref. XR67990

All information in this leaflet is correct at time of going to press.



# Link

NEWSLETTER CHRISTMAS 2012

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Don't forget to send your articles or any news that you would like to see in future issues to: [secretary@wdssg.org.uk](mailto:secretary@wdssg.org.uk)



NEW FEATURE p2-3

## Editor's Note

Welcome to our special festive edition. The group has had another very successful year and I would like to welcome all the new members that have joined us through the year.

We have a new Member Spotlight feature, which I hope will inspire some of you to send me your own experiences so we can continue this series in future editions.

I look forward to seeing you next year and hope lots of you can join us for a very exciting Family Day in the summer. Finally, I would like to wish you all a Merry Christmas and a Happy New Year.



Nicki Turley



Archie is our adorable, seven year old son who is now happily ensconced at Meath School in Ottershaw, Surrey. He started in September 2012 and it has been a long learning journey for all of us to get to this point.

For those who are not aware, Meath is a primary school run by ICAN, a charity that specialises in helping children with communication difficulties. The school takes children whose predominant difficulty is speech and language, but often have other difficulties.

As the parent of a child with WDS, we found it incredibly hard to find the right school for Archie when he came to school age. We did not want him to go to a Special Needs school and we were desperate for him to learn to socialise with mainstream children and have access to the education that they did. So we sent him to a tiny local infant school where he had one-to-one support and a weekly visit from a SALT. He was very happy there and the staff really tried hard to include him and make the effort to learn to sign. However after two years, both spent in reception, he had made very little progress educationally and socially and was far behind his peers.

So after Year 1, we bowed out of mainstream and had him placed in our nearest Local Authority special needs school. This really opened our eyes as to what Archie could potentially achieve. Very quickly we saw progress with his fine motor skills and his desire to learn. It was a great day when he wrote his own name! He also started to say more words and was very determined to speak. However, he was receiving minimal targeted Occupational Therapy (OT) and irregular Speech and Language Therapy (SALT). He needed to be doing TalkTools and the Nuffield Dyspraxia Programme on a daily basis and the school did not have the resources to be able to do this or to teach him to use his computer/AAC device so that they could integrate its use into the classroom. Further more he was not in a total communication environment and had no non-verbal peers.

We felt under enormous pressure to try to make up for the lack of therapy in school by doing lots at home. This put so much pressure on all the family as Archie hated doing it and the other two children were not receiving the attention that they needed. I had a permanent feeling of failure and that I was not doing enough to help Archie overcome his difficulties.

At his first Annual Review in November 2011 his school had warned us that in the future they may not be able

to meet Archie's needs. Therefore we needed to know where the best alternative settings for him were and how urgent the need to move him was.

We started to look around at other Local Authority (LA) options but quickly realised that they did not have the expertise and total communication environment that Archie needed. The obvious specialist settings to consider were Meath, Moorhouse and St Mary's Bexhill. We were impressed by them all but felt that Meath would suit him best at this stage. We struggled with the fact that he would have to be residential during the week but knew that we needed to give him the best possible chance to develop to his full potential and that a school like Meath would give him that opportunity.

Knowing that we would have to put forward an impressive case to convince the LA to pay for an out of county school, we engaged an experienced education lawyer and with his guidance, commissioned in-depth independent assessments on Archie by an Occupational Therapist, Speech and Language Therapist and Educational Psychologist who all had experience in writing reports that were aimed at supporting cases to be put to LA's.

The assessments made us realise that Archie really did need to be placed in a specialist school as soon as possible. He had a very spiky cognitive profile and was really trying to talk. He was in desperate need of focused OT and intensive SALT, plus he needed peers also using AAC devices. Fortified by our determination and armed with a very cool and equally determined barrister (plus supporting arguments from the school and his SALT) we made our case at the Annual Review in May 2012. We concluded the meeting by asking the LA to fund an assessment at Meath School with a view to placing him there. Secretly I made a provisional (and optimistic!) booking for an assessment for September 2012, which was the earliest they could see him.

The LA would not look seriously at our request without more "evidence of need" (despite the evidence from his SALT) so with some trepidation we passed them our final assessment reports along with a draft revised statement as a working document and waited...and waited... for an answer.

We also had a call from Meath saying that there had been a cancellation for an assessment and would we

like Archie to take the place. This was right at the end of term and we still had not heard from the LA so we decided to go ahead and have the assessment done privately. At least we would know whether they would accept him and if they did not we could look at what the alternatives were.

The assessment proved that Archie was just the kind of child that would benefit from a Meath Education – one hurdle was crossed! We also found out when there, about their Summer Camp. We signed Archie up to the four day camp (they take a certain number of non-Meath children) as we felt it would be good for him to finally do something fun for himself - it was always his sister who went off and did all the fun things - and would give us some idea of how he would cope on his own away from home. It happened during the first week of the holidays and Archie LOVED it, giving us the confidence to press on with our mission to get him in there!

We were expecting the LA to try to fob us off with another county school and were bracing ourselves to go to tribunal. However, unbelievably in mid August we received a call saying that the LA could not meet his needs within the county and that Meath School was the closest geographically that could. They had caught wind of the fact that he had already had his assessment (and thank goodness he had!) so were in discussions with Meath about getting him placed in September.

After two nail biting weeks of negotiating his Statement so that all parties were happy - and getting final funding approval - we were home and dry. Archie had two days at his old school (we only found out on his first day back that he was definitely in) and then without a tear went off to Meath the following Monday. The care and school staff are amazing with him and although he had wobbles during his first week about not coming home after school, I asked him when I picked him up whether his new school was better than his old one, and with a huge grin and a thumbs up, I had a resounding YEAH!

We know that he is in the right school for him – for once the work that he does is totally appropriate for him and is presented to him in a way that he understands and is engaged by. Each class at the school has a Speech Therapist who works alongside the teacher and they also have a full-time OT and OT Assistants. He is getting his therapy and is surrounded by peers like him. He is not alone. It is a huge weight off our shoulders.

We can now relax about Archie's education for a few years at least.... The next mountain to climb will be trying to get our 2 year old (William) into Meath. He also has WDS!! After being down the route of mainstream and non-specialist Special Needs schools, we can see that they do not work for our boys, with the complex needs and difficulties that WDS presents. We are not sure how we will manage it, but we will.

Annabel Bates

## We're booked!

We have managed to book next years Family Day already, so this is a sneak preview of what exciting things will be in store for us.

All of us on the committee hope that you like the new venue we have chosen. Don't forget to put in your new 2013 diaries Sunday 23rd June.

### About the venue

Since 1982 the Thames Valley Adventure Playground has offered a unique range of adventurous, therapeutic and educational play activities in a safe, caring and stimulating environment, catering for both children and adults with all types of disability, however mild or profound.

### Indoor facilities

Large interactive Soft Play area with ball pool and intelligent lighting.

Multi-sensory and music rooms offer the latest technology for both stimulation and relaxation.

Main playroom - you can enjoy arts and crafts, touch screen computers, a games room, quiet area and lots of toys and games.

Changing areas and toilets have wheelchair and hoist access.

### Outside facilities

Secure play areas - you will find a wonderland of exciting, robust equipment just waiting to be explored. The area around the building is home to our wheelchair roundabout and swings. Follow the pathways past the sand pit and splash pool, under the "wobbly bridge" and through the gardening areas, down to the castle. Here you will find the aerial runway (with harness bucket seat), mega slide and the climbing structure. Beyond you will find the pond, picnic areas and the entrance to the wilderness garden. Use the elevated walkway to view the lake before you return to the sand pit or venture on to the safety surfaced games areas with adapted bikes and electric cars. Visit our new activity annexe overlooking the lake, with its craft area and activity spaces. Enjoy a game of crazy golf or visit the toddlers' area.

The Playground experience is totally unique and offers something for everyone. It has no formal catchment area, and users come from a wide area around the Thames Valley, covering 9 counties. They visit with their families and as individuals, or with groups from schools, playschemes, day centres and residential units.

The Thames Valley Adventure Playground is an OFSTED-registered day care facility, run by a voluntary Board of Trustees. On-site care is provided by 4 full-time, 3 part-time and 10 sessional staff, supported by a loyal band of volunteers.

We are a Registered Charity with annual running costs in excess of £320,000, and only 5% of our income this year coming through Local Authority funding. For the remainder, we rely on the efforts of our fundraising committees and the support of local people, business community and organisations.



Reg. Charity No. 278336  
**THAMES VALLEY ADVENTURE PLAYGROUND**

for children & adults with special needs

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## THE LONG ROAD TO MEATH\*

\* This article is for the purpose of sharing the personal experiences by the member supplying it. WDSSG wish to convey that in reproducing this article, they show no bias on any opinions or advice given.