



## **EVE News**

March 2010, Issue 2

Hello from the Chair:

Welcome to the second EVE news and my thanks go to all who have sent articles. In fact I received so many articles that three of them from Dorothy will be featured in the next edition.

I reflected on the last issue bearing very much in mind it was our first attempt, and felt as it was going out to Local Authorities and other interested parties it needed restyling. Feedback from other EVE members re-enforced this view so Caterina has very kindly taken the time to look at a format for us by using a Skills for Care template. I feel this looks very professional and has only made a minor difference to the number of pages required. I would ask all of you to look at this style and feedback your comments. This edition features articles from Christine Bond and Dee Frost which focuses on experiences of receiving services - not just from statutory services but also a personal perspective in how life in a wheelchair can be so de-humanising. I think it's important that EVEnews not only provides information by highlighting relevant websites but also reflects the stories, experiences, issues and views of EVE members. I would ask you to take this into account when feeding back your comments on this style and format.

Dee gives an account of the International NWO Conference and there was one reference that struck a huge chord with me which related to the mental health seminar she attended on violent and challenging behaviour and the inclusion of service user involvement which she felt was at best patronising. I have witnessed as an in-patient on mental health acute wards numerous examples of how challenging behaviour is dealt with and been far more terrified by the staff reaction in hurling a patient to the ground, than in the behaviour of the un-well patient. These incidents still unfortunately occur but with a better equipped, trained and skilled workforce they will become very much the exception and not the norm. For many years mental health nursing did attract a very

controlling type of personality, at times completely at odds with their general nursing counterparts and I do, as many others do, bear the mental scars. However life is for living and thankfully although I shall never forget these memories, my motto is seize the day-Carpe Diem!

Unfortunately we have lost one of our dear members, David Swann who passed away earlier this year. David brought a unique perspective to EVE as he and his wife lived in residential care in Cambridge for a number of years and that experience influenced us all. One of David's best stories was about how he actually attended one of our meetings - he knew the code to get himself out of the care home, otherwise he would not have been able to attend. David did laugh on telling of his "great escape" and we also found it highly amusing. However those present at the meeting were left in no doubt as to the serious implications of this story; lack of dignity and respect; having freedom taken away and ultimately having no voice at all to challenge the system. David was highly intelligent and articulate and was able challenge the system. We shall miss you David.

This leads me into asking you to consider opening our membership again, I would be grateful if, in all the various networks we have, EVE could look for new members. Unfortunately Dorothy after many, many years of actively campaigning on the issues of Older People et al, has had to review her current commitments due to her body not being able to keep up with her brain! It is with enormous regret that Dorothy can now only attend EVE occasionally. However Dorothy being Dorothy and not wishing to let the side down is keeping an eye out for someone to attend when she herself is not able to. Thank you Dorothy for all your efforts, you are very much appreciated. Please continue to send in your valuable comments and attend when you are able to. From Tuesday March 30th Dorothy's email address will change to drunnicles020@btinternet.com. Her home telephone number 01223 462318 will remain the same.

Just a reminder that the next EVE meeting is on Friday April 16<sup>th</sup> at Wolfson Court Cambridge, starting at 10.30am, I look forward to seeing as many of you as possible. Skills for Care have an interesting piece of work for EVE to become involved in around Direct Employers and employing Personal Assistants and will be one of our main agenda items for the foreseeable future.

Kind regards as always

Carol

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## **A personal perspective on Personal Budgets, by Christine Bond**

Over the last couple of years you may have heard a lot about the Personalisation Agenda and making services more about what people want rather than what is on offer. But what does this mean in practice? I have been involved with Personal Budgets both personally and through my work. The following points are my personal views of having my own personal budget.

I have been accessing Direct Payments and employing my own staff since 2004. I employed my first support worker through Access to Work and then employed a personal assistant via Social Services Direct Payments a while later. I have always had a mixture of agency provision and Direct Payments as I felt that this was the most beneficial arrangement. Agency provision meant that I had regular support in the morning and knew that there would always be help available with no worries about unexpected sickness. Employing my own staff during the day meant that I had the flexibility to arrange support when I needed it.

I have always had support through Disabled People's Coalitions' both in Essex and Norfolk to help with the paperwork, to manage my money and more importantly run my payroll! I would, however, recommend you attend one of the free workshops run by Inland Revenue so you have a basic understanding of tax, National Insurance, holiday and sickness pay. Details can be found on their website:

[www.hmrc.gov.uk/bst/index.htm](http://www.hmrc.gov.uk/bst/index.htm).

You can if you wish, do all of the paperwork yourself but I didn't want the stress and worry about getting it wrong. Using the old Direct Payment system worked reasonably well but I found that the limitations placed on me i.e. how many hours respite, support at meal times etc I was entitled to was very restrictive. When I had an opportunity of having a Personal Budget I jumped at the chance and my budget started on the 18<sup>th</sup> January 2010.

Personal Budgets in Norfolk like a lot of areas is very new and there are still a few things that will need refining. Although I consider myself to be a well informed person, I have had to think differently. I am no longer limited to fixed numbers of hours, rates of pay and certain activities. I can now do what I like as long as what I want to do is legal, meets my identified care needs (not as ordinary on-going living expenses) and it keeps me safe. In some counties OT equipment is included but this is still separate in Norfolk, some needs that are health orientated are also exempt.

## ***Process***

Each county will very slightly differ in the process, but the process I followed was: Assessment to ensure I was eligible for services (As I already had Direct Payments this was not carried out).

## ***Financial assessment***

Your level of income/saving will determine if you are entitled to a free service, contribute towards a service or do not qualify. There is no difference if you have a Personal Budget or not.

## ***Filling in a questionnaire***

Depending on where you live and how you answer the questions will affect the amount of money you may have. You can fill this in yourself or with help. Each response has to be agreed by your Social Worker. Filling in this questionnaire helps to establish the level of support you will need with daily living. In addition to this I was asked questions about what is important to me, what things do I like, what things don't I like, what works well, what doesn't and what are my desired goals and outcomes. Being asked what is important to me is something no one has ever asked me before. During previous assessments I was always telling people what was going wrong. This felt like a more positive and empowering approach.

## ***Budget allocation***

The amount given is usually for 12 months and will need to cover all your needs. Whatever you do not spend will be taken back at the end of the year.

## ***Writing a support plan***

This is very personal to YOU and can be in what ever format you like. One of the biggest changes to me was having a back up plan for the first time. My personal care and support is provided mainly by my husband and up until now there was no plan if anything happened to him. With a Personal Budget I have been able to allocate some money to provide 24 hour agency care for 2 weeks in the event of an emergency. I have also changed the times and lengths of time I have support to best meet my needs. My husband can now have breaks during the year to enable him to go cycling because I am able to increase the hourly rate to employ a casual PA to cover this break.

## ***Support plan approval***

Once approved then a start date is agreed and you are on your way.

## ***Monitoring and paperwork***

To ensure that you are spending the money as agreed you will be asked to evidence your spending through providing copies of wage details and receipts for costs over £50.00 (but I would recommend you have receipts for everything).

### **3 month review**

A review is carried out after 3 months to make sure everything is working out and if not this is a good opportunity to alter your plan. However, this can be done at any stage if need be. There will be another review after 10 months to plan for the next budget.

### **Things to think about when working out a budget**

You have three options with your budget. You can either have the budget as money (Direct Payment) or ask your Social Worker to arrange the service for you (a Direct Service) or a combination of the two. As with everything, each approach has its own advantages and disadvantages. I find Direct Payments give you more choice and control but there tends to be a lot more paperwork and organising to do.

In Norfolk, Independent Living Norfolk (part of Norfolk Coalition of Disabled People) can support you to do this. A Direct Service is easier but tends to cost a lot more so there is likely to be less money to do things. If someone is happy with the level of support they currently receive then things can stay exactly the same if there is enough money in the budget. You do not have to use your entire budget but I would recommend that if there is any spare money then this should be allocated to a contingency fund to deal with any unexpected emergencies.

If you are employing your own Personal Assistant/carer/support worker, you will need to have them CRB checked and should always have employers insurance. If you are going to be employing any extra staff you should also include some advertising and recruitment costs.

You should also consider the rate of pay you want to pay your staff? Are you going to pay any extra for weekends, evenings or Bank Holidays? Remember you will need additional money for holiday pay, employers National Insurance contributions, sickness pay, pensions (if applicable) and out of pocket expenses like mileage. What would happen if your PA is off sick? Will you need any cover and who would provide this? I allocated some money to pay agency staff in this case and I have employed a casual PA to enable my husband to have some respite and who could cover in an emergency.

You should think about whether there are likely to be any increases in cost during the 12 months of your budget. For example are the Agency fees going to increase in April? Also consider if there are there any training needs i.e. lifting and handling or food hygiene.

It was recommended that at least 20% of your budget is allocated as a contingency fund. Unlike the old Direct Payment system, there is no extra money if there are any unforeseen circumstances. However, if your needs change then you can ask to be reassessed.

If you allocate money for respite or a break away consider some form of insurance.

I hope this personal perspective has been useful or interesting.

**Christine Bond 24/02/10**

## **Contribution by Dee Frost**

### **Care First Careers**

Skills for Care (SfC) are working closely with the Department of Health and the Department for Work and Pensions to support the delivery of Care First Careers across England. Care First Careers, is a government led initiative which aims to help 50,000 young people (18-24), who have been unemployed and on jobseekers allowance for 6 months, into jobs in social care. Job Centre Plus is responsible for the national roll out of Care First Careers.

### **National roll out of Care First Careers**

There have been three pilot sites for the initiative started October 1<sup>st</sup> 2009. The national roll out was launched on January 25 2010, a sum of £1,000 allocated to each young person which will go with them to be used by the employer on training needs; (this can be used by all whether a large provider or an individual Direct Payment/Personal budget user). There is a Pre Employment Training (PET) programme of 60 hrs. To determine if a young person is suitable for Social Care employment, a series of interviews, quizzes and questionnaires are also used. One point that is essential to remember is that there are so many different jobs within Social Care, from being a driver, an agency care worker or as a personal assistant.

I have attached the Direct Payment user leaflet that gives information, plus the Care Route Pathway (this includes the 60 hour pre-employment training that must be undertaken) developed by Skills for Care for Care First Careers.

My involvement started when James Cross asked me to be on the Steering Committee for the pilots at Department of Work & Pensions. I became involved in weekly telephone conferencing with DWP and regular updates.

My main Skills for Care contact was with Jan Sheldon who leads on the project, with whom I had much discussion, mainly bemoaning the fact that Job Centre Plus & DWP seem to be so caught up in filling out forms and their outdated views on social care regarding the wants and needs of users with any form of impairment that it was so obvious that not only do the grass roots need thorough training, but it needs to include micro/individuals to large employers.

In understanding this it is not all about traditional personal care needs. All different types of employers, the management of Job Centres (high management and low) also need to have far more understanding, especially about individual employers using a direct payment to fund the employment of a P/A. As a user of services and an employer with peer connections to other people, my views were sought on the care route pathway, the pre-employment training and many issues regarding the engagement of users and what we as users need and want. With my agreement, my details were also given to the Department of Health, where I was able to give advice on where, who and how information on Care First Careers should be given.

I was heartened when I read through the 60hour pre- employment training, as much emphasis is put upon the need for holistic cover, not purely traditional personal care. I know many of the users of social care wish that all staff should undertake this general training before getting a job.

### ***Care First Careers***

Care First Careers is part of the Government's young person's guarantee that everyone between the ages of 18 and 24, who has been looking for work for six months will get a job offer, work experience or training. It makes £75million available to fund up to 50,000 jobs.

### ***Skills for Care***

I am increasingly frustrated by the seeming lack of knowledge about what to do on a practical level for individuals employing staff. This is for people who employ staff at an individual level, but seems it is just tacked on to the end of their training and does not seem to have substance. It appears tokenistic, as though a box can be ticked to enable staff to say they have included individual employers. Hardly any user has heard of them, everything is mainly web-based.

The funding to help in accessing training is laughable. The NDMS-SC for users cannot in the main be filled out by the majority of users without tremendous amounts of support. For example a great deal of physically impaired people are not designated as primarily being learning disabled in any form, but these people need a great deal of support in areas especially like these. Bob my original Co-Chair has asked me to put his story in as he believes it shows how the many users in the peer support network (Direct Payments Users Network) feel:

"I have Cerebral Palsy, am married with 3 kids, used to work/drive in London as a youth worker. I have employed my own staff since 1997, I am now on a Personal Budget. Most of the information from Skills for Care went over my head, all I know is that if I used it to help train, it would cost me an arm and a leg; they only want to know about agencies.

The Council and other organisations don't know about them- Skills for Care. At first Dee explained about what they are aiming to do and generally could see it was positive but its ways of supporting individuals who employ are daft. I feel Skills for Care is a joke to people like me".

I do talk about Skills for Care to people who employ their own staff and the principle is received overall positively, issues surrounding the following were repeatedly brought up, but I feel these can, to a certain extent, be helped if good support/information/ talking and listening is available:

- "We need to train our staff for our individual needs."
- "If my staff are highly trained they will want more pay or will leave for jobs higher up ladder".

However when they see how Skills for Care are really working, people do not want to know .THEIR LIVES ARE DIFFICULT ENOUGH.

The only people who seem to be able to use and understand Skills for Care are people involved and highly motivated or provider businesses (MY INDIVIDUAL P/A IS A PROVIDER BUT NOT A BUSINESS!!!).

We need a concerted effort to show the positivity around new ways of working, especially around the issue of individual employers.

### ***More than just a tick***

I am pleased to see that Skills For Care Eastern are taking this on board and are working towards tackling this issue, trying hard to get funding for more involvement, and spreading the word about Skills for Care and its relation to individual employers, but this only seems to be really looked at by our Eastern group.

An example of professional contracted services who work with Personal Budget/Direct Payment users not knowing about Skills for Care was emphasised to me just recently.

I was approached to present to Independent Living Advocacy (ESSEX)

This is the organisation tendered and contracted by Essex County Council to give advice and support in the area of employing your own staff (especially the legalities of being an employer i.e. tax, holiday entitlement, contracts) they also support people to get their PA's by helping to advertise, interview and research for information regarding specific needs).

We need perfectly placed advocates that Skills for Care can inform and publicise to, as they are the first point that cash payment users employing their own staff will have contact with. So surely Skills for Care should let them know about the training of staff, as they can inform and direct the user about Skills for Care training etc. Most of the advocates had not heard of Skills for Care, let alone what they do. No information had ever been sent to their offices.

My presentation used PowerPoint as I felt this was the clearest manner in which the audience would understand my message. It was very hard going as I first had to get over their negativity to yet other government initiative which they knew little about. I spent 2 hours explaining what Skills for Care main aims and objectives and felt that the message was greeted with general interest and positivity. But they, as an organisation for users who employ and also tendered to give users help, support information and guidance were aggrieved that as usual they felt that there was a 2 tiered system and that Personal Budget and Direct Payment users who act as employers were again at the bottom of the pile.

### ***International Integrated Health & Social Conference: January 21<sup>st</sup> & 22<sup>nd</sup> 2010.***

In January I attended this 2 day conference. Although aspects were interesting it seemed very focused towards health and also professional research with little actual involvement of grass root staff (who are actually working at the coalface).

One mental health seminar that I attended was on user inclusion within training and use of methods towards violent and challenging behaviour. Making staff realise their reactions were misplaced and that there are other ways of working through these incidents which treat the individual with respect and dignity. The mental health service user was able to show the ways in which they should be treated (keeping their dignity etc). It was good that a user of services was involved but the way that they were patronised by the other members of the team was awful to say the least.

For instance they were given the title of Associate Lecturer BUT were not paid for their expertise. It was if because a user of services were given a title the user would feel grateful for only that. It was like they were being patted on the head and being told they were good boys and girls!! The ethos of having user involvement was good but there needs to be full and proper recognition.

Just to give a flavour of the so-called communication between health and social care. I put myself down for a workshop on training PA's!!! So I went along thinking I would hear about Personal Assistants BUT NO it was about Physicians Assistants!!! Confusing or what!!! To someone like myself it confused me and I am pretty involved within the social/health agenda.

I was appalled by the lack of common access issues to accessibility of which could have so very easily caused loss of life: i.e.

- “In accessible rooms (1<sup>st</sup> floor). ALL fire precautions were in 6 font on a little diagram chart, that told me to run down the stairs to a designated point. There was no evidence of EVAC chairs or people trained in evacuation procedures that I could ascertain”

- “There was only one set of women’s accessible loos on each floor, the cubicles so small a wheelchair could not turn round in them. Indeed I saw one poor women having to leave the door open whilst her PA attended to her needs.”
- “Every single table was too low for me to get my chair under”.
- “Accessible car parking was a joke, I understand that there may have been a need for more of this type of parking than at other conferences BUT no plans regarding this were put in place. I need a space that will allow for my wheelchair to come beside the passenger door. The only way I could achieve it was by parking a long way from the entrance)”
- “Signage poor in places (very few types of pictograms etc)”

The list could go on and on. I have made James Cross and Lee Stribling aware of this, and it is now put into place that a fully qualified disabled access auditor using a power chair (which is often larger than a manual) will audit all venues BEFORE Skills for Care use them.

One positive note was that Skills for Care staff were on hand all the time for help. This was given in a fantastic way, and is very creditable.

At lunch on the first day I met with the CEO of Skills for Care (I didn’t know who she was until after I had mentioned EVE and the Eastern region). I also spoke about the fact I had passed the first round for “Entering the Dragons Den” and now was meeting the dragons, bidding for funding, explaining about the project; getting information out about Skills for Care and new ways of working to users of all impairments, Local Authorities and others. Sadly I did not win and NO funding for this project will be forthcoming.

All in all I was not impressed with the form that the conference took, it seemed that the line between academics researching what we need and actually understanding that not all of us need to be looked upon as vulnerable, was not understood. Or that there still is a whiff of patronisation with employers “knowing” what’s best for us.

Partnership between health only looking from medical model and social care only looking from social model, showed the vast chasm between the two.

I am sorry that my piece is negative in many ways but I felt I needed to vent my frustrations.

A point I must make is that all of the issues CAN be overcome but it is a case of “slowly, slowly, catchy monkey”.

The work we do in partnership with Skills for Care is at times frustratingly slow BUT we will get there in the end.

**Dee Frost 15/03/10**

## **Contribution by David Rolph**

This is David Rolph from Lifestages UK Ltd, which is a Social Enterprise and a active EVE member. We would like to offer anyone help with Payroll and Bookkeeping who does not have access to a Payroll or Bookkeeping, we charge £10.00 PA for your Books and £20.00 per Month for your Payroll.

In addition we have been contacted by people who are unsure about how to set up their HMRC Payroll software and for this we charge a fee of £30.00 to help you through the process. We are currently considering setting up some group training to help you through it all, also helping you with an introduction to Quick Books. Contact David Rolph, Telephone 01255 674982, Mobile 07538 278234 or email

[lifestagesukltd@btinternet.com](mailto:lifestagesukltd@btinternet.com)

Also I have just gone through my first annual review with my social worker for Personal Budget and this is a steep learning curve.

*David Rolph 22/03/10*

## **SKILLS FOR CARE: ACCOLADES 2010**

Nominations are now open for the Accolades; further information is available on the national Skills for Care website:

<http://www.skillsforcare.org.uk/accolades/accolades2010/accolades2010.aspx>

Some of the categories are particularly relevant to people who use services and carers, and these are:

Best individual employer who employs their own staff

Best partnership with people who use services and /or carers

Best partnership supporting the transformation to personalisation

We could be grateful if you could distribute information about all of the Accolades to your contacts, highlighting the categories above to people who use services and carers and organisations you are aware of, who have contact with them.

If you would like more information about The Accolades, please contact

[Lee.Stribling@skillsforcare.org.uk](mailto:Lee.Stribling@skillsforcare.org.uk), or telephone Lee on 078113 92584 where she would be very happy to talk through the criteria with you.