

Richmond Users Independent Living Scheme (RUILS) is a charity and not-for-profit company limited by guarantee.

It is an independent, grassroots, self-help organisation that is user run and led by its peers – the people who use its services.

Help us to help each other

As a self-help group of individuals who are receiving Direct Payments, we value your knowledge, skills and experience and invite you to share your know-how with others.

For further information about volunteering opportunities or the services and events mentioned here, please contact us at:

RICHMOND USERS INDEPENDENT LIVING SCHEME (RUILS)

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Registered Charity No: 1127896

Company No: (England & Wales) 6682677

RUILS acts as the champion, representative and peer supporter of all disabled and older people who have social care needs.

It serves those who are in receipt of a Personal Budget or use Direct Payments, Personal Assistants or other means of support to achieve greater independence and well being.

OPTIONS is produced with the support of:



Tim Mott Associates

www.timmottassociates.com

Disclaimer

The information contained in this newsletter is intended to provide only a general outline of the subjects covered. It should neither be regarded as comprehensive nor sufficient for making decisions, nor should it be used in place of professional advice. The editor and RUILS disclaim all responsibility for any loss arising from any action taken or not taken by anyone using the information in this publication.

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In this issue ...

- **Save money - build a 'pool'!**
- **What makes a good Personal Assistant**
- **What you said about what we do**

community living alternatives for people with additional support needs

If you would like a copy of this document in large print, Braille, on CD or as a summary in a community language, please contact RUILS. Tel: 0208 831 6083. Email: info@ruils.co.uk

Aby uzyskać kopię niniejszego dokumentu w formacie dużą czcionką, Braille'm, na płycie CD lub w skróconej wersji polskiej, prosimy o kontakt z RUILS.

यदि आपको इस दस्तावेज़ की कॉपी बड़ी लिखाई, ब्रेल में, सी डी पर या हिन्दी में इस का सारांश चाहिए तो कृपया RUILS से संपर्क करें।

Nese keni nevoje qe kopjen e ketij dokumenti te keni me shkronja te medha, ne gjuhen e te verberve (Braille), ne CD ose si permbledhje ne gjuhen shqipe, ju lutemi kontaktoni RUILS.

如果你想得到這份文件的大字體印刷、盲人點字、光碟的版式，或有意索取中文的摘要版本，請跟RUILS聯絡。

اذا كنت ترغب بالحصول على نسخة من هذه الوثيقة مطبوعة بحروف كبيرة او بلغة برايل او على اسطوانة سي دي او ملخص باللغة العربية الرجاء الاتصال بـ RUILS .



Welcome

Dear Reader,

In the last issue of 'Options' we said we would check to see that your social care or support is easy to access, is fair and offers the full benefits of real choice and control.

Well, we've listened to what you have to say and have taken action on two key issues.

Firstly, we have identified some common 'hiccups' in the current system for delivering social care (Self Directed Support) and are working on your behalf, with Richmond Social Services, to 'iron-out' these problems. In particular, we will try to limit the rules that inhibit the choice and the flexibility of your support, reduce the amount of official paperwork and confirm that information you need is easy to access and understand.

Your replies to our recent customer survey is the second issue we have addressed. You will see from the report on page 09 that, despite your overall satisfaction with what we do and how we do it, we are taking steps to improve the performance of our own services.

Another previous commitment we made was to give you advice and share ideas that we think will help you to make the most of your Personal (social care support) Budget. Thus, on page 04 you can read about getting more for your money by 'pooling' your Direct Payments. Page 06 gives our reader's views of what qualities they look for in a good Personal (care) Assistant. Throughout this issue you will also find useful tips on monitoring your Personal Budget payments and reducing your daily-living costs. In addition, page 05 invites you to enter 'The World of Universal Wisdom' – more familiarly known as the RUILS' Forum!

Finally, we think Self Directed Support and the use of Direct Payments are fundamentally good ways of helping disabled and elderly people to live better lives. David's story on page 08, may convince you of why we believe this to be so.

The Editorial Team

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Info Box

Self Directed Support gives people who are eligible for social care, a sum of money (called a Personal Budget) to spend on their personal and domestic support. It can be used to help disabled and elderly/frail people remain independent and living at home.

The recipient of a Personal Budget is able to decide how the money is spent, by saying what service they want and/or by being given money to buy the support themselves. They have the choice to have as much, or as little, direct control over the money as they are comfortable with. It is up to each individual to decide what is right for them.

A **Direct Payment** is one way that a Personal Budget can be paid out. Recipients of a monthly Direct Payment have full choice and control over their spending and is the way the Council will provide funds if you want to employ your own support (care) worker or commission a support service, including that provided by a homecare agency.

NEWS IN BRIEF

Together As One (TAO)

Following the closure of Newlands House, the Mereway Day Centre and Centre 32, a new drop-in service has risen from the ashes. Called 'Together as One', a group of clients and volunteers offer local support to anyone experiencing loneliness or social isolation, particularly, if they are the result of mental health issues.

TAO offers space to get to know one another, to exercise, to play board games or to use art materials. In addition, they offer meals at low prices and the chance to go on outings.

Located at the United Reform Church in Second Cross Road, Twickenham, (near Twickenham Green), TAO is open Monday and Thursday, 11am to 4:30pm. For further information, contact caroljegbo@hotmail.co.uk, or why not just drop in?

A warm welcome to

Surabhi Dhondiyal

– Independent Living Advisor

I have joined RUILS as an Independent Living Advisor and enjoy the opportunity it gives me to meet people from different walks of life. I moved from Canada a couple of years ago and while I miss the snow, and would you believe it, the cold winter weather, I have since learnt to enjoy the rain and grey skies of London.



My family and I live close to Bushy Park and that is the favourite haunt of my two children, who like nothing better than belting cheery hellos to the deer and ducks that abound there. In my spare time I like to read Terry Pratchett's Discworld series as they are funny and a wonderful way to end my day.

I try, as much as possible, to use my bicycle to get to work and my current project is to find a bike seat that feels like a comfy”.

Caroline Thorogood – Community and Volunteer Co-ordinator

I am very excited to be taking on this new and complex role for RUILS.



I have lived in Teddington for 14 years (which is the longest I have ever lived anywhere!) and I am passionate about the area.

Having originally studied Social Psychology, I worked extensively in research, communication and marketing before taking a break from paid employment to spend more time with my children.

After a number of years of volunteering with adults with learning difficulties, helping at my local school, a bit of studying and lots of chauffeuring children around, I knew I was ready to return to work that would ideally be challenging, interesting and deliver real benefit to the local community.

In terms of hobbies I enjoy reading and yoga, but I have not yet learnt to combine the two!

Nominations Invited

RUILS is a user led organisation. This means that the majority of our Board of Directors (the people who govern RUILS) use social care and direct their own services.

The invitation to join our Board is now open. If you wish to put yourself or another registered member of RUILS forward for election as a Director, please complete and return the nomination form or contact: 020 8831 6083 or download it from our website www.ruils.co.uk.

Annual General Meeting 2010

RUILS will hold its AGM on the afternoon of Wednesday the 15th September at Clarendon Hall, Twickenham.

Following the great success of last year's meeting, we have decided to offer a similar opportunity for you to meet key advisors, Council officers, and a selection of agencies and voluntary groups that can help you to manage your care or support.

Save money – build a ‘pool’!

We look at sharing your Direct Payments to get the support you need.



As disabled and older people or parents of disabled children, we face the prospect of the rising costs of services and even stricter rationing of our Personal Budgets. Thus, it is important that we spend wisely and get the most out of every pound. But how can we do this? Well, one way is to pool your Direct Payment (DP).

‘Pooling’ is putting all or part of your Direct Payment together with the contributions of others, to buy a service or activity that you can then share.

The idea has been adopted by formally constituted social care bodies called mutuals or co-operatives (1). Mutuals are run by and for the benefit of its members. Typically, they are small-scale, highly reactive and offer a flexible approach to meeting its member’s support needs. This could include small organisations owned by the users themselves and staffed by their Personal (care) Assistants. For example, it could involve a group of older people with similar support needs pooling their Direct Payments to acquire economies of scale.

Local Pools



A local example of a mutual pool is the ‘Out and About’ group. Young adults with a learning disability who were former school mates, have pooled their Direct Payments to set up a friendship group. They employ a paid organiser to help them to go out together and to do different leisure activities.

“ We are going to all the home Chelsea matches together and I think they’re learning a lot about being in a crowd, travelling, etc. as well as enjoying the football. Next thing we want to try is to get everyone to entertain their friends by cooking them a meal, probably followed by a Wii sports tournament. ”

Out and About Group Member

A similar pooling idea led to the ‘Stepping on Out’ (2) project. A group of adults with learning disabilities, have put their DP money together to run a not-for-profit business that makes and sells greeting cards. The team employ a manager and work from a shop in Twickenham making and selling their handmade products.

The Guide to Pooling

RUILS’ Guide to pooling your Direct Payments’ is a practical guide that provides a basic tool-kit to such essentials as:

- getting started,
- different ways of employing and sharing staff,
- how to ‘pool’ and manage your money,
- tips to make sure everybody involved is safe and happy.

“ The guide looks great – really accessible, very informative and practical. ”

Out and About Group Member

As well as giving working examples, the guide also lists other ways to make economies by ‘pooling’. There is a checklist of things to think about before you decide to pool, a worked-out example of a jointly pooled budget and how to find and employ someone who is suitable to deliver your shared support.

Any recipient of a Direct Payment could benefit from pooling. For example, a group of seniors could pool their DPs to start a theatre group. So, if you need help to build your own pool or find others who want to share the same support, then contact RUILS (3).

Ed. Notes:

- (1) To find out more about mutuals and co-operatives click on; www.cooperatives-uk.coop
- (2) ‘Stepping on Out Project’. Monday, Wednesday & Friday, 10:00am-4:30pm at 35 Hampton Road, Twickenham Middlesex, TW2 5QE UK. Tel: 020 8744 8440 Email: office@steppingonout.org.uk Website: www.steppingonout.org.uk
- (3) To post a message for people to join your pool, go to www.ruils.co.uk/ruils_forum the subject ‘Pooling DPs’. To get your guide, call 020 8831 6083 or email info@ruils.co.uk



Useful Tip

Remember, what you buy with your Direct Payment money must always help you with a personal need or difficulty that you have previously identified in your Self Assessment Questionnaire and Support Plan. For example, if Social Services agree that your disabling or age-related condition stops you meeting people and has led to you becoming housebound and lonely, then a Care Manager should approve you pooling your DP to pay for someone to set up a social pool. They will see this as appropriate spending that has led to a positive outcome, namely, establishing and maintaining social relationships to dispel loneliness and isolation.

See ‘Options’ issue 9 for more about outcomes.

ruils forum

New RUILS Forum now live!

The new RUILS Forum is now live and we would love you all to be a part of this. The forum will give you the opportunity to

- find out about exciting things going on
- find out about services provided by different people and organisations
- be an active part in ongoing discussions
- or even create your own discussions

The RUILS Forum provides useful information and discussions on a variety of topics and information about what’s going on here at RUILS and also locally and nationally.

We look forward to seeing you on the forum and want to say a big thank you to you for helping the RUILS community grow.

Join us now at www.ruils.co.uk/ruils_forum

What makes a good Personal Assistant?

The launch of our 'Personal Assistant (PA) of the Year Award 2010' has prompted us to ask the question of those who are best placed to know.

Domestic care workers get a lot of bad press. Yet, those of us who are on the receiving end, know that employing your own Personal Assistant or PA can make a big difference to what we do and how well we live.

Personal Assistants or PAs are legally employed by a disabled or elderly person or someone with mental health needs to do the daily tasks or help to achieve the goals that they (the employer), find hard to do on their own. The PA's wages are paid by the person receiving the support using either their own money or, if they are eligible, that provided by the Council as a Personal Budget and issued to the recipient each month as a Direct Payment.



Enabler not carer

The reasons why some people prefer to employ their own staff are many and varied. But, most people report preferring them to traditional agency carers because the relationship is more personal, more equal and control over the way the PA works rests with the person receiving the support.

“ My PA is willing to be guided by me and to do what I ask without imposing their solutions, own preferences or values ”

Meanwhile, as the name suggests, traditional care workers 'look after', 'watch over' or 'do something to' the passive client. This relationship is seen by some recipients as not being very equal. Most of the power and decision-making seems to rest either with the care worker or their agency and as a consequence, the disabled person's independence and quality of support is diminished.

“ The agency carer made me feel like a number on a job sheet ”

To mark this change, the name Personal Assistant (PA) or support worker was chosen by people who employ them. The expectation is that PAs adopt a more person-centred approach to their work. That is, they recognise that the person is their boss and someone who has the right to take control, to take risks and to make their own decisions.

Thus, a PA acts as a facilitator and enabler.

“ They may act as my arms and legs but not my brain ”

Choice and control remains firmly with the recipient of the support and the PA may be seen more as one of a work colleague – although the boundaries of the relationship can get blurred!

“ The relationship with my PA resides in a grey area: too intimate to be strictly business (it's hard to think of the person helping you dry off after a bath as an employee), yet too enforced to really be friendship ”



Direct Payments are paid in advance

Remember - the Council usually deposits your monthly payment in advance. Thus, on the 26th or 27th day of any month, your bank account will be credited with the money you need for your following month's support and to build up your funds for such future items of expenditure as, Tax and national Insurance or your staff's holiday pay.

Qualities of Personal Assistant

Everyone has their own ideas of what makes a good PA - here are some examples:

- “She understands the daily problems I face but avoids pitying or seeing me as a helpless 'victim'”,
- “... often anticipates my practical needs and how I like things to be he gets on with them without me needing to ask”.
- “...picks up on the way I'm feeling but does not judge or dismiss how I am with a silly comment like; “There's others worse off than you”. I know there are, but right now I'm having a bad day.”
- “ (The PA) has encouraged me to make the most of my interests. I really get a kick out of his quiet but warm praise for what I do. It makes me feel better about myself”
- “ You've got to have someone who is trustworthy and honest”,



- “I look for a PA who pays attention and is a good listener - they hear what I want and how I want it to be done – I can then relax and not have to be on my guard all the time”
- “(The PA) ... is a good time keeper, reliable, polite, patient, thorough & approachable”,
- “(The PA) ... is good humoured, never 'in a mood' and can see the funny side of things.
- “My PAs must be willing to take a 'back-seat', to respect my privacy, not betray confidences or 'gossip' about me to others – it's a responsible job”,
- “ I need someone who has a positive, practical, down-to-earth, common sense approach, is unflappable and doesn't 'throw a wobbly' at unexpected set-backs”,
- “... is a person who is aware of their own weaknesses, what they dislike and their prejudices (they) acknowledge and learn from their mistakes”.

PERSONAL ASSISTANT (PA) AWARDS 2010

If you employ a good PA or support worker, then enter our PA Award 2010 and you could win a prize for both of you.

Complete the enclosed entry form or contact Ben on our helpline 020 8831 6083.
E-mail: info@ruils.co.uk or download the entry form on www.ruils.co.uk.

Every little helps

David's story shows how a small amount of money and a flexible and imaginative response to his assessed needs has achieved outcomes that far out-weigh their cost.

"When I moved to Richmond the world looked dark and I used to wake up many mornings and felt the sky was going to fall in as soon as my feet hit the floor. I had a big operation in my tongue because of cancer. I had no hope for the future. I also suffer from aggressive depression and experienced several admissions to a mental ward because I was suicidal.

I have to mention that as a result of my operation on my tongue, speaking was painful and this has affected my speech. When I speak most people don't understand me very well and sometimes won't try to understand me, which is a big disaster. So because of my lack of communication every day I experience more loneliness, isolation and as a result, this increases my depression.

However, my social worker suggested I apply for Direct Payment (DP). She then helped me to complete the self-assessment using the new system of Self Directed Support and helped me to write my Support Plan. I was also supported throughout these steps by RUILS.

From the beginning of using my DP I started to hire someone from an agency to clean my house regularly. Keeping my home clean is very important to me - a clean house gave me a very good feeling and reduced my anxiety.

I also managed to put some of my payments towards the gardening and I can't explain how spending that small amount of money has made me feel. I am very cheered by having help to keep my garden maintained. This is very important to me.

After I was diagnosed with secondary cancer, my care needs increased and I began using my DP towards gym membership and travel expenses to help me get

out in the community. Sometimes, when I became very depressed I visited friends or a family member. I have also paid for a family friend to travel to England to support me which really made me very happy.

I am so amazed by the creative and flexible ways I can use my Direct Payments to meet my needs. For someone struggling to cope in the way that I do, this has made a big difference to my mental health.

Since receiving DP I've never felt like committing suicide again and I haven't been admitted to hospital anymore.

I continued to receive support from RUILS and together we talked to the care co-ordinator about buying a laptop. This meant I could have communication with my friends and family through emails which has really helped me stay well. I also used it for research, keeping in contact with the hospital, hospice's staff, nurses, my social worker and RUILS. I have to emphasise that by having a laptop this has given me a new 'window' on life. I don't feel as lonely now.

I would like to say I appreciate and thank all the lovely people from RUILS who are my big supporters and who have given me my freedom, always ready to help and advise me and I owe them my life. Specifically I would like to add my appreciation to Jackie Jones.

In conclusion, despite my diagnosis and ongoing health needs and with no chance of a cure or knowing how long I will be alive, being able to take more control over my life and arranging my support needs to suit me, I am now more positive and able to fight my depression and cancer and the many challenges this world has for me. I have even started to write my life story as a journalist and I hope to be working on this project with a student from a London University".



Money Saver

Shopping for one? Take advantage of 'Buy 1 – get 1 free' offers - do your shopping with someone else (a neighbour or your Personal Assistant), and then divide the bulk buys.

What you said about what we do

Thank you to everyone that took the time to complete and return our recent survey. Over 100 of you did this and have provided us with very useful information about what we are doing right, how we can improve and what services we should be developing.



Current Services

Over 80% of our clients were satisfied with the services that we currently offer and 87% would recommend our services to others. 81% were very satisfied with the website, leaflets and guides that we produce and 77% said that they would recommend these to others.

Over 86% of 'Options' readers said that it was accurate, relevant, accessible, attractive and interesting with 90% saying that they would recommend it to others.

A good report card! But there is always room for improvement.

For some people the process of setting up their support didn't happen quickly enough and they felt that they weren't always sure what was going to happen next.

Some of these delays were due to the new social care processes, called Self Directed Support, and we are currently working with the Council to identify where this is not working and to help to put things in place to improve this.

In our team we are putting new measures in place so that you know what to expect from us and that you get the information and feedback that you require.

For example:

- We have made a member of staff available to keep in touch and follow up with those of you that are using the paFinder service.
- We are developing a Customer Charter. This will set out our standards of service performance, including the time frames for their delivery. We can then measure our performance against these standards and you will have a clearer idea of what you can expect from us.
- We are developing the paFinder service so that it will be available online. You will be able to do your own web search and find your Personal Assistant at your own pace. We will still be here to help, but the internet option will speed up the process and will help us to keep the Personal Assistant's information up to date.
- Providing there are enough job seekers, we will try and offer you more choice in the number of potential PAs for you to employ. *Continued p.10*

New services

It was very encouraging to learn that you wanted us to give you more help in the future rather than less. Thus, the majority of you welcomed the suggestion of new services to help you manage your Personal Budget, to have a drop-in surgery and to offer a service that keeps in touch with you to make sure that your support is still working. It was also helpful for us to know that you have an interest in training events for Direct Payment employers. There was particular interest in learning about how to give clear instructions to PAs and in setting up and maintaining the relationship with the PA. There was also a lot of interest in training for Personal Assistants - the majority wanted workshops to help their Personal Assistants (PAs) to become better at what they do.

There was also a majority wish that we should continue supporting individuals to develop their strengths and skills and to help them find better ways of living with a disability or chronic illness.

As a final endorsement, we were very pleased to see that the majority of you wanted RUILS to act on your behalf as your 'champion' and to make your collective voice heard. I think it fair to say that we would consider it an honour.



Watch your payments (Direct Payments)

1. Ask the bank for monthly statements beginning on the 1st of every month.
2. Encourage anyone in receipt of your cheque payments to pay-in their cheque as soon as possible. This will ensure your next bank statement shows all the 'out-goings' for that month. Prompt processing of your cheques avoids your statement showing a misleading monthly balance that shows you have more to spend than you really have.
3. Remember to complete your cheque book stubs so that you can record each item of expenditure against the balance of your account.

Being a Good Boss

Once you have employed your own support worker, how do you keep them and make sure they give the right support?

If you are eligible to receive social care funding from the Council, then one of the choices you have is to take your Personal Budget money as a Direct Payment (see p.1). This will allow you to use the monthly cash payments to employ and pay the wages of your very own support worker or Personal Assistant (PA). Whilst this gives you a lot of control over your care or support, employing your own staff is a two-way thing – your Personal Assistant has to work in a way that is right for you (see p.6) but you have to be a good boss so that they can be happy and effective workers.

So, how do you become a good boss? Well, here are a few ideas:

1. Think about the job. Have you written a job

description that describes the support worker's duties and responsibilities? This will prepare your PA for the tasks and routines that they must do and show them that you are a boss that is organised and likely to offer consistent and manageable work.

2. Compensate your staff fairly and adequately. Try to pay according to the local market rate, always give your staff their full holiday entitlement and allow them sufficient rest breaks if they work long hours. Keep accurate records of hours worked and pay their wages on time.

3. Provide safe and reasonable working conditions. A safe work setting (your home) shows your PA that you have thought about what will help them do their work well. Similarly, give your staff all the

materials (gloves, aprons, etc.) they will need to do their job properly.

4. Be tolerant. A good boss realises that because employees are humans too, some things are truly beyond their control. So if something goes wrong and it is not something that happens all the time, allow for some human limitation. For example, remember to have a good back-up plan should your Personal Assistant be unable to get to work. It's not their fault if they are unexpectedly ill or have an emergency at home but it is your fault if you haven't prepared for such an event.

Of course, your tolerance should not be to that point where your employees abuse it by giving mediocre results because they think you would not mind.

5. Be open and honest. Be clear about how and when you want tasks done. Discuss any problems as they arise. Don't let them go by without comment – they will only cause a bigger problem later on. Keep your PA posted about any changes and listen carefully about what they have to say. If you take the trouble to ask for suggestions and try out their ideas you will receive more feedback from them because, as their employer, you have valued their contribution. If there are some things about your support that is not negotiable i.e. anything to do with your body, then make this clear from the start.

6. Establish a balanced working relationship. Whilst it is good to make your PA feel welcome and be part of the family setting, it is important that they are not treated as your new 'best friend'. They are not a replacement for some missing emotional attachment in your life so avoid seeking their good opinion by lending them personal items or money, or letting them off doing essential tasks that you know that don't like doing.

At the other extreme, avoid treating your PA as the family 'scivvy' or servant. They are paid to support you to do those things you can no longer do for yourself. They are not paid to do the bidding of other

family members unless this directly helps you to maintain your previously held role as say, a parent.

7. Praise and reward. People like to hear they've done the job well, and a good boss will ensure that employees get the appropriate feedback and acknowledgement. When rewarding employees you don't have to be as excessive as Richard Branson, who bought an island for staff to holiday on – gestures can be as simple as marking your PA's birthday.

8. Positive Attitude. You cannot expect your employees to produce excellent results if they are always working in a stressful or 'cold' working environment. Try to be optimistic and smile. Joke with them, laugh with them, talk to them. It will be good for you and your employee.

9. Patience. Teaching people how you want things done does not happen magically. It may take time and effort so try to exercise patience.

10. Empathy. A good boss has genuine concern over his or her employees. They realise that they are people too with needs and feelings. Being able to put yourself in the shoes of your employees will make you understand better what they need to be able to produce better results.

10. Hire and fire. If, having provided all of the above, your PA still not up to the job, then try offering extra training or the services of an intermediary. If these do not help, seek advice on the correct dismissal procedure and act courageously to weed them out. Do not allow a bad apple to spoil your life – it's too important a thing for that.

Conclusion

So, being a good boss is not something that happens overnight. It is an ongoing learning process with struggles along the way. But once you are able to achieve a balance between your needs and those of your PA, you know that you are on your way to being well supported.