

Welcome to Options

What is the future for social care or support in an age of austerity?

Throughout the country, local authorities are changing their services so that people have more choice and control of their community and home care support. Called ‘-Personalisation’, this reform aims to provide assistance that ‘fits’ an individual’s personal needs and aspirations. The drive to personalise involves the transformation of adult social care so that all systems, processes, staff and services are geared up to put people first.

These ‘root-and-branch’ changes, are happening at a time of severe economic recession. The people who rely on social care or support and those in councils and provider organisations who commission and deliver personalised services, have all been hit by the debt crisis. They are suffering from cuts to social care budgets, workers losing their jobs, the closure of voluntary organisations and a regressive social care market place, that is being suffocated by a reluctance to fund new initiatives.

Sceptics argue either that Personalisation can’t happen when resources are so tight or that it has always been part of a political agenda to provide cover for cuts. But let’s look at this more closely. Personalisation in social care is part of a wider shift in our society towards the full inclusion of all people. It is not a government invention. It emerged from the struggles of disabled people and their allies. Three decades ago, they worked out how to achieve independence and avoid services that trap them in limited lives. The social model of disability and legislation on Direct Payments are tangible evidence of this. More recently, personal budgets, individual support plans and self assessment of needs, have added to the development of choice and control.

It is true, that the momentum of reform has slowed. A less vibrant voluntary sector and care agencies that are reluctant to invest in personalisation re-design, share this responsibility along with penny-wise local authorities. However, this does not take away the fundamental right of disabled and older people to have choice and control over their home and community support. Those of us who will be hardest hit if reform falters, must defend personalisation to avoid slipping backwards to a past (still present for too many) of acceptance of institutionalised service models which denied us our right to equality. There are many perversions of self-direction out there - but where we see these we must not fall into the trap of blaming personalisation itself, but rather work to show how it can be done properly and support people to achieve this goal.

RUILS’ commitment to Direct Payments, led us to ‘champion’ Richmond’s reform of social care. ‘Options’ also publicised the vision of independent living and issue No.13 is no exception. It features the very topical issue of how to identify and calculate the true costs of living with a disability (p.05). ‘Best of both worlds’ (p.04), reminds reader’s that commissioning a care agency and employing a Personal Assistant(PA) do not have to be mutually exclusive. Page 10 features two, new ground-breaking ways that make recruiting and self-managing your own support worker, a whole lot easier. To further ‘wet the appetite’ for personalised support, we include an invitation to enter our ‘PA Award 2011’.

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News in brief

Richmond set standards of service.

The Council's Adult Social Care and Community Services Directorate has published a customer care, "Standards of Service" guide. This sets out what response you can expect from staff and the timescales in which they will do it. Some typical standards include:

- If you need long-term Council support from a social worker, you will have the same case worker throughout the process.
- If you need a personal support plan it will be completed within 4 weeks of your assessment, unless your personal circumstances prevent the Council from doing so.
- Once Adult Services agree that care or support should be provided, the services will start within a maximum of 8 weeks of your initial contact with the Council.

If you require any further information on these standards then contact:

Tel: 020 8831 6446 or Email:

ACSCChangeManagement@richmond.gov.uk

Hardest Hit Rally

Despite travel difficulties, a band of intrepid RUILS' members, took part in the May 11th rally and lobby of MPs. They were protesting against the proposed changes to welfare benefits and the eligibility criteria that governs benefit entitlement. In particular, and in common with the other 5,000 plus demonstrators, they believe that the coalition government's plans to reduce spending on disability benefits by 20%, is a way of throwing people off benefits. As one marcher said; "If you say you are changing the eligibility 'test' to save lots of money, then you know the outcome of the entitlement assessment before you start. The reforms are designed to fail people who have real and genuine needs".



Get a life

Social life networking is yet another new idea from RUILS that seeks to resolve loneliness and encourage affordable outings.

At a recent RUILS DP Pooling workshop, getting together with others became quite a focus point. Armed with ideas and energy Susanne Morris volunteered herself to do something about it. Now a few months on Susanne is busy creating a list of people who have personal budgets and who want to register their interests and hobbies so she can start to link people together. Susanne has seen first hand the tremendous advantages linking up with other personal budget holders and their PAs can bring. She would be delighted to help others do the same.

If you are interested in joining the Social Life Network, please email susannemorris@ruils.co.uk or call the RUILS helpline on 020 8831 6083

Best of both worlds

Over 400 of Richmond's elderly and disabled residents prefer to employ their own care or support worker. But those who rely on traditional care agencies need not miss out – they can have the best of both worlds.

The self-management option

Direct Payments, or DP for short, are cash payments made by Richmond Adult Social Services to individuals who have been assessed as needing social care services, including care or support in the home, short breaks, assistance to go out in the community, or special aids and equipment.

DP can be made to people with a disability, illness or long-term condition aged 16 or over, to people with parental responsibility for a disabled child, and to carers, aged 16 or over in respect of help to support their role, people who use mental health services and people with learning disabilities. You must be able to consent to have a DP and have the capacity (with the help of others if needed) to manage one.

The amount of DP money that you will be given depends on a two assessments – joint appraisal by you and a social worker, of your care or personal support needs and a 'means test' of your finance resources.

DP money can be spent on anything that would otherwise be provided by your Social Services or can be shown to meet your assessed needs and agreed wellbeing outcomes. This can cover a wide range of purchases from; a Personal (care) Assistant, a 'sitter' for a few hours a day, short respite breaks, or a laptop to aid remote learning, shopping and/or sustaining links with your family. You can use DP money to pay a spouse, civil partner, or close relative but not usually, if they are living in the same house.

If you choose to take your council-subsidised Personal Budget as a Direct Payment, you have direct choice and control over your daily living arrangements, including how your support is delivered and by whom. However, there are added

responsibilities – for example, becoming a legal employer of a support worker or personal assistant (PA) and recruiting your own staff. There is free help and advice available to do this.

The agency option

Using a commercial home-care agency frees you of any legal responsibilities as an employer, avoids having to find or train a support worker or securing back-up 'reserve' staff, should things go wrong. However, you do lose some control over who provides the care or support and how and where it's done. There are also difficulties if you want flexibility in what support tasks are done during a visit and an agency is more expensive than employing directly.

It's not all or nothing

Whilst it may seem difficult to decide which of these options offers you the best quality of life, there is a third way, namely, spending your Personal Budget on a mix of directly employed and agency hired help. For example, some folks employ their own PA for most of their daily care or support but have also booked a local agency to provide a service at other times. This seems to work best when the agency is commissioned to provide regular visits, say at weekends and Bank Holidays.

In addition, you can also get the agency to cover irregular or infrequent visits such as when your PA is on holiday or off sick. Should you want this emergency cover, please note that you will need to agree this arrangement in advance and it will help you to secure this back-up service if you are already a regular client.

To find out more about Direct Payments contact our helpline Tel: 020 8831 6083.

Social care changes



Counting the cost

What are the extra costs of living with a disability and why is it important to know what you spend?

Benefits subsidise Council support

Since April 2011, Richmond Council regards certain welfare benefits as income that must pay for some of the costs of a person's social care or support.

Benefits like Disability Living Allowance (DLA) and Attendance Allowance (AA) are now included in the calculation of your personal contribution - the amount you pay each month towards your care or support. So, if your DLA (care component) is £73.60, the Council ignores £20 of this and then adds the remaining £53.60 to any other income you have before calculating your personal contribution.

Benefits like DLA and AA, were originally introduced to pay for the extra costs of living with a disability. But now that they have been earmarked to subsidise the Council's contribution, you may wish to identify and cost all your disability-related expenses to confirm that the £20 allowance is sufficient.

“ Attempts to quantify disability costs vary considerably—from as little as £7.24p to as much as £1,513 per week. ”
(Demos Report 2011)

What are disability-related expenses (DRE)?

Everyone is unique, so, it's not possible to identify all the disability - related expenses. However, they are likely to be costs:

- that are directly attributable to your disability, illness or long-term condition and/or to overcoming the social and environmental barriers facing people with impaired function or health,
- that might be thought of as luxuries by a non-disabled person but are essential to your well being,

- which both disabled and non-disabled people incur but your expenditure is greater because of your illness or disability.

“ I need to get my milk in single-pint cartons because I have trouble lifting and pouring. I need to get it delivered by the milkman, because I can't get to the shops unaided. I, therefore, pay more per pint, compared to the that paid by someone who can go to the supermarket and buy a 4 pint bottle. ”

To identify your DRE, consider your spending in all these areas of daily living.

Counting the cost

To decide if your DRE amount to more than the £20 weekly allowance, follow these steps. Note: the term 'disability', is used here as a generic term for all physical or sensory impairments, age-related and mental health conditions or long-term illnesses.

- 1. Identify DRE** Use Table.1 to list all goods, services and payments that you legitimately incur.
- 2. Check eligibility.** For each item of expenditure, apply the checklist (Table.2)
- 3. Calculate Cost.** For each item, calculate its weekly cost. To work out the average weekly cost of an expensive item that has, say, a 10 year life, divide the total cost by 520 (weeks).
- 4. Check weekly expenditure.** Add up the cost of all your DREs. If they total more than £20 a week, seek a review.

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Table1. Disability Related Expenses (DRE)

ITEMS & SERVICES OF DAILY LIVING	Examples
DIET	Food, drink, supplements for special diets & allergies. Culturally specific or pre-cooked & delivered meals.
AIDS & EQUIPMENT	Purchase, maintenance, insurance & repair of special equipment and/or essential domestic & communication aids. e.g voice-activated, hands-free phone.
CLOTHING & FOOTWEAR	Special clothing, footwear, repairs or replacements (due to heavy wear & tear) or essential adjustments e.g need to buy two pairs of the same shoe due to feet of different sizes.
LAUNDRY	Extra wash loads, special washing powders. Laundrette or dry cleaning charges. (Average weekly use is 3 loads per single person, and 5 loads per couple).
HEALTH TREATMENTS & SERVICES	Complimentary therapies & fitness sessions. Private medical, dental, optician fees
MEDICAMENTS & HEALTH PRODUCTS	Non-prescription medicines, personal hygiene items and/or medical products e.g. vitamins, non-allergenic creams.
PERSONAL SUPPORT	Indirect costs of live-in support e.g extra bedding, wear-and-tear, household bills. Private interpreter (sign-language), childcare, sitting/respice service.
TRAVEL EXPENSES	Medical/holiday insurance for travelling with a pre-existing condition. Motor insurance for other driver.
TRANSPORT & PARKING	Hire of specialist transport (e.g. taxis, Dial-a-Ride, mini cabs, 'Shopmobility' hire), extra fares for escort & parking for visits to surgeries, clinics, support groups, work, shopping, family.
UTILITY SERVICES	Water/energy costs to manage health needs e.g. air-conditioning or constant heating.
HOME MAINTENANCE	Decorating, repairs, gardening & modifications.
GIFTS & GRATUITIES	Gifts/payments/tips to help maintain informal support.

Table 2. DRE Checklist - what's a legitimate cost?

Answer all questions.

- | | | |
|---|------------------------------|-----------------------------|
| 1. Do non-disabled people normally incur this cost? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 2. Would you buy this item if you did not have a disability? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 3. Could this item be readily, willingly and reliably provided for free by family, friends, volunteers or neighbours? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 4. Does this expense help you to manage either the functional impact (e.g.sight) of your impairment, overcome a social (e.g. no family support) or environmental obstacle (e.g.access)? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 5. Is the cost over & above your weekly DLA mobility and/or care allowance? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 6. Would the management of your independence and/or disability be substantially and detrimentally affected if you did not incur this expense? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 7. Do you think your social worker would regard this expenditure as 'reasonable'? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 8. Is the item or service usually provided free-of-charge, subsidised or prescribed by your G.P, physician or other statutory service e.g. Local Authority or government-funded scheme or allowance? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 9. Was this item identified in your Support Plan as being over and above that which could be met by your Personal Budget? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 10. Do you believe you spend more than non-disabled people on this 'necessity of life' because your consumption is much higher? e.g. above average electricity bills to run specialist medical equipment. | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 11. Is the price of this product or service exceptionally high because you have a pre-existing disability that attracts an excess fee or premium? e.g named-driver insurance, single-occupancy room booking. | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 12. Does your disability necessitate the need to buy more expensive items or high specification products? e.g. hands-free, voice-activated mobile phones, ready-meals delivered to home because you encounter difficulties in preparing a meal. | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 13. Do you pay a fixed charge for a product/service even though your disability prevents its usage? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 14. Was this item expensive and a one-off purchase that was intended to provide long-term support over many years? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| 15. Does your disability mean that, unlike non-disabled people, you cannot take advantage of this item being offered at a discounted price? e.g last-minute travel fares. | Yes <input type="checkbox"/> | No <input type="checkbox"/> |

16. By incurring this cost, do you avoid having to receive a much more expensive item or service that the state would have had to provide? Yes No

17. Are you paying for the on-going upkeep of disability-related items that were originally provided at no charge, by a statutory service or charity? Yes No

If you answered 'No' to questions 1 to 3 and 'Yes' to all other checklist questions, then the items you have identified should be regarded as legitimate disability-related expenses.

How to appeal

Write to the Richmond Adult and Community Services, 44, York Street, Twickenham, TW 3BZ.

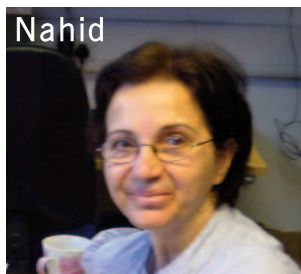
Your letter should detail the extra costs relating to your disability. Keep any evidence of your spending or contact charginghelpline@richmond.gov.uk or Tel: 020 8831 6400.

Celebrations

Volunteers – essential to what we do

RUILS celebrates the role of our volunteers and the extra qualities they bring.

As a user led organisation, volunteers play a crucial role in all aspects of the work that RUILS does and we'd like to take a moment to thank these unsung heroes!



Nahid

Our team is hugely enriched by the support of Nahid, Patty, Maribel, Anna and others who work on wide ranging projects in the office. Another volunteer, Susanne Morris, has seen a real need for people to be

able to get out and about and enjoy sharing interests and socialising together and has initiated a new project to make that happen.

We are also thrilled to have five volunteers who are now trained buddies or peer supporters who are busy helping us with our pilot buddy scheme (thanks to Bob, Gareth, Amanda, Trudi and Gregg

– many of whom already give of their time very generously not only to us but also to other voluntary organisations).

Thanks of course to all our clients that volunteer their time to come to 'Your Say' and share their views and ideas to help ensure that the voices of service users are heard in key places. And thanks to our trustees who put in so many hours to steer the organisation as well as pitching in with mailing out 'Options', helping run events and taking part in consultations, to name but four!

If you are interested in volunteering, joining 'Your Say' or would like to find out more about Susanne's project please call or email Caroline Thorogood on 020 8831 6271.



Anna

“Volunteering for RUILS is fantastic, it has given me so many opportunities to develop my skills and meet many new and interesting people. I love going into the office, the staff are so welcoming and make me feel a valued part of the team. Every day is different as many new opportunities arise. Volunteering not only gives me a reason to get out of bed in the morning, it also gives me a sense of worth. I feel great giving something back to the community and have made some really good friends in the process.”

Getting it right

You say, we do

Recently, you told us how well we are doing and what you do, or would like to do, with your Direct Payments. Here is some of what you said and what we will do to address the issues you raise.

The RUILS' Survey

Firstly, a big thank you to all those who completed our annual survey to judge how well we help you to find and manage the right personal care or support. Also, congratulations to the winners of the survey's lucky-dip, Amanda Winterburn and Stephanie Dryja have both received a £50 gift voucher.

“ exceptionally kind, understanding and helpful especially with making one feel secure - very important with so many new changes, and not knowing what to expect, I was very impressed ”

We are always keen to know how well we are doing and where improvements can be made. Fortunately, you are never shy in telling us both the 'good' and 'bad'.

Key advisors perform well

Overall, your satisfaction with our services is high. It's particularly encouraging to confirm that you value the support offered by our Direct Payments and Brokerage advisors. They help you to plan, find and buy personal support and a clear majority of you were pleased with their assistance.

More choice of support workers needed

The survey also reveals that the suitability and choice of Personal (care or support) Assistants (PAs), particularly those with specialist care or support skills and experience, is still an issue for some of you.

“ Although the PA (support worker) I employed is excellent, I did not consider that the choice was particularly wide ”

Whilst this is, chiefly, a question of the supply and demand of job-seekers, we believe our new online 'tools' (see p.10) will help address this problem. It will make it easier to match people looking to work as a personal (care) assistant with potential employers. In addition, it will allow registered site users to do a pre-recruitment check of the experience and training a candidate has and the kind of work that they would like to do

Valued support with improving standards

Perhaps, most encouragingly, the majority (80%+) of you, see us as a organisation that you would recommend to others. You also value our help: to write and set up a support plan and manage a Direct Payment, to better understand how this and Self Directed Support, work and to help make positive changes in your life.

“ With the help of the team at RUILS I feel that if it wasn't for all their caring help I wouldn't be here today this is why RUILS is the best avenue to go to if you need help with disability issues ”

We have also noted that you need our help to be more confident employers and know more about the variety of support that is available.

Although you reported a marked improvement in the speed of our response and in being kept up to date with the progress of your case, there is still more we can do to improve our performance. To address this, our new Customer Charter (see www.ruils.co.uk), will help us to regularly check our performance against standards that have been set by service users.

Direct Payment spending

The survey also gave us some insight into your spending of Direct Payments and what support you'd like to buy in the future. It is not surprising that the majority of you are using the money to employ your own support staff. However, you would also like to have a budget to go out, visit places of interests and other social activities. This is helpful to know, and we will use this to look at getting some of these social needs met. For example, we will be contacting those who expressed an interest in theatre outings to see if we can find a way to 'pool' part of your Direct Payments to develop a group that goes to the theatre or cinema (see p.03).

Finally, and encouragingly, you report that we are making a positive impact on your confidence and ability to try new things, to take manageable risks and to know more about your rights and obligations. This confirms our view that user-led organisations are best placed to support their peers. However, any sense of complacency is tempered by knowing that we are still only reaching a small number of people who could benefit from Direct Payments. This must change because the cuts to social care spending means the most marginalised and isolated elderly and disabled people will need all the help they can get!

Getting it right

Ground-breaking new sites

Employing a care worker just became a whole lot easier. Our new, websites makes Direct Payments an even easier way to employ your own support staff.

It is well known that using Direct Payments (DP) money to employ your own care or support worker, is the most cost-effective and flexible way of getting good support at home. But, whilst the popularity of DP is still growing, some people are reluctant to benefit from this form of social care. Mostly, they fear that the fuss and bother of employing a paid care worker, outweighs the greater flexibility and value-for-money that Direct Payments brings.

Well, the launch of our two new sites means that worry and effort has just got a whole lot easier. By visiting 'www.find-a-pa.co.uk' and 'www.employ-a-pa.co.uk', you will find 'tools' to find and manage your own staff. In keeping with our usual way of working, they were developed and tested by service users so that they are easy to use and take away much of the worry and stress of being an employer. They are also free to residents of Richmond.

www.employ-a-pa.co.uk is an online recruitment handbook. It takes the Direct Payment employer

through the step-by-step recruitment and employment process. All the information that you need is in one place. There are lots of examples and useful documents that the can be downloaded and used e.g. job descriptions, reference request letters. There's a tool to help you to build your own contract of employment and a pick-and-mix facility allows you to select, print or save the documents and information that you want in your own personalised handbook

www.find-a-pa.co.uk is an online version of our 'paFinder' service. Potential Direct Payments employers and job-seeking Personal Assistants (PA) both register on the site so that searches can be made to find a support worker or for a job seeker to find a job opportunity. PAs and employers can talk to one another through the site – that way no personal information is exchanged until the potential employer is ready to interview. The site also enables visitors to do their search, in their own time and at their own pace.

RUILS staff can still support people who need extra help or who do not have access to the internet. For example, they will: print and post a profile of PAs who match your requirements, meet PAs that have registered on the site and provide all the contents of the web handbook by email or as paper copies.

At that's not all

Like all our services, the internet tools are free to holders of a Personal Budget. They also compliment our other services which support those who, like the 400 elderly and disabled residents of Richmond, wish to live as independently as possible in their own home.

Personal Assistant of the Year 2011 Award

ATTENTION, all who use a Direct Payment to employ their own paid support worker or as we prefer to call them, Personal Assistant or PA.

Following the success of last years' competition, we are pleased to announce the launch of our Personal Assistant Award 2011. Last year, Marta Jagielska - PA to Lynette Jacobs, pipped a handful of deserving candidates to be our worthy winner and the recipient of a £100 gift voucher.

Our award celebrates the work of Personal Assistants (PAs) who are employed by disabled people, using Direct (cash) Payments from their Personal Budget. Our effort to publicise the benefits of personal support workers, foreshadowed the government's recent drive to accelerate and support the growth of a PA workforce that can provide personally tailored care and support with skill, compassion and imagination.

So, if you use a Direct Payment to employ your own Personal Assistant and believe that their dedication, reliability and willingness to go the 'extra mile' has made a difference to your independence and well being, then why not enter them into our competition for Richmond's Personal Assistant of the Year 2011? Remember, both the winner and their nominee receive gift vouchers - £100 for the PA and £50 for the employer.

To enter, complete the enclosed entry form or get help to do so by calling our helpline (Tel: 020 8831 6083) or download the form on www.ruils.co.uk.

The last date for the return of entry forms is Monday 22 August 2011.



Marta (middle) receives her award from Richard Kember (Chair) and Cathy Maker (Chief Executive) of RUILS.

RICHMOND USERS **INDEPENDENT LIVING SCHEME (RUILS):** help to plan your care or support impartial advice on spending your Personal Budget guidance to make good choices help to manage & control your care or support ideas to get the most from your direct (cash) payments help to employ your own support workers opportunities and solutions to live well and better lives.

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)

Disability Action and Advice Centre
4 Waldegrave Road
Teddington
TW11 8HT

T: 020 8831 6083/4

E: info@ruils.co.uk

www.ruils.co.uk

Registered Charity No: 1127896

Company No: (England & Wales) 6682677

OPTIONS is produced with the support of:



Tim Mott Associates

www.timmottassociates.com

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

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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。

إذا كنت ترغب بالحصول على نسخة من هذه الوثيقة مطبوعة باحرف كبيرة او بلغة برايل او على اسطوانة سي دي او ملخص باللغة العربية الرجاء الاتصال ببويلس RUILS .

