

**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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**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.**

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Tim Mott Associates

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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](mailto:info@ruils.co.uk)

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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।

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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 .



#### **In this issue ...**

- **ELECTION SPECIAL – social care and our future well-being.**
- **PERSONAL BUDGETS – what can I buy?**
- **ESSENTIAL REMINDERS – to make the most of a Personal Budget**

community living alternatives for people with additional support needs



# Welcome

## Dear Reader,

Richmond Users Independent Living Scheme (RUILS) was formed by a handful of people with disabilities sitting round a kitchen table and deciding to improve their quality of life by making Direct Payments a more workable option.

Direct Payments is a means-tested cash payment made in the place of a regular social service provision to an individual who has been assessed as needing support. The payments offer us more choice and control over who, what, when, how and where our essential daily-living support is provided and most of us use the money to employ our own support (care) worker.

After some banging on 'closed doors' and the waving of placards, the founder members of RUILS managed to raise the profile of Direct Payments and to date, there are some 300 beneficiaries.

Then along came Self-Directed Support (SDS). This whole-system change in the provision of social care builds on the benefits of Direct Payments. It acknowledges that elderly and disabled people, have the capacity, ambition and entitlement to say what their support needs are and how these can best be met. And, just like Direct Payments, if the correct values and ways of working are in place, people receiving social care under the umbrella of SDS will benefit. They should feel less like they are having something 'done to them' and more that they have care or support that fits them (more personalised) and is of their making. In addition, recipients of a Personal Budget (money paid under the SDS system) who choose to hold and spend the money themselves, will have the financial clout of a paying customer to get the most 'bang for their bucks'.

For government and local authorities, this last outcome is appealing. Confronted by shrinking budgets, the demographic 'time

bomb' of an aging population and a reluctance to fund welfare services by way of general taxation, the statutory authorities need to target public funds more accurately and ensure 'value-for-money'.

So, whilst social care remains under-funded and the current economic climate threatens to 'dumbdown' the more personalised SDS approach, RUILS sees its role as twofold. Firstly, to retain and uphold the original values, working methods, universal entitlement and benefits of SDS. Secondly, to ensure that you, the reader, are given the help you need to 'ride-out' the economic storm and the unsettling changes that arise from any 'root-and-branch' change in the way social care or support is provided.

The Spring issue of 'Options' demonstrates this commitment to make SDS work for you. The article on p.4 offers a way to check that your Personal Budget spending is in line with the Council's guidelines. 'Essential Reminders' on p.9, offers a list of important things to do and rules to follow to get good support. In addition, our 'Election Special' (p.7) is a RUILS' exclusive - it features the replies of local prospective parliamentary candidates to issues affecting our future well-being.

Finally, as a vote holder, we urge you to do something to protect your own interests. When supporters of a political party knock on your door, tell them you will vote for the candidates (both MPs and local Councillors) that can best improve your life as a disabled or elderly person. Ask them how they will protect social care budgets, promote your equality and introduce new measures to improve your life. Then we urge you to cast your vote. Not to do so will keep us at the bottom of the next council's and government's agendas and doorstep promises will remain where they are – out in the cold!

## The Editorial Team

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# NEWS IN BRIEF

## RUILS' Customer Survey

Many thanks to all of you who answered our survey. We had over 100 replies. Your answers will help us improve our performance and have already been used to plan our future services.

We will publish the survey results (warts and all) and develop an action plan to solve those issues that you have identified as falling short of our usual standards.

Finally, all identifiable respondees were entered into our prize draw. The winners are Richard Liebeskind, Leon and Hester Treloar and Flora Grasso. Congratulations to them and a final thank you to everyone who took part.

## 'YourSay' looks at homecare agencies

RUILS puts a lot of effort into looking at the quality of our services but also those offered by other organisations. Top of our list are the commercial 'homecare' agencies that charge for the care or support they provide in your home (see Issue 8 of 'Options'). We are gathering details of what they do and how they do it. In particular, we have asked them to complete a questionnaire that will show how their services fit our individual needs ('personalised' support). Each agency's response will be scrutinised by our 'YourSay' consumer group and our findings published. In the meantime, page.11, contains a list of those agencies that took the trouble to respond to our questions at the first time of asking.

## Innovations Award



A pat on the back for all RUILS staff, volunteers and Trustees. We (and the Council) were nominated as a finalist in the national Local Government's award for innovative services to disabled and elderly residents of Richmond. The recognition of everyone's hard work and commitment was given the official stamp of approval at the award ceremony, held at Downing Street and hosted by Dame Denise Platt and Minister of State, Rosie Winterton MP.

### Ed. Notes:

Issue.8 of 'Options' featured an article identifying the different approaches adopted by traditional agencies and those offering a personalised service. To receive a printed copy, contact our Helpline; 020 8831 6083.

Email: [info@ruils.co.uk](mailto:info@ruils.co.uk) or view a back-issue of 'Options' on [www.ruils.co.uk](http://www.ruils.co.uk)

## WHAT CAN I BUY WITH MY PERSONAL BUDGET?

### A do-it-yourself guide to spending.

Provided you are eligible for support from the Council, a Personal Budget is money you will be paid from their adult social care funds. It is to help you remain living as independently and as safely as possible in your home.

You can use your Personal Budget to pay for some or all of the goods and services that you decide you need. However, because the money is allocated from the public-purse, the Council needs to be sure that what you buy is appropriate. In other words, you are spending it on things that will benefit or enhance your current and future well-being. So,

how can you be sure that your spending stays within the rules?

### How do I decide if what I buy will be OK?

As a general rule, you can buy most things, as long as it is legal and meets your assessed personal support needs and the agreed outcomes described in your Support Plan. (See Info Box.A)

Always seek advice If you have some doubts about what you can buy with your Personal Budget. However, try answering the following questions to check if your planned spending will be OK.



### CHECKLIST

1. Will the support or equipment I buy help me meet one or more of my personal support needs?
2. Will what I buy help me to achieve one or more of my agreed outcomes?
3. Can I clearly demonstrate to the Council that what I buy will have a direct and obvious benefit to my living with a disability or age-related condition?
4. Will my life and well-being be maintained or made easier as a result of my purchase?
5. Will my choice of spending satisfy the Council that it will not expose me to abnormally dangerous, harmful or abusive situations or activities?
6. Is what I want to buy legal?; for example,
  - a. pays your staff at least the minimum wage (Currently £5.80 for workers aged 22 and over)
  - b. does not pay 'cash-in-hand' to your employee (support worker),
  - c. pays wages only to someone who is registered with the Revenue & Customs
  - d. does not involve gambling,
7. Would what I want to buy, normally be paid for by using other sources of income? e.g.
  - a. Cigarettes and alcohol
  - b. Electricity and gas bills
  - c. Rent, mortgage payments or unpaid debts,
  - d. Clothing and food

If so, I must NOT use my Personal Budget money for these goods and services.
8. Is what I want to buy normally supplied by the National Health Service or by the housing authority? If so, I must NOT use my Personal Budget money for these services.
9. Am I sure that the service or goods I am planning to buy are not;
  - a. already provided for free or at low cost by informal (not-for-profit) help,
  - b. by existing community amenities or
  - c. by sharing or making links with other people with the same needs as mine?
10. Does any of my Personal Budget spending pay people that live with me? This is not normally allowed and includes:
  - a. Your spouse (husband or wife)
  - b. your civil partner
  - c. a partner with whom you live as a couple
  - d. a close relative with whom you live, or the spouse or partner of that close relative

(Note: Contact the Council to check on the exceptional circumstances when an exemption to this rule can be made).
11. If I choose to buy some residential care, does my stay only pay for temporary short-break respite care?
12. Do you think that the cost of this item or service would;
  - a. normally be regarded as reasonable and 'value for money'?
  - b. be so high that you would have nothing left in your Personal Budget to buy a service that satisfies a more important and essential personal need.

#### Ed. Notes:

You can save up money, perhaps for a holiday or equipment, but this should be justified. If you build up unspent money that is more than 8 weeks of your usual allocation, and you can't justify this on the grounds that it will be used for an agreed outcome, you may be required to pay part or all of this back.



#### Tips

Self Directed Support does encourage Council's to assume that individuals are capable of making the best choices for themselves at any given time. Your Support Plan will need to demonstrate why the choices you have made around spending your Personal Budget are the best and most sensible choices for you and how they will help to meet your outcomes.

13. Is what I plan to purchase 'fit for purpose'? That is, does it 'do what is says on the tin'? (i.e. If a low-cost portable air conditioner did not relieve your heat stroke symptoms, it would not meet your needs but a more expensive model might and therefore, be a justifiable expense).
14. Have I purchased all my 'essential-for-living' and 'must have' support needs before spending anything on things that would be 'desirable' but not 'life threatening'?
15. Will I be able to show proof of purchase should the Council wish to trace my spending?

If you are sure your answers to this checklist would not be challenged then the Council will probably agree that your spending is appropriate way of using public money. If you are in doubt, then seek further guidance by contacting the RUILS helpline (020 8831 6083).



### Info Box A: Examples of what you can buy with your Personal Budget

There are many ways to spend your Personal Budget and a benefit of Self Directed Support is that it encourages different and creative spending.

These few examples of spending are listed under an outcome and illustrate the link between the two.

**OUTCOME –** To be fit and healthy, to lose weight and to have the energy and strength to do as many every-day things as I can.

#### My Personal Budget spending;

- pay your fitness, swimming or yoga membership fee.
- make a payment towards a friend's membership fee at the gym in exchange for their regular practical support while you also 'work out'.
- employ a Personal Assistant to prepare regular, healthy meals.

**OUTCOME –** To go to work, 'hold down' a regular paid job and have a career.

#### My Personal Budget spending;

- paying for a work colleague's petrol in return for a lift to work.
- paying for a course on computers or touch-typing.
- paying for driving lessons.

**OUTCOME –** To be a more confident more outgoing person who is comfortable with meeting new people and is able to make and keep friends.

#### My Personal Budget spending;

- buy software and a webcam (camera) so you can see and speak to friends and family.
- pay someone to assist you when attending a regular community event
- pay subscription to join a dating agency, friendship group or online 'chat room'
- purchas lightweight portable ramps to make a relative's house wheelchair accessible.

**OUTCOME –** To live in a tidy, clean, safe and comfortable home.

#### My Personal Budget spending;

- employ someone to do everyday household tasks such as cleaning and laundry.
- make a one-off payment towards specially adapted gardening tools that will help you to maintain your garden.
- buy a telecare alarm service so you can alert people in an emergency.

## YOU DECIDE – Election Special

Our future well-being will be affected by the political party that governs this country after the next General Election. But, which candidate deserves our vote?

In this exclusive feature, RUILS invited local parliamentary candidates (See Ed.Note) to respond to our questions. Here's what they said.



- disabled person as early as possible;
- The complexities of the benefits and support systems;
  - Continuing discrimination and ignorance towards people with disabilities.



**LIBERAL DEMOCRATS**

Labour promised fairness, but it hasn't happened for many people with disabilities. The benefits system is so complex it can be almost impossible to work your way out of poverty, especially if you need extra support. As a local MP I am approached by numerous local disabled people faced with obstacles to disability benefits including health checks often unfairly administered.

**Q.2.** Despite the many initiatives of the last 15 years, Disabled People remain six times more likely to be unemployed than the general population. Why do you think Disabled People find it so difficult to secure employment, and what is the one biggest thing your party would do to improve the situation?

**Q.1.** The current Government has committed to achieving equality for all Disabled People by 2025 - what do you think the greatest challenge will be in achieving this ambitious target?



The key challenges are:

- Ensuring that disabilities are spotted at an early age by Health Visitors so that the maximum support can be given to every



Ensuring that access to support, training and education gives disabled people a better chance in the job market. The Conservative Party will also offer new support, such as a Personal Advisor to help them plan their return to employment.

#### Ed. Notes:

The brevity of some candidates responses indicates compliance with our request to limit replies to a total of 200 words and should not necessarily be interpreted in any other way.



There is not the adequate help or support which is needed for disabled people who are looking for work; my party would seek to improve this by using voluntary and private sector providers to offer detailed advice and support for disabled people in seeking and sustaining a job.

**Q.3.** What is the one most important measure your Party would implement to ensure that the benefits of Self-Directed Support and the personalisation agenda are not lost in the future struggle to curb public spending?



Concentrating spending on the poorest and most vulnerable disabled people in society. This would mean reallocating Child Trust Funds from better-off families to the poorest and those with disabled children. In addition, incapacity benefits will be reviewed to reallocate the funds from those who can work to those who need assistance out of unemployment, whilst protecting disability benefits for disabled pensioners.



At a local level, the council has promoted self directed support for those who want it. But, nationally, severe budget restraints mean an honest party cannot promise to significantly increase benefit payments but there are other steps that we can take. For example, everyone who is entitled to a benefit should be allowed to claim it. At the moment trying to navigate the health and social care systems can be a complete nightmare: so many different rules about entitlements, so much confusing jargon, not enough information about the options available. We want to make every department, local authority, and business give people with disabilities the fair deal they deserve. We will offer independent help to hundreds of thousands of people by piloting a network of patient advocates dedicated to providing information, guidance and support.

**Q.4.** What role do you think local authorities should have in creating a vibrant community of User Led Organisations in their areas?



- Ensuring that user-led organisations are aware of the DDA before being granted funding;
- Treat complaints about disability discrimination with the same urgency and importance as any other form of discrimination in all areas where the local authority has power over the group.



The Government did promise an increase of User Led Organisations; however local authorities in general have not been quick to take these up. We see these as a valuable aspect of independent living and as such, we remain committed to ensuring that (they) have the means in place to be implemented across the country. I am currently working with local mental health patients seeking user-led alternatives to the closure of Centre 32.

#### Ed. Notes:

Prospective parliamentary candidates(Twickenham) for the 2010 General Election; Conservative Party – Deborah Thomas, Green Party – Steve Roest, Labour Party – Brian Tomlinson, Liberal Democrats – Vincent Cable MP.

The Green Party candidate was unable to meet our editorial deadline but did offer the following; “I am currently in transit to the USA. I will not be able to respond in the time frame you have outlined, but I want you to know that I am very interested in this topic.

Although I worked for several years as a volunteer for the Salvation Army, I have not had a great deal of personal experience with Disabled people. But having been very involved in social welfare and care for the disadvantaged the issues are very close to my heart”.

## Essential Reminders

Our helpline and home-visiting advisors are frequently asked the same questions – here is a selection.

### Q. What is the difference between a Personal Budget and a Direct Payment?

A **Personal Budget (PB)** is the amount of money the Council gives to you to fund some or all of your social care or support costs. The amount you get is related to the level of your support needs. Your Personal Budget has to be spent on those things identified in your Support Plan that both you and Richmond Council have agreed are necessary. You may choose to top-up your Personal Budget using your own funds.



You can choose to look after all or part of your Personal Budget. If you decide to hold and spend it yourself, then the Council will arrange for you to have your budget as a **Direct Payment**. These monthly payments are made into a bank or building society account that you set up for this purpose.

So, in summary, a Direct Payment has the following key features:

- You receive and manage your (Personal Budget) money instead of a service being

arranged or provided by the Council or other agency.

- Your Personal Budget spending is made by you to achieve your planned future care or support.

### Q. What other ways can my Personal Budget be managed?

If you want someone else to look after the money on your behalf, you can choose one or a combination of the following options;

- You can ask the Council to keep and manage your Personal Budget - they will arrange your care or support. (Called a ‘Council Managed Account’).
- You could arrange for another organisation, such as a commercial homecare agency, established voluntary group or charity to hold and spend your Personal Budget. (Called an ‘Individual Service Fund’).
- You can get a relative or friend to act on your behalf. (Your Personal Budget is paid as a ‘Direct Payment ‘).

### Q. Is my Personal Budget a state benefit?

No. It is also not treated as personal income - it does not affect other allowances or state pensions and is not liable to income tax. However, Personal Budgets are funded from public money and there are rules that apply to its use.

### Q. What is a Resource Allocation System and indicative Budget?

To find out how much social care funding you might get, a calculation, called a Resource

Allocation System or RAS, is made by the Council. The RAS allocation is indicative – that is to say it provides a helpful indication of what money might be necessary and appropriate to get the support you need. In giving this indication it enables you to start making realistic plans, based on a realistic budget. The RAS does not provide a “ceiling,” and there are instances of people ending up with more than their indicative allocation - or indeed less, where they genuinely don't need it.

### Q. What if my support needs change?

If your circumstances change so much that you need more (or less) care and support, then you can ask the Council to review your situation.

You can, however, revise your Support Plan because you think that there might be a better way of meeting your needs. You can do this without talking to the Council, so long as it is within the amount set for your Personal Budget and it still meets the aims of your Support Plan. If you are unsure always seek advice from a Care Manager.

### Q. I want a service from a registered homecare agency but it is not on the Council's approved list. Is this alright?

Yes, you can choose to buy a service from a homecare agency that is not on the Council's approved list, but you will receive your Personal Budget as a Direct Payment and will therefore, negotiate your own service contract with the agency.

### Q. I've been told to include 'outcomes' in my Support Plan, but what is an 'outcome'?

An 'outcome' describes what your life will be like, what you want to achieve or change in your life, as a direct result of being able to get the support

that you need. What you buy with your Personal Budget money must help you achieve your chosen outcomes.

## Social Care

### What disabled and older people want.

Social care is a mixture of money, aids/equipment and support services that help disabled people and older people;

- take care of themselves.
- live full, active and healthy lives.
- join in with other people.
- enjoy the good things that come from independent living.

As recipients of social care;

- People want services that work together to help them stay well, to be in control of their lives and to live at home for as long as possible.
- People want a simple way of knowing what care and support services they can expect, and how much help they will get to pay for them.
- People want to get the same kind of care and support services everywhere in England.
- People want a fair system so they are sure they will not be left without the help they need when they need it.
- People want more money for the care and support system, sharing the costs fairly between the government and themselves.

## Homecare Agencies

The RUILS' 'YourSay' group invited all homecare agencies serving the London Borough of Richmond to answer questions about how their services are delivered.

The agencies featured on this page replied to this survey within the time requested.

**Carewatch Kingston Upon Thames**  
Tel: 020 8330 0070

[www.carewatch.co.uk/office/kingston-upon-thames](http://www.carewatch.co.uk/office/kingston-upon-thames)

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United Response is a top 50 national charity supporting people with learning disabilities, mental health needs and physical disabilities to live the life they want.

0208 246 5200

Email: [info@unitedresponse.org.uk](mailto:info@unitedresponse.org.uk)



**First Call Care Services Ltd**

We provide specialist support to people with a learning disability at home or in the community.

For more information please contact Gina Baker on [gina.baker@enara.co.uk](mailto:gina.baker@enara.co.uk)

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Eleanor Nursing & Social Care  
157 Uxbridge Road, Hanwell, London W7 3SR

### Promoting healthy independent living

Chrysalis Homecare is a leading home care provider and offer a range of personalised services, tailored to meet the individual requirements of each of our service users.

**Our services include:**

Personal care · Mobility assistance · Medication assistance · Meal preparation · Help going to bed · Light house duties · Accompanied visits · Shopping



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