

# BEST CHARITY OF THE YEAR - and much more besides



Alternative ways to living at home for people with extra support needs

# Welcome to Options



Dear Readers,

RUILS is Richmond's 'Best Charity of the Year 2011'. This accolade, together with our nomination as finalists of the 'Local Government Innovations Award', RADAR's 'People of the Year Award' and highly commended in the 'UK National Independent Living Award', is a record of which we are justifiably proud.

To celebrate these achievements, 'Options'-14 is packed full of the ways we 'caught the judges eye'. On page 09, 'My Story' tells how we supported a young woman to re-build her life following the onset of a life-changing illness. If, like her, you'd like to employ your own personal (care) assistant, then page 08 features our ground-breaking guides and on-line services to take the stress, and much of the work, out of being your own boss. Alternatively, if you're a parent or guardian of a teenager, then the article on page 06 describes how we are building the 'stepping stones' from children's to adult social care services. Should sharing your home appeal to you, then there's much to think about in the 'Shared Lives' feature on page. 04. This describes a daughter's efforts to set up live-in support for her Father. Last but not least, page 10 outlines just a few of the less well publicised ways we have made a difference.

Of course, those of you who know us well, will know that our services are founded on a very individual and personally-tailored approach. This derives from the fact that we are one of the few truly user-led organisation in the borough. This means our volunteers, and the Trustees who oversee RUILS, are themselves, people who rely on social home-care and assisted living support. They also live with the daily challenges and frustrations of managing a disability or long-term illness and so know what works and what doesn't. Having these 'grassroots' connections also helps us to respond quickly to un-met needs and develop original, but practical solutions. This way of working also makes sure that the people we serve have real choice and control over the extra support to which they are entitled.

But enough of the self-promotion. Turn the pages to see for yourself how RUILS can make a real difference to your independence and quality of life.

Best wishes

The Editorial Team

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# More about RUILS

RUILS is something different and something special. We are different because of who we are and we are special because of the way we work.



*RUILS Business Awards 2011*

Our claim to be different is because, unlike many other charities, we are user-led. This means that the people who oversee the running of the organisation and who help to deliver our services, live similar lives and share similar experiences to the people they serve. Many of them need extra personal help from time to time or throughout their lives because of a disability (impairment), old age or ill health. They also experience the same daily inequalities, prejudices and exclusions as their elderly and disabled peers.

But, you may ask, why is the difference of being user-led important? The answer is simple. Because we rely on assisted living to gain a measure of independence, we know what works and what doesn't. We are 'experts by experience'. Consequently, we know that our schemes and services have meaning and deliver what is really needed because they are grounded in reality and shaped by those who benefit from them most.

We are special because of the way we always work. Our 'grassroots' connections have taught us

that, for individuals to get the personal help they really want, we must involve and consult them in all that we do. Nothing about them is done without them. We call this special way of treating and responding to people, 'person-centred'. It seems an obvious way of working but it takes time, sensitive listening and skill – qualities that many large public organisations and private businesses find difficulty in reconciling with their drive to meet targets and profit margins.

RUILS believes that the unique combination of being not-for-profit, user-led and person-centred, is a model for delivering future personally tailored social care services. The values and principles that underpin this approach also ensure people get what they want. And what they want is; control over their lives, enabling them and their families to maintain and improve their well-being and independence; to be able to proportionally managing the risks they take; for dignity and respect to be at the heart of any interaction with professionals and to access high quality services and support closer to home and at the right time.

# Shared lives

You may be living alone in a property that is bigger than you need or can easily manage, but you don't want to move. One solution might be to have someone come and live with you.



Over the past 18 months I have been organizing live-in support for my Dad, and discovered myself on a sharp learning curve, digging into questions of housing legislation, employment law, and interpretations of leave. Finding the right person was the first challenge, but once that was done, here are 6 issues that I have struggled with.

## Personal Assistant but not a tenant.

Initially we advertised for someone to work a few hours a day, living rent-free and earning some income that would fit around other work/studies. A lawyer pointed out to me that you cannot talk about rent or rent-free, unless you really want to take on being a landlord, and all the housing law that it implies i.e. if someone does care or support work in return for reduced rent, they are a tenant, with tenancy rights that go beyond employment law and possibly beyond the end of employment contract.

As needs increased we shifted to a 'proper' full-time live-in Personal (care) Assistant (PA) role. Even then we made sure to use the right terminology: there is an employment contract and a 'service occupancy' agreement. The PA is not a tenant, but lives in the house 'so as to better perform duties of work'. This

means when the job ends, so does the right to live there. Does this matter? Well, you always hope not, but when my aunt's friend died, her long-standing carer simply stayed put.

A service occupancy agreement is dead simple. See Hull PA fact sheet:

[www.hull-pas.org.uk/index.php?idsection=5&subid=19](http://www.hull-pas.org.uk/index.php?idsection=5&subid=19)

## Calculating leave.

I never thought it would be so complicated or expensive. If you do an office job for 8 hours a day 5 days a week you get 5.6 weeks of leave per year plus bank holidays. But when a personal support worker does a 6 day a week job, is needed to work on some bank holidays, and has a 'day' that combines working hours, time off and sleeping in the house (on call in emergency), what counts as a day's leave?

First I took the 6 day weeks as norm and multiplied by 5.6 days – though I read something recently that suggested this was more generous than legally required for a 6 day/week job. Then we added on the bank holidays to make the total number of days leave per year - 36. This means the PA gets a day off for each bank holiday, but it's not necessarily taken on a bank holiday. It is just a day in the pot.

But the question soon arose: how to treat incomplete days? What if 6 hours leave is taken: is that one quarter of a day ( $6 \times 4 = 24$ ) or one half day (roughly half of a 13 hour working day, excluding the on-call night). I soon realized that if you can't translate a 'day's leave' into 24 working hours: the leave pot would be huge and cost of providing cover unaffordable. I have not yet got round to checking what others do. I think some just say that leave must be taken in whole 24-hour chunks. We deal with it by counting 13 hours as a leave-day, and tracking leave-nights separately.

### **Booking and covering leave.**

Who chooses which days or weeks can be taken as leave? Employees will want to choose some dates to fit around their own friends or family. But the employer may also have specific weeks when s/he is away, with family, not needing care, and some weeks will be much harder to fill with cover, for example when other support providers are also away. So we agreed at the start, the employee can choose one week and other weeks need to be discussed and planned in advance.

But the bigger issue has turned out to be the cost of leave. Looking at spend last year, I was rather shocked to realize that we spent almost half as much again on other temporary support, on top of the main PAs' salary/tax/NICs. Some of this is daily time-off, but much is cover for leave. And the cost of covering leave depends on two key factors: firstly how small the chunks are, and secondly how much advance notice is given to organize alternatives. When we end up piecing together 2 hours from one employee and 2 hours from another, or resorting to agency hourly rates, it gets expensive. When we can organize cover for a whole week in good time, each day's leave costs us less. The implication is that I need to be

organised in booking cover in advance, but also have a strong reason to discourage lots of small chunks of leave.

**Time-off.** Personal Assistants gets 2 hours off per day and 24 hours per week; a statutory requirement I believe. Again it sounds simple. But if my Dad and the PA are both in the house during this 'time off' it may not be so clean cut. He may call on them for help, knowing they is there, and she says she cannot feel truly 'off' but only 'on call'. At weekends the PA usually stays put, so it helps that my Dad spends this time with family. If that's not possible, we end up with my Dad, a stand-in PA, and the main one who is 'off' sharing the house together, which is not ideal.

### **Roles.**

Anyone who has shifted from daily home-care visits to a live-in PA will know the ripples extend to the roles of many others - family members, other who help, and of course the disabled person at the centre. It has worked well for us, but it did take time to adjust. And it continues to change. Who does the pills? Who organizes the rotas for the fill-in staff? Who pays for what? Just yesterday I gave the PA authority to open personal post marked as from the hospital or doctor – so that appointments don't get missed. Change is constant.

### **Help and advice.**

This was all done on a self-funded basis and did not involve the Council (it is not in Richmond). But the internet and disability networks have been great. We use the FISH insurance (recommended by RUILS) which comes with technical support, a nanny-tax agency as there are 3 support workers on the payroll, the Fact Sheets on the Hull PA website, and conversations with RUILS members and staff. I'd have been lost without.



### **Useful Tip**

Do you want the security of knowing that there is someone else in the house or do you want someone to provide help with household or personal tasks? It is important you are clear about the nature of any arrangement from the outset.

# Steps to Adulthood & Independence

**We look at how RUILS is helping young people with social care support needs to plan the first steps towards adulthood and independence.**

Earlier this year RUILS was approached by Karl Burgess, the Transition Development Officer in the Borough, to work in partnership with his team to develop person centred transition plans for young people between 14 and 16 years of age in Richmond. As an organisation that champions person centred thinking in all spheres of our work we welcomed the opportunity.

## **Planning early is planning well.**

Transition planning can make a big difference to a young person's life. Research and experience tells us that the earlier we support them to plan for their future, the better outcomes they achieve. Effective person centred transition plans are developed in collaboration with young people and their families. They are encouraged to think about key areas of transition, such as housing, employment, friendships, relationships, health, and finances. The process also involves getting to know the young person, what is important to them, what they like, who their friends are, and what they hope do in the future.

**“** *The person centred plan is really focused on getting to know my daughter as a person; it is different from the usual assessments she has had.* **”**

*Parent*

Planning for the future also means being aware of opportunities that exist by way of services and resources and the necessary information required to make the most of them. To that end, we have been informing families on what is available in the Borough in areas such as housing, college options, and social activities.

Often families are not well aware of Self-Directed Support (SDS) and what it will mean for their young person. And so we have been ensuring everyone understands the process and what follows around the time the young person turns 18

years. We have also made sure they are aware of innovative opportunities such as pooling personal budgets (Page 08). This scheme helps break social isolation while at the same time saving money. Pooling personal budgets is an area that RUILS has pioneered and we have been doing some very interesting work with young adults in Richmond.

Transition planning is particularly useful for young people with learning disabilities. It requires sensitive decision-making, appropriate risk assessment and thinking 'out of the box'. The relevant and timely dissemination of information around key areas of change means that a young person entering adulthood can do so with understanding and confidence. The planning tells everyone who is involved, what the young person wants to achieve and how they want to attain their goals.

### Shaping a meaningful future

When we meet parents and carers, most have already started to think about their young person's future, but many families find that transition planning is really the time when they start to robustly think of ways forward.

Having now engaged with families, we are beginning to get a sense of what is working, what needs careful thought and what resources need developing or overhauling. All the families that we have worked with remain very concerned about housing, employment, health planning, having friends and building and maintaining social relationships for the young person in the family.

*“ I am concerned about what (my daughter) will do once she leaves school. I don't like the idea of a day centre but don't know what is available in the community in an inclusive setting for her. ”*

Parent

Transition planning brings together families, schools, children and adult services to work in synergy to ensure a seamless transition for the young person. Reality is a bit different. For instance schools don't always engage in transition, as their responsibility ends when the pupil leaves school and any planned future outcomes usually

fall within a broader school remit that is often overlooked.

### Not settling for less

Some of the other challenges that face transition planners are dealing with a culture of low aspirations and even lower expectations. It is, therefore, important for all those involved to make a conscious attempt to 'push the envelope', to question the status quo, and not to settle for less.

On a positive note, the parents and carers have been keen to engage with the transition team and to see things move forward for their young person. Thus, it was in this spirit of collaboration that we organised an informal coffee morning for parents and carers. The idea was to give families an opportunity to speak with professionals in social care, who could answer questions on various issues around transition. It was also an opportunity for parents and carers to meet each other and share their experiences.



As an endorsement of the value of person centred transition planning, the Borough has extended our project by six-months. This gives us an opportunity to make further progress by offering more opportunities for families to meet and share their views.

For transition planning to succeed the result has to be tangible and meaningful for the young person and not just tokenism i.e. enforced leisure and pretend work. Planning a young person's move into adulthood is a chance for them to explore their hopes and dreams and in the end, to gain independence and to have real choice and opportunity. To achieve this, we continue to encourage everyone involved to think creatively, push boundaries and leave long-held assumptions aside.

## Web 'tools' to aid assisted living



**Employ-a-pa.co.uk** If you need a guide to employing your own support worker try this site. It will take the mystery and much of the worry out of employing and managing your own Personal Assistant (pa).

The website uses jargon-free words and contains over 30 downloadable templates and easy-to-follow charts to navigate the more formal matters of employment. A unique contract building tool also helps you to create, save and re-use a customised job contract. **www.employ-a-pa.co.uk** is a must-have resource for those self funders and recipients of Direct Payments who enjoy the choice and control to be had by employing their own support worker.

**Find-a-pa.co.uk** Finding someone to work as your Personal Assistant(pa) has got a whole lot easier – you just sit at home and pick the person that is best for you.

By browsing the personal profiles of job-seekers you can see how well they match your personal support needs and personality. An easy to arrange follow-up interview will confirm the suitability of the match. Job done – begin life at home supported by the person of your choice, doing what you want and how and when you want it done.

**www.find-a-pa.co.uk** also allows Personal Assistants to find a job and employer that fits them.



**Pooling Direct Payments** This guide was put together by people who pay for their personal support using a council-subsidies Direct Payment but who want to make the funds go further by 'pooling' the money to buy shared services.

This how-to booklet on sharing (pooling) Direct Payments will interest anyone who has insufficient income and wants to share the cost of a Personal Assistant or other means of support. It offers D.I.Y. tools and bite-sized information on how to 'pool' your money with others including: getting started, ideas on ways to spend your Direct Payments, what options you have when employing staff, how best to manage the shared cost, tips to make sure everybody involved is safe and happy and where to get more help and advice.

To order go to [www.ruiis.co.uk](http://www.ruiis.co.uk) or ring: 020 8831 6083/4



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# My Story - life can have meaning after all seemed lost.

My name is Somajeh, I am 31 years old. I was diagnosed with Hyper Mobility Syndrome in 1998 and with Cerebella Ataxia in year 2000. At the time I was a law student at London Guildhall University. Because of my condition I had to drop out of the course permanently. As a result, my life took a new turn!



The trauma, had a huge impact on my family as well. But, with their incredible help my strength of character, determination and my passion for life, has kept us all going. By the year 2004, I lost the ability to walk and unfortunately, now need to use my wheelchair to get around.

That was the time, I felt like there was no air to breath anymore. I felt helpless and hopeless. The situation was becoming intolerable and my family were so upset seeing me like this.

Until one day the social services found out about us. We had a friendly meeting first. Then, there was RUILS!

The social services and RUILS really made it happen for me! We were all introduced to Direct Payment (DP) for the very first time. Ms Jackie Jones was the first person we met from RUILS. With her help and the social services, we managed to put in the support I needed to start living again. Since then, we have all have been receiving ongoing support from RUILS.

Then in May 2006, I left my family home to live independent in my own one bedroom flat. In order for me to achieve my independence, it was very essential to have the help and support from social services, including the occupational therapist, the social worker and of course RUILS. Everyone came together and opened a new avenue to my life! RUILS, helped us understand Direct Payments. They guided us to make the most of the financial support we received.

Now, I live happily in my own home. With the help and support of my family, especially my mother, I can choose and employ my own personal assistants. We are in regular contact with RUILS. We know we are not alone anymore!!

THANK YOU RUILS FOR EVERYTHING!

Somajeh Ashraghi

# When Harry met Sally

RUILS' peer partners help shape best practice.

It's hardly a love story but when Harry met Sally - and Sue and Lynn – good things happened!

Harry Blankson, Sally Bardsinkski and Sue Pitt all use Direct Payments to pay for their support needs. They were invited to a meeting of the Council's Self Directed Support (SDS) Best Practice Group. Chaired by Lynn Wild, Adult Services Manager, this monthly forum creates learning opportunities for Health and Social Work professionals around the delivery of SDS (social care).

At RUILS' suggestion, the theme of the meeting was looking at Direct Payments (DP) from the service-users perspective. Enter Harry, Sally and Sue. They all told their stories, emphasizing the flexibility that DP offers and how this helps them to achieve greater independence. Harry explained how being able to use direct payments to employ his own Personal Assistant (PA) had enabled him to return to work following a paralysing injury. Sally gave a vivid account of life as a disabled Mum with 4 children, and Sue told of how, as someone with a visual impairment, she has been able to use her DP to volunteer for a number of local charities. In Lynn's words,

“ We listened to service users experiences, which were overwhelmingly positive about how direct payments gave them real choice and control and the opportunity to live meaningful lives. ”

But there were some lessons to be learned too. Lynn continues. 'We heard about the issues which make using DP's difficult. These include; cumbersome processes, need for regular reviews, lack of clarity on how money could be spent, uncertainty about the level of record keeping required and the need to clearly communicate the support services available to guide people on such topics as safeguarding and employment law".

All in, the meeting was incredibly enlightening and very positive, whilst leading to some clear action points for all parties to help improve the overall process and maximize the benefits. Lynn thanked Harry, Sally and Sue for their honest and very useful contribution to the forum.

Watch this space for further episodes.

## Making a difference

RUILS over-riding purpose is to make a difference. Our 'Can Do' approach has ensured this happens behind the scenes as well as with our award-winning services.

### Speaking out

RUILS has never shied away from speaking out on behalf of our members. In the last year we have petitioned and protested against the cuts to social services and welfare benefits. Most recently, we worked with the Council to look at the impact their Personal Contributions Policy is having on people who rely on social care. Our volunteers have also done much work 'behind-the-scenes'. Most notably,

our Peer Mentoring programme has provided informal, one-to-one support to others who experience similar challenges of living with a disability.

### Self-help works best

We have also helped new self-advocacy groups like "Taking Control" and "Together as One", to form and begin the important work of representing the interests of their members.

“ Taking Control has always been "under the wing" of RUILS as far back as I can remember. It was sometimes tempting to take them for granted - help came so easily - but the truth is, of course, that they all had another job to do as well, and in general they neither expected nor got anything in return for helping us’ ”

*Paul Harris (Chair Taking Control)*

*(Carol Ajegbo – Secretary TAO)*

“ Together As One (TAO) started a user-led drop-in service early in 2010 and RUILS have supported us right from the start. Because it is a constant struggle to raise the money to pay the rent for the drop-in service, TAO needs to keep costs to an absolute minimum and have very much appreciated RUILS' help in producing leaflets and other documents for the plays we have produced, our AGMs and our advertising within the community. ”

### Rewarding good practice

RUILS knows how important it is to have the right people helping you. So, to promote good practice, RUILS set up the 'Personal Assistant (pa) of the Year Award'. This celebrates exceptional personal support offered by a paid support worker. This year was the second time we have run the event and as before, the quality of the candidates was very high. The PAs all work for an older or disabled employer who uses Direct (cash) Payments from the Council to recruit and manage their own personal support. Without exception, the nominees reported having a special working relationship with their PA that was unlike any other they had previously experienced. Most notably, they speak with genuine warmth and enthusiasm about how the relationship has helped them to do more things than they had ever felt was possible and that has added to their sense of wellbeing.

This year's winner of RUILS' 'PA of the Year' is Connie Yates. She was nominated by two of her

Direct Payment employers, Jayne Hill and Yvonne Green. Their glowing testimonials describe Connie as, 'a kind, understanding, caring, empathic and reliable person'. Most notably, she has helped those she supports to be 'more confident, to cope with anxiety and to stay fit.'

The judges also highly commended the work of Jayne Sparks. Her employer is Daphne James. She describes Jayne thus; "She always encourages me to make my own decisions and I want to thank her for helping me to change my life in so many ways."

Everyone at RUILS applaud both Connie and Jayne. Their dedication and way of working are examples of good practice that we all celebrate and encourage.



*Connie (centre), 'PA of the Year.'*

### Last but not least

Volunteering gives back much more than is given. Amanda, this year's winner of RUILS Volunteer Award 2011, expressed this sentiment after Cathy Maker presented her prize and certificate of recognition.

Her view is shared by all of our volunteers but there is no doubting that Amanda's contributions to RUILS are many and varied. She is of course, famous for the supply of her delicious home-made cakes but the judges did not allow this to influence their choice – much! Instead, they were impressed by her 'can do' approach, her reliability, willingness to do anything that is 'thrown' at her and, despite fluctuating health and a physical impairment, always presents a 'sunny' disposition.

We think ourselves very lucky to have Amanda as a volunteer, peer buddy and, most recently, a Trustee. Her award is well deserved. Many thanks, Amanda. Oh! and those scones are very, very nice too.

**R**ICHMOND 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](mailto:info@ruils.co.uk)

[www.ruils.co.uk](http://www.ruils.co.uk)

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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 .

