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Real lives: promoting recovery through personalisation and peer support

Rachel Perkins, Julie Atkins, Nicole Hunter, Poppy Repper, Peter David Robertson, Phoebe Thornton and Sue Thornton

Dr Rachel Perkins is based at ImROC, London, UK. Julie Atkins is a PAL (Peer and Ally for Living), Nicole Hunter is the Director, Poppy Repper is an Operational Manager, Peter David Robertson is a PAL (Peer and Ally for Living), Phoebe Thornton is a Manager at Crocus Café, and Sue Thornton is the Director, all are based at Real Lives, Nottingham, UK.

Abstract

Purpose – *The purpose of this paper is to describe the development of Real Lives: a community interest company that provides peer support for people who face significant mental health challenges using personal budgets.*

Design/methodology/approach – *The paper offers a descriptive summary of the vision behind Real Lives and the successful realisation of this vision in practice based on interviews by the first author with the directors, Operational Manager, Cafe Manager and “Peers and Allies for in Living” who provide support to clients.*

Findings – *The successful development of Real Lives shows that it is possible to utilise peer support and personal budgets to create small, values based, financially viable organisation outside the statutory sector that is part of its community and can provide outside the statutory sector. A service for people facing significant mental health challenges that is personalised, recovery-focused and puts the client in control and is focused on helping them to do the things they want to do and pursue their aspirations.*

Originality/value – *Real Lives is an innovative recovery-focused service that is part of its community and offers a model for utilising Self-Directed Support and personal budgets and that might be replicated by others.*

Keywords *Community interest company, Peer support, Personal budgets, Self-Directed Support, Mental health, Recovery*

Paper type *Case study*

Real Lives is the brainchild of Sue Thornton and Nicole Hunter. Established in October 2012 their vision was to create a recovery focused service that utilises peer support and personal budgets to promote choice and control and facilitates hope and opportunity. Peer support from people who have faced similar challenges is often central to recovery (Chamberlin, 1977; Repper and Perkins, 2003, 2012; Shepherd *et al.*, 2008; Slade, 2009): to fostering hope, enabling people to recognise and develop their talents, get back in the driving seat of life and explore their lives possibilities following a diagnosis of mental health challenges (Repper and Carter, 2011; Repper *et al.*, 2013). Personalisation emphasises the importance of enabling people to have greater control over the supports and resources they need in order to rebuild their lives, participate as equal citizens and pursue their own ambitions and aspirations (Alakeson and Perkins, 2012). “A personal budget is an allocation of social care or NHS resources or an integrated allocation of both that is controlled by an individual and can be used to meet identified goals” (Alakeson and Perkins, 2012, p. 3). It is therefore, an important tool for helping people in their journey of recovery.

Sue and Nicole collectively had some 50 years’ experience of working in the NHS as nurses and managers, and, crucially, experience in business as well. They had been central in attempting to develop recovery-focused services in Nottingham:

Statutory services really struggle with personalising support and giving people choice and control. We felt we had gone as far as we could go in changing statutory services to make them more recovery-focused. The sheer size and superstructure stifles creativity and change (Sue, Director) (Plate 1).



When they left the NHS they wanted to go back to basics and create a service clearly focused on helping people to do the things they want to do. They identified a gap in the market in Nottingham: there were no smaller providers who could offer bespoke services in the mental health arena. Their aim was to create a small, values based, organisation outside the statutory sector that valued the expertise of lived experience and could be flexible and responsive to individuals wishes, preferences and needs. An organisation that reflected these values and responsiveness in relation both to the people it employed and the people it served.

Their vision was of a service that could offer both peer support and put choice and control in the hands of those whom it serves (including choice of the worker who provides support). They felt that Self-Directed Support and personal budgets offered the opportunity to do something very different.

Realising the vision: establishing Real Lives

We wanted a structure that reflected community involvement and commitment to social change without the superstructure of a Board. We were the visionaries and we wanted to work quickly and effectively without endless committees (Nicole, Director).

They therefore, chose to establish a community interest company. Each invested £20,000 of their own money and Real Lives was born. Having decided on the business model, their first step was to employ an Operational Manager – Poppy Repper – to help them to realise their vision:

I had been working as a bank Occupational Therapist in Forensic Services. Sue invited me round and asked if I wanted to work for her in Real Lives, initially for a year to see if it would work. To start off with I didn't really know what I was doing or what Self-Directed Support was [...] We opened in October 2012 and spent 3 months learning how to do things. This world is hard to navigate, it is not easy for a small provider to break in and there didn't seem to be anyone to go to for help. We had to work it out for ourselves – policies, pricing, website, and marketing – and spent a lot of time visiting various social care and health teams talking about our vision and our service (Poppy, Operational Manager).

They received no statutory support and had to work out how to navigate the system themselves. Information and advice were hard to come by, and it was not possible to get onto the local authority list of “approved providers” as this is only open to new providers every three years and they had missed the specified date. They wanted to gain accreditation to demonstrate their credibility and discovered “Disability Direct” – a Centre for Independent Living in Nottingham (<http://disabilitydirect.com/nottingham/>) – who provided an accredited directory of local providers:

This helped us start to think about what we had to do, but we have only had one referral through there (Poppy, Operational Manager).

For the most part they relied on extensive networking and word of mouth to gain referrals. Sue and Nicole “put themselves about” and utilised their extensive networks among health and social care managers and professionals on the ground.

“Peers and Allies for in Living” (PALs) were recruited, but to start off with there was quite a bit of waiting before they were gainfully employed:

In January 2013 we got our first referral. I went to meet her immediately, but it took two months to get the support plan approved and another two months to get the money into our account. At this point we only had another 6 months to see we could make Real Lives work. We had to work out how to speed things up or we wouldn't survive! (Poppy, Operational Manager).

We started with a small trickle of referrals. To start off with we responded to every request and were very frugal, we didn't even switch the heaters on! But the number of referrals grew and by October – a year after we started – we had a referral every day. Then we could take stock and start making demands on refers. We gained in confidence, developed a proper referral form and started challenging and negotiating with referrers (Poppy, Operational Manager).

To start off with there was just Poppy, the Operations Manager, and a few PALs. Two years on Real Lives has 48 clients (who have ranged in age from 18 to 95 years) and 18 PALs (who have ranged in age from 18 to 60 years – for biographies of current PALs see www.real-lives.co.uk/choose-your-pal-2/) providing support from 1 to 27 h per week. They have a turnover of £120,000 and have recently gained Care Quality Commission registration. They have developed a reputation for supporting people who are turned down by other providers, including people who have made heavy use of inpatient and accident and emergency services and people from forensic services.

Real Lives also needed an accessible “heart” that, in keeping with the values of the organisation, was a part of its community: a safe place where PALs, clients and the community could meet. An office did not meet these requirements, so Real Lives has at its heart the Crocus Café (www.crocuscafe.com). Fortuitously they came across a community café that had originally been set up to bring the community and students together and had developed a reputation for serving good vegetarian and vegan food. However, it was about to close because it had accrued some £6,000 of debts: Real Lives took it over debts and all: it does not quite support itself, but it is a central part of the organisation.

Crocus Café continues to attract an enormously varied clientele. When I visited there was a PAL meeting with a client, an elderly gentleman who lives on the local estate, an assortment of students working on their laptops, a group of people from the Learning Disability programme down the road and a local artist came in to bring more of her work that is exhibited and sold in the Café:

You meet so many wonderful people and the clientele are different every day. There are lots of students and clients and PALs and transgender people. Anything can happen here. One day a film director came in to hire the Café for a film about knife crime. The film crew used the toilet and bought jewellery made by a local blind woman. Another day a man came in who had been in hospital and he had no shoes on. We paid for a taxi for him to get home.

The cafe is open 10 a.m.-3 p.m., Monday to Friday and 11 a.m.-3 p.m. at weekends. It offers free Wi-Fi, toys for children and caters for various functions including weddings and a feminist film festival. On one evening per week, clients, PALs and other staff come together to cook and eat a communal meal:

Crocus Café is critical in making Real Lives part of its community and it is a really good café in its own right. It has a reputation for serving good vegan and vegetarian food and is popular with vegetarians. Everything is homemade and we try to cater for all dietary needs including gluten free dishes, and things suitable for those allergic to dairy and nuts (Phoebe, Café Manager).

The café also has a system of “suspended meals” for customers who need a meal but cannot afford the cost. People who come to the café are invited to pay for an extra meal that can be given to someone who needs it.

Real Lives is able to use its resources, including the café, very flexibly to meet the needs and wishes of those whom it serves. For example, one woman was referred but her resources meant

she was not eligible for a personal budget. She did not want to pay for support herself so she volunteers at Crocus Café. She was very isolated, so this arrangement meets her needs for somewhere to go and social networks, but it also meets the needs of Real Lives as she works well and contributes to the running of the café.

After 12 months Real Lives broke even and has started paying back Sue and Nicole's £40,000 initial investment. Sue and Nicole do not take a salary, but as Directors take an active part in the organisation, working on average three days per week each. In addition to the Operations Manager and PALs it employs an administrator and Café Manager.

How Real Lives operates

PALs are recruited from among people who have lived experience of mental health challenges, trauma and life experience who want to work and use their skills but do not want a full time job. To retain the choice and flexibility that lie at the heart of Real Lives, PALs cannot be guaranteed work, so all are employed on "zero hours" contracts:

I find it good to not to have fixed hours. It gives me the flexibility if I am not feeling well. It also makes me more flexible for clients (Julie Atkins, PAL).

All PALs are DBS (Disclosure and Barring Service) checked. Initially they were paid the minimum wage, but Real Lives aspires to ensure that everyone is paid the "Living Wage"[1] and they are well on the way to achieving this ambition. If they are on benefits then their hours can be limited to fall within the "Supported Permitted Work" rules.

Every PAL receives training and supervision (for which they are paid) and has a "Wellness and Development Plan". This identifies their aspirations, any other commitments they have and their vulnerabilities: how they will know if they are struggling at work, what they will do if this happens and what the Operations Manager can do to help. PALs are provided with assistance in career development and some have gone on to other jobs and further study (Box 1).

Every new client is seen by Poppy, the Operations Manager. She helps the person to develop their own "Wellness and Safety Plan" which starts from their ambitions/goals, the support they want and what they want to get out of the support. It also describes their warning signs and environments where they feel unsafe:

I don't pass them on until I'm happy I have got their Wellness and Safety Plan established. If there are worries or problems after that I can take them on again, or work alongside the PAL, or offer the PAL more supervision, whatever is needed (Poppy, Operations Manager).

Each client chooses their own PAL. From the profiles on the web site (www.real-lives.co.uk/choose-your-pal-2/) clients are encouraged to select two to three PALs who they can then interview. The profiles of PALs on the web site outline their previous work experience, interests, likes, dislikes and activities outside work. Clients can turn down a PAL at their first meeting and there is a formal review after four to six weeks when they can opt to change their worker ... and they can request a change of PAL any time after that. The same applies to the PAL: they can opt not to take on the person at the first meeting, after the first review or subsequently. If the person does not want to choose a PAL then Real Lives attempts to match the PAL to the person: someone with similar interests to the client, someone with skills the client would like to develop, someone who might act as a good role model, someone who has similar experience as a peer or someone who reflects a similar demographic to the client. However, they still try to offer as much choice as possible: should they wish, the client can opt for a different PAL at their first meeting, at the four to six week review or subsequently should they wish to do so.

Once a PAL has been identified, they take over from the Operations Manager and provide the agreed support, supported by the Operations Manager as necessary. Clients may be seen at home, in town, in the Crocus Café, contacted by telephone ... whatever suits the person:

Our aim is to work alongside someone in their recovery, to promote their independence and skills and enable them to do the things they want to do. With the client we develop individual

Box 1. Peter Robertson's journey as a PAL

- Whilst receiving care through the Early Intervention with Psychosis (EIP) Team, I was in the process of applying for Peer Support Worker Training through the local NHS Trust. I was alerted to a paid working opportunity with Real Lives by two separate people. So I did some research. At first I didn't like the sound of people paying fees for support because I thought they had to pay the money themselves. After I talked it through with my worker in the EIP Team, who explained about Self Directed Support and Personal Budgets, I decided to make contact with Real Lives.
- So I came for a meeting. I liked the environment. I liked what I heard. I liked the idea of people having control: "one size fits all" doesn't fit most people. The meeting put my doubts to rest.
- I was then asked back for 4 days training. The training was good. It expanded upon what I already knew from motivating and encouraging people at Recovery College and in the successful football team and social groups I was involved with at EIP. Compared to the Peer Support training I received through the NHS, the Real Lives training was much more "real". Less rules. More about being yourself and not being restricted by boundaries and procedures. We're allowed to be more real with Real Lives.
- When I was assigned my first client, I was extremely anxious about starting work again.
- I initially saw the client whilst shadowing his existing PAL. I was due to cover while she was on leave for 3 weeks. After that, the support went very well. He had previously requested a male PAL, so I was asked to continue working with him. He required help around his flat and in the community. I assisted him with his finances, diet, everyday tasks and we would spend 3 hours per week in town walking round the shops.
- He has changed a lot. He is more confident and his mood is brighter. Because of his financial circumstances he has to pay for his 6 hours per week himself. He chooses to pay because he feels the support helps him. He has engaged in study at the Recovery College. He also returned to the gym for a short amount of time and regained a good level of fitness. He has lots of ideas and likes exploring different possibilities. I support him to try things out and see what works for him.
- I frequently see him making what I think are mistakes. I say what I think, but if he wants to go ahead I support him. It's sometimes difficult, but it is important to let him lead the way, make his choices and hopefully learn for himself about what works and what doesn't. Throughout all of the ups and downs, I like to keep a bit of humour and banter going. I believe keeping a smile on my face has a lasting positive effect.
- Being a PAL at Real Lives has given me a route back into paid employment. I currently work on average 16 hours per week without benefits. I used to worry about the uncertainty, but I use my spare time for my other interests, such as sitting on the committee of "Next Step Network" (a peer led mental health support network that runs support groups and helps people back into the community).
- "I love what I am doing. Peer support is everything I believe in. I enjoy using my experience to help others: turning the negatives I've experienced into positives, making good out of the bad".

plans and can always renegotiate, change and develop these plans. There are some boundaries, for example, the number of hours support provided for within their personal budget, but contracts are always negotiated with the client so both PAL and client know what to expect (Poppy, Operations Manager).

It's an organic thing. You have a brief to start but then it's about how the client wants their recovery to go. We adjust things to what they want. The important thing is letting the person lead – it's what they want to do that counts (Julie Atkins, PAL) (Box 2).

Real Lives makes a real effort not to "give up" on people. For example, Operations Director Poppy described how it took 18 months to develop a Wellness and Safety Plan with one man:

He was very isolated and he hated his flat. When he was referred to Real Lives he researched the company on line and interviewed us at length about how the company works, payments etc. Once he was satisfied with the answers he only wanted me to work with him: he disengaged when a PAL

Box 2. PAL Julie Atkins description of her work with one client

- “She started off just staying in the house. To start off with her goals were really her daughter’s goals for her: going out, going on the bus, going to the theatre. But she was physically and mentally unwell and grieving the loss of her husband. I started working with her to find out her goals. She wanted to go shopping, but the bus was just too hard, she couldn’t face it. So we go out in a taxi that we negotiated should be paid for by her Personal Budget. So now she can actually be able to go out. She wouldn’t have gone out if we had waited until she felt up to the bus. I see her twice a week for 3 hours and have been working with her for two years. She is a lot more chatty, she is dressed when I arrive, she decides where we go. She still has her down days, but she is a lot more confident and she has found her voice with her daughter, so now she decides what she wants to do”.

took over. So the support consisted of him popping in to the Café. The Self Directed Support Package was reviewed. It was agreed that he would spend 0.5 hours with me each week, but would also see a PAL for 2 hours. A PAL was found who had similar interests and challenges to the client and they hit it off immediately. Now he chooses not to meet with me! (Poppy, Operations Manager).

Real Lives try to be very reflective and to learn from what goes well as well as things that do not go so well, and adjust what they do accordingly. It is not only support that is personalised, but also the rules governing how this support will be provided. Throughout they try to avoid “organisational rules” in favour of “individually tailored rules”:

It sometimes feels like we are winging it, but that’s part of being flexible and dealing with each situation individually: rules can be broken by circumstances so long as we all know what has been agreed (Poppy, Operations Director).

We are a small team so we can make decisions knowing that we will be supported (Phoebe, Café Manager).

Concluding comments

It is difficult for me to describe the sense of community, hope and acceptance that I felt walking into the Crocus Café that lies at the heart of Real Lives, and talking to the Directors, Operations Manager, Café Manager and PALs who had made a reality of the vision of a different kind of service: one that is really flexible personalised, recovery-focused, part of the community. A service that values the expertise of lived experience and does all that it can to put the people it serves in the driving seat of their lives and the support they receive to live them (Plate 2).

Those responsible for establishing Real Lives are rightly proud of what they have achieved:

I think looking back that I am proud that we are really in a position where we have a team of people who really get what Real Lives is about and want to be part of it. That we are really able to provide a flexible, personalised support that puts the client in control and is focused on helping them to do the things they want to do and pursue their aspirations (Sue, Director).

I am proud of the fact that we had an idea and we did it independently, by ourselves. A high quality service that looks after its staff. We have succeeded in bringing together the business and the ethics and the vision (Nicole, Director).

Plate 2 www.real-lives.co.uk



However, as one PAL remarked “I worry about all the people who aren’t getting the service” (Julie Atkins, PAL).

I suspect that Real Lives could grow and grow in size [...] but I doubt that it should. Perhaps replication is more important than growth. The spawning of lots of different, independent, “Real Lives” that are part of their own communities, rather than one large entity that whose sheer size stifles local co-production and creativity and creates the type of anonymity for individuals and communication problems that can jeopardise safety:

I will know it is too big when me, and Sue and Nicole don’t know every PAL and every client personally. It relies on being a community in the community: a family where everyone knows everyone else (Poppy, Operations Manager).

I am sure that its size, and the way in which everyone (staff and clients) know each other, and share a vision and values, are important in making Real Lives a flexible, responsive, safe and genuinely recovery-focused service that really helps people to get back into the driving seat of their lives and “is transformative to the people we employ as well as the people we support” (Sue, Director):

It lets everyone be themselves and supports everyone to grow – both staff and clients. I have grown more in 2 years here than in any other job. I believe in what we are doing. We are bringing mental health into the community. We work alongside people. Whatever the support plan says, if a person wants something else we negotiate it with the social worker. The way Nicole and Sue relate to me is reflected in how I work with PALs and how PALs work with clients. I am free to be as recovery-focused as I want to be – it’s the way we are (Poppy, Operations Manager).

It’s wonderful. I didn’t have any vision of me getting into work. It’s helped me you get back into doing things, get back into life. Helping other people makes you feel good about yourself. The ethos and the philosophy are spot on. I’ve been mentally ill and around mental health services for a long time. It’s so different from anything I’ve experienced before. It feels like a big family. We learn from each other and I’ve developed my own style. It’s a new beginning, a new way forward for mental health services. It’s a fresh start for PALs and the people we work with. It provides the next step in recovery for PALs and clients (Julie Atkins, the first PAL employed by Real Lives).

Note

1. In public policy, the “Living Wage” is calculated to be the minimum necessary for a worker to meet those needs that are considered basic. The calculation is based on the Minimum Income Standard for the UK, the product of research by Centre for Research in Social Policy, funded by the Joseph Rowntree Foundation. The research looks in detail at what households need in order to have a minimum acceptable standard of living. Decisions about what to include in this standard are made by groups comprising members of the public. The Living Wage is therefore rooted in social consensus about what people need to make ends meet. It is not the same as the minimum wage, which is set by law and can fail to meet the requirements of a safe, decent standard of living in the community. At the time of writing the Living Wage outside London is £7.85 and the Minimum wage is £6.50 and PALS were paid £7.20 per hour. For further information see www.livingwage.org.uk

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