Personal Health Budgets and Independent User Trusts

Using independent user trusts to manage personal health budgets

Personal Health Budgets and Independent User Trusts

Using independent user trusts to manage personal health budgets

By Jo Fitzgerald

With assistance from: **Professor Luke Clements**, Cardiff Law School; **Robin Murray-Neill**, personalisation advisor; **Rita Brewis**, Health Lead for In Control

2011.05.16

Contents

Personal Health Budgets and independent user trusts

Aims and scope of paper

The aim of this paper is to outline the role of independent user trusts as a 'third party' option for people wanting a personal health budget. Independent user trusts were explored principally in the case of Gunter v SW Staffordshire PCT[1], which sets out the key legal principles.

This paper discusses the purpose of a trust, details how they work, what they can and cannot do and the role of trustees. There is also information on setting up a trust. This paper is not formal guidance; it is intended to provide information to people who are considering setting up an independent user trust

What is a personal health budget?

Personal health budgets are a way of giving people more choice and control over how their health needs are met. They are new to the NHS and are currently being piloted across England – information on personal health budgets and the pilot programme is available from www.personalhealthbudgets.dh.gov.uk

They are based on an individual knowing how much NHS money is available to meet

specific health needs and allows individuals and their carers more choice and control over the way this money is spent. A personal health budget is centred on a support/care plan that sets out the person's health needs, the amount of money available to meet those needs and how it is going to be spent. The individual should be able to do this in ways and at times that make sense to them having agreed the outcomes that must be achieved. The budget can be held by the PCT, given to a third party to manage or given as a direct payment (in approved Department of Health pilot sites only[2])

What is an independent user trust?

Independent user trusts are one of several third party 'mechanisms' that can be used to manage a personal health budget. An independent user trust is a commitment on the part of trustees to manage an agreed sum of NHS money (or other resources) in a way that puts the individual at the heart of decision-making and gives them choice and control in their life.

They are one of the 'tools' that an individual can use to manage a personal health budget where a direct payment is not possible, (*the Primary Care Trust may not be eligible to offer direct payments*), not desirable (*the individual may not want a direct payment*) or not feasible (*the individual may not be in a position to manage their own budget*). An independent user trust will probably appeal most to individuals with large or complex packages of care or where a shift in power and control is felt to be of paramount importance.

Independent user trusts are also known as user controlled trusts, independent living trusts, user independent trusts. Whilst the use of several labels is confusing, Judge Collins (*Gunter v South Staffordshire PCT*, 2005) suggests that the "name matters not". There is no material legal difference between them. Equally confusing, is the tendency to use acronyms i.e. IUT, UCT, ILT or UIT.

What does the law say about independent user trusts?

There is very little law in this area so advice about trusts and their legality has tended to be vague. Since the demand for independent user trusts is likely to increase with the development of personal health budgets, it is vital that Primary Care Trusts and individuals understand what is possible.

The NHS Act 2006 ("the 2006 Act"), section 12 and other provisions allows Primary Care Trusts to contract with third parties to provide services, including holding personal health budgets (Personal health budgets: first steps, 2009). The most commonly cited example of a health-related independent user trust is the case involving Rachel Gunter, where the judgment ruled that a properly constituted independent user trust was a third party for the purposes of section 12, in the same way as a private sector or voluntary organisation:

Gunter v SW Staffordshire PCT

In 2005, Mr. Justice Collins was asked to judge whether it was legal for Rachel Gunter's parents to set up an independent user trust to administer funds to provide health care for their daughter at home.

He concluded that there was indeed power to do this on the basis of two key rulings:

- An independent user trust is an organisation for the purposes of section 12. If properly established, the trust would be independent both of the NHS and the person receiving care, making it an independent agency equivalent to any other agency set up to provide care.
- A Primary Care Trust can transfer funds to an independent user trust to meet an individual's health needs.

Mr. Justice Collins acknowledged the need for satisfactory governance arrangements "to ensure financial accountability and a proper co-ordination between management and staff". He also highlighted the need for clinical governance, support that meets minimum standards and "a scheme spelt out to govern the way in which the necessary care is to be provided" but he was not specific about the detail. It is the Primary Care Trust's responsibility to work out with the individual (or their representative) what the exact mechanisms should be in any given situation to ensure that they are able to take control of their life with appropriate safeguards in place.

What are the core principles of an independent user trust and trust deed?

An independent user trust consists of trustees who hold money or other assets for the benefit of a third party – the beneficiary. The number of trustees can vary but if a family member wishes to be a trustee there needs to be at least two other trustees. The family member (or the patient, if the patient has capacity) does not control the trust since they are in a minority on the Board. This means they cannot exercise a veto.

A trust is a legal entity that follows clear rules set out in a trust deed. A trust deed should be independently witnessed and must:

- State the purpose of the trust
- Have clear rules that will be followed
- Name the trustees
- Be witnessed independently
- Be registered with the Inland Revenue if the trust employs staff on behalf of the individual
- Include details of what would happen if the trust is no longer required.

An independent user trust is non-profit making and any surplus on winding up must be repaid to the PCT.

The terms of the trust deed determine the tax consequences and so it is important to seek advice on this.

What can an independent user trust do?

In the case of an independent user trust set up to manage a personal health budget, the trustees will be responsible for managing the budget and providing the care/services agreed in the care plan.

An independent user trust can employ staff and make purchases. If the trust employs staff, the trustees become the legal employers. This role brings responsibilities so it is important that trustees have access to up-to-date information and adequate support. Trustees are also responsible for ensuring that an individual's health outcomes are being met and that contingency arrangements are adequate.

The structure and processes within an independent user trust can also act as a financial safeguard; they should be transparent and provide a clear record of decision-making processes and outcomes. This can help Primary Care Trusts meet their legal responsibility to ensure that public money is used properly and for the purpose of meeting someone's health outcomes.

What is involved in being a trustee?

Becoming a trustee should usually be seen as a long-term commitment with clear responsibilities. However, the role is not undertaken by someone on their own. It is recommended that the trust board should include between three and six trustees which can include friends, family members, advocates, peers, and anyone else who understands and supports the purposes of the trust (Holman, 2001[3]).

If necessary, trustees can be co-opted for a short time to deal with specific issues. A wide range of people and perspectives provides the greatest safeguards for an individual. In the case of Gunter, the commissioners requested that one of the trustees be an employee of the public body funding the care package but this is not essential.

Ideally, trustees should know the individual, what is important *to* and what is important *for* them. This means taking account of both the health care professionals' opinions on appropriate health care *and* the person's views on what matters most to them. In the case of a personal health budget the support/care plan should set out clearly what care and support has been agreed.

Trustees should also be familiar with the details of the trust, agree with the constitution and be willing to act on it. Potential trustees must declare conflicts of interest with the decision-making required by the trust deed. If a conflict exists this must be reviewed.

On a practical level, trustees may undertake many of the day-to-day tasks involved in running the trust i.e. preparing accounts, managing the payroll and being a good employer. However, there are voluntary organisations and self-directed support services who can also fulfil these roles, either as advisors or as subcontractors of the trust.

Finally, a willingness to work in close partnership with the individual, health care professionals and other trustees is crucial. Good working relationships are paramount because decisions made by the trust are legally bound to be unanimous. The budget holder should be central to all decision-making so the trustee's role is to "*use their responsibilities in ways that pass power to the individual*" (Holman and Bewley, 2001).

Independent user trusts and trust companies

A trust company is very like an independent user trust, the difference being that a trust company is a company 'limited by guarantee' and the trustees are called directors and certain other formalities are satisfied.

Whatever the preferred 'structure', there are various pro's and con's so it's important to seek good legal advice. An independent user trust is simple to set up, for example, but 'off-the-shelf' companies can also be easily bought. Company directors have limited liability although this advantage can be overstated. Both entities have distinct tax rules.

More information on the different types of trusts is available at
www.hmrc.gov.uk/trusts/types/vulnerable.htm

How to set up an independent user trust

There is work involved in setting up an independent user trust but the individual arrangements will, by necessity, form a part of the overall process of negotiating the personal health budget.

Whilst individuals' arrangements will differ, the overall process will look something like this:

1. The first step is to find a group of people who are willing to be involved. They may, or may not, be people who participate in the care/support planning process.
2. At this stage, it is helpful to gather information, make contact with relevant organisations and read useful material.
3. Deciding how the trust should operate will need careful consideration and will necessitate detailed discussions between all interested parties i.e. the individual concerned (or their representative), the Primary Care Trust, social worker etc. This is the ideal opportunity to discuss financial matters, clinical governance and risk enablement. Whilst it is important to safeguard the individual, it is equally important to empower them and to ensure that arrangements shift power and control as close to the person as possible.
4. Once an agreement has been reached, the trust deed can be drafted (see above). It is wise to seek legal advice at this stage.
5. A contract is required between the trust and the Primary Care Trust.
6. The trust will need to open a bank account with a minimum of two signatories.
7. The trust should take out appropriate insurance.
8. The trust is now ready to receive funds.

Support for the trust

Some trusts will deliver substantial and complex packages of health care so it is important that support is available to trustees to carry out their duties. The *degree* of support required for trustees and employees of the trust will vary depending on the skills they bring. However, the *type* of support required will be very similar to the help offered by direct payment support schemes i.e. help with drafting advertisements, job descriptions and contracts, a payroll service, advice on health and safety issues etc.

For large and specialist care packages, it is possible to employ a private "case manager". A private case manager usually charges by the hour and will assist with the delivery of complex care, specialist training and support and clinical governance. A case manager is useful in situations where the number of hours of support exceeds say, 70 hours per week, the individual has complex health needs and where the trust needs specialist advice on an on-going basis. The trust would normally contract directly with the case manager.

Governance arrangements

The more sizeable the budget, the more thorough the financial governance will need to be. The Primary Care Trust will want a financial return and accounts may need to be audited. It is important to include financial management costs when the budget is being agreed.

The other main governance aspect is the need to put robust systems in place to ensure the care and services provided by the personal health budget meet the individual's needs and are agreed in the plan. Systems need to be in place to review the plan and monitor and minimise the risk to the individual and to learn from mistakes. The term "clinical governance" is often used in this context to describe issues of quality and accountability. The measures in place will vary according to the perceived risks involved in supporting the individual. Trustees should be aware of the issues.

Conclusion

Independent user trusts are a useful method of delivering a personal health budget. The relationship between the two is clear and is evident in the following quotes:

A personal health budget:

> *"A **Personal Health Budget** helps people to get services they need to achieve their health outcomes, by letting them take as much control over how the money is spent on their care as is appropriate for them"*

PERSONAL HEALTH BUDGETS: FIRST STEPS, DH, 2009

Likewise,

> *"Remember, like direct payments, **Independent living Trusts** are just a tool. They are not, at heart, about money. They are about making something happen by enabling people who need support to control money and decisions about it. They embody a vision of possibility: it is possible for this person to live a full life in the way they want, to control their life, to be part of a community. They embody a vision of possibility for society, promoting the values of community and inter-relationship"*

HOLMAN AND BEWLEY, 2001

Endnotes

1 **R (Gunter) v SW Staffordshire PCT (2006) 9 CCLR 121**. This case may be accessed free of charge at the BAILLI website at http:/www.bailli.org/ew/cases/EWHC/Admin/2005/1894.html

2 **There are around 60 pilot sites across England**. These sites need to get specific approval from DH to be able to offer direct payments.

3 **Holman, A. and Bewley, C. (2001)**. Trusting Independence: A practical guide to independent living trusts. Values into Action and Community Living

Mitchell James Ltd

Self-direction in health

Published by Mitchell James Ltd

1 Clarence Park
Beardwood
Blackburn
BB2 7FA

Tel - 07801 056832

Email - jo.fitzgerald21@googlemail.com

Link to this document - www.scribd.com/mjdocs