

## **Parkinson's UK policy statement Control, choice and personalised services in health and social care**

*“Choice doesn't seem to be on the table - there are very limited respite care facilities which makes 'having choice' just a utopian dream.”*

*“If I knew what the alternatives were then I would ask.”*

*“There is great inequality across the country. It depends where people live.”*

People affected by Parkinson's

### **What we believe**

**Parkinson's UK believes that everyone affected by Parkinson's should be empowered to exercise choice and control over their care and support needs. Everyone affected by Parkinson's should:**

- **have choices about health and social care made clear to them in all circumstances.**
- **be equal partners in decisions about their health and social care, supported by a workforce that is competent and educated about Parkinson's.**
- **have access to the right support, with good quality advice and information to enable them to manage their care effectively.**
- **have access to a range of health and social care services which are available locally and nationally, in order to exercise real choice.**

### **Why we believe this**

Health and social care services are being reformed across the UK, putting people in more control of the care and treatment they receive. The aim is to help people identify their needs and to make choices about the support and treatment available to them. For the purposes of this statement, we use **self-directed support** as a general term for the agenda.<sup>1</sup>

In social care, choice might involve selecting a traditional package of care from a provider of social care services. Or it might be the use of direct payments or personal budgets (see Appendix 1) to employ someone to provide support, or pay for creative ways to keep healthy and independent, such as gym membership. Carers can also use direct payments in similar ways, for example, to pay for breaks from caring.

In England more choice in healthcare might mean selecting which hospital to go to or which GP practice to be registered with. Personal health budgets (see Appendix 1) are also being

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<sup>1</sup> In social care in England the concept is often referred to as **personalisation**, in Wales reference is made to **citizen-centred services** and Scotland the framework to deliver more person centred care is termed as **self-directed support**. In Northern Ireland reference is to **independence and choice** which is delivered through joint Health and Social Care Trusts. Appendix 1 contains further common terms.

piloted in England and will be rolled out in future years. In other parts of the UK there is an emphasis on a person centred approach to health.

The experience of self-directed support has been very positive for some people affected by Parkinson's. Being able to choose how and when care and support is provided can help people manage life with a long-term fluctuating condition. However, the idea of more choice and control in social care and health is yet to become a reality for many people.<sup>2</sup>

We believe the following actions need to be taken if self-directed support is to benefit people affected by Parkinson's:

### **Improve data collection**

At present it is difficult to identify how many people with Parkinson's use personal budgets and direct payments, or how much they receive, as data isn't collected by condition.<sup>3</sup> Governments should collect this information to help identify where improvements could be made to the system.

### **Reform delivery and funding of long-term care**

Some people affected by Parkinson's are going without the care they need because of pressures on social care budgets and services are being cut. For example, direct payments can be set so low that people say they have to "top up" with their own money to buy the support they require. It is important that self-directed support is not used as another way to make cuts, at the expense of a person's needs. All governments need to address these underlying funding issues in long-term care.<sup>4</sup>

### **Improve the information and advice on offer**

It is hard to make choices if information and advice is variable or non-existent. For example, people who arrange and pay for their own social care can find it hard to get advice, because the state isn't involved in their care. In health, it can be difficult comparing which hospital or GP to choose. Good quality information is vital and must properly funded: national advice supported by local information and support for people to articulate their needs (advocacy), is key.

### **Ensure genuine choice across health and social care**

Across the UK there are still restrictions on choice. For example direct payments are not available in residential care or NHS continuing care. Giving people genuine choice also means enabling them to have their care organised for them, if they want. Many people feel under pressure to make choices or use direct payments at a stressful time of their lives, and do not want the extra responsibility. This is where proper support to make decisions is helpful.

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<sup>2</sup> For more information on the UK and international evidence and research, see *SCIE research briefing 20: The implementation of individual budget schemes in adult social care* (2007, updated 2009)

<sup>3</sup> The results of the personal health budget pilots in England may provide some information when published in 2012. See [www.personalhealthbudgets.dh.gov.uk](http://www.personalhealthbudgets.dh.gov.uk) for more information.

<sup>4</sup> Our policy statement *Funding and delivery of long-term care* has recommendations for change which includes releasing more money into the system, through both increased investment but also through preventative measures that help people before they reach crisis point, and better integration of health and social care services.

### Develop the services on offer

There also needs to be a choice of services available. For example working age people with Parkinson's can find care and support services are more focussed on older people. People who live in rural areas can find there are fewer options open to them, or cannot travel to their service of first choice. Decisions to cut services can reduce choice further. Those who decide what services are available (commissioners) should work with people affected by Parkinson's to ensure their needs are met.

### Build safeguards into the system

People employed by care services are obliged by law to have more background checks than those employed by individuals using direct payments or personal budgets. There should be conduct and training requirements for directly employed staff, to safeguard against abuse and ensure care standards are met.<sup>5</sup> Safeguards are also needed so that people aren't left "on their own" if things go wrong with their choices, and to ensure everyone gets the opportunity to make choices.

### Workforce education and training

It requires skill to help people express their needs, so workforce training is important. This is particularly important if people have complex needs, where staff may prejudge someone's ability to make choices. Training for all health and social care staff is essential to understand the complex and fluctuating nature of Parkinson's.

## What's the evidence?

An internal project conducted by Parkinson's UK during 2010 aimed to identify the experiences of people affected by Parkinson's in relation to self-directed support.<sup>6</sup> People affected by Parkinson's reported:

- a lack of information about what services exist, and their quality and safety.
- a lack of awareness about what self-directed support is, and what makes a person eligible, despite the obligations on social care services to promote and offer direct payments to people.
- variability in the support available to help people make informed choices or engage with the agenda (such as brokerage, advocacy and support as an employer).
- concerns about the potential bureaucracy and responsibility involved in direct payments and personal budgets.
- assessments for help that didn't recognise the full and fluctuating nature of Parkinson's, or led to very little support.
- a lack of services to choose from, including respite services for carers.

The findings complement those which have emerged from more general studies across the UK. For example, an evaluation of individual budget pilots in England<sup>7</sup> found older people felt

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<sup>5</sup> For example, there is evidence that options for background checks are not being used by some people in receipt of direct payments in England. Source: Skills for Care. *The Employment Aspects and Workforce Implications of direct payments* (2008).

<sup>6</sup> Parkinsons UK (unpublished) *Choice, control and personalised services – final report* (2010).

<sup>7</sup> Glendinning, C et al. (2008). *Evaluation of the Individual Budgets Pilot Programme: Final Report*. Social Policy Research Unit, University of York, York

less positive about them compared to other client groups. As the majority of those affected by Parkinson's are over 65 years this is an issue that needs further exploration and consideration. Research on carers found their positive experiences of using direct payments can be undermined by the burden of administering them.<sup>8</sup>

The findings also complement feedback from the 2008 Parkinson's UK Members' survey,<sup>9</sup> and a parliamentary inquiry,<sup>10</sup> both of which found clear issues with a lack of information or professional advice, as well as problems accessing services, treatment, therapies and equipment that are vital for meeting people's needs.

## **What Parkinson's UK is doing**

We campaign for improvements to the way social care is funded and fair access to care services. We are working to ensure that people are aware of their rights to health and social care through our information resources, advisory services, country and regional teams. We also train health and social care professionals working with people with Parkinson's so they are better educated about the condition.

As a charity we are reviewing what we can do to help people with Parkinson's exercise more choice and control over health and social care support and navigate the system. We want to hear what people's experiences are. Please contact the Social Policy and Campaigns team (see below).

## **Acknowledgement**

We are grateful for the advice and guidance of our Policy Panel in shaping this position paper on control, choice and personalised services. The Policy Panel consists of people with experience of Parkinson's who meet on a regular basis to help guide the charity's position on a range of policy issues.

## **Further information**

Please contact the Social Policy and Campaigns team. Tel: 020 7963 9307 or email: [campaigns@parkinsons.org.uk](mailto:campaigns@parkinsons.org.uk)

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<sup>8</sup> Carers UK. *Choice or chore. Carers' experiences of direct payments* (2008)

<sup>9</sup> Parkinson's UK. *Life with Parkinson's today – room for improvement.* (2008)

<sup>10</sup> All Party Parliamentary Group for Parkinson's Disease. *Please mind the gap – Parkinson's disease services today* (2009).

## Appendix 1: Terminology and legislation

**Direct payments** are cash payments given to service users in lieu of community care services they have been assessed as needing. They should give users greater choice in their care. The payment must be sufficient to enable the service user to purchase services to meet their needs, and must be spent on services that users need. Like commissioned care, they are means-tested and some people will therefore contribute to the cost of their care.

Local authorities in England began to offer Direct Payments in 1996 following the Community Care (Direct Payments) Act. In 2002 they were introduced into Northern Ireland by the Carers and Direct Payments Act (Northern Ireland) 2002 and are offered by Health and Social Care Trusts. Similarly section 7 of the Community Care and Health (Scotland) Act 2002 introduced a range of provisions relating to direct payments in Scotland. In 2004 legislation was introduced in Wales and this has recently been updated with the Community Care, Services for Carers and Children's Services (Direct Payments) (Wales) Regulations 2011

Legislation since has developed in each country, so that social services have a duty to offer direct payments widely to individuals (although there remain some exceptions to this rule).<sup>11</sup>

**Personal budgets** are an allocation of community care funding given to users after an assessment which should be sufficient to meet their assessed needs. Users can either take their personal budget as a direct payment or (while still choosing how their care needs are met and by whom) leave councils with the responsibility to commission the services. Or they can have a combination of the two. **Individual budgets** differ from personal budgets in covering a multitude of funding streams, besides adult social care: Supporting People, Disabled Facilities Grant, Independent Living Funds, Access to Work and community equipment services.

There is no legislative framework for personal or individual budgets. However, policy has been to encourage their development in England and Scotland and pilot them in Wales. In England, the ambition<sup>12</sup> is to provide personal budgets for everyone eligible for ongoing social care, preferably as a direct payment, by April 2013. In Scotland, a national strategy for self-directed support, to be complemented with new legislation, aims, amongst many objectives, for a radical increase in direct payments and individual budgets.<sup>13</sup> In Wales the aim is to develop a model of self-directed support.<sup>14</sup> Different approaches to self-directed support, including individual budgets, are being piloted in a number of local authorities in Wales.

**Personal health budgets** are being piloted in England. The term is used to describe a budget that is spent on meeting the health care and wellbeing needs of people, generally those with a long term illness or disability. The budget makes it clear how much money is available for the person's NHS care (excluding emergency and GP care). The pilots are reporting in 2012.<sup>15</sup>

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<sup>11</sup> For more information, see the Disability Alliance Factsheet 5 Community Care Direct Payments. [www.disabilityalliance.org/f5.htm](http://www.disabilityalliance.org/f5.htm)

<sup>12</sup> Department for Health, a Vision for Adult Social Care (2010).

<sup>13</sup> Scottish Government, Self-directed support: a National Strategy for Scotland (2010)

<sup>14</sup> Sustainable Social Services for Wales – A Framework for Action (2011)

<sup>15</sup> For more information, see Department of Health's personal health budgets learning network [www.personalhealthbudgets.dh.gov.uk/](http://www.personalhealthbudgets.dh.gov.uk/)