



The Direct Approach

Disabled people's experience of direct payments

Summary of findings
and key recommendations

SCOPE

Introduction

Direct payments do exactly what they say. Instead of receiving support services directly from their local authority, disabled people can opt to receive the equivalent amount in cash. With cash in lieu of services, disabled people can buy in and tailor their own support package to suit their needs.

Local authorities have been able to offer direct payments to people aged between 18 and 65 since 1997. In 2000 the Carers' and Disabled Children's Act made direct payments available to 16 and 17 year olds, carers and people with parental responsibility for disabled children. And finally, in April 2003 it was made compulsory for local authorities to offer direct payments to all individuals who are entitled to social services and meet the eligibility criteria for direct payments.

Research since the inception of the Act has highlighted the huge difference direct payments have made in enhancing independent living in terms of giving choice and control to disabled people and facilitating social inclusion. Yet disabled people also express concerns that some local policies and practices remain as barriers to the opportunities offered by direct payments.

Aim of the research

The aim of the research was to:

- identify the strengths, weaknesses and barriers to accessing direct payments from the perspective of three groups: disabled adults, 16 and 17 year olds and those with parental responsibility for disabled children in England.
- identify, from the perspectives of the above three groups, the factors which create the maximum choice and control when accessing direct payments.
- provide learning opportunities for national and local government, support schemes, health and education agencies.

Research methodology

The data for the research was collected via 38 in-depth, semi-structured face-to-face interviews. The respondents were from 33 local authorities across England. Of the 38 respondents, seven were trying to access direct payments and the remainder were receiving direct payments. Of the latter, 15 were adults, five were young people and 11 were children. Of the seven respondents trying to access direct payments, three were adults, one was a young person and three were children.

The report

The report is divided into four parts. The first three parts focus only on the data gained from those respondents who are currently receiving direct payments. Part four focuses on the seven respondents who are trying to access direct payments. The key recommendations can be found at the end of this summary. More detailed recommendations can be found in the full report.

Part One – Getting direct payments

This section explores how the 31 direct payment recipients found out about the scheme, why they applied and the level of assistance they received.

Finding out about direct payments

- For those who found out about direct payments from their social services department access was much smoother than for those who heard via other routes.
- Voluntary organisations were raising awareness amongst harder to reach groups such as people from minority ethnic communities, people with communication impairments, high levels of need and people with learning difficulties.
- The internet is a popular method for finding out about direct payments.

Reasons for applying for direct payments

- Choice, control and flexibility are the key reasons people applied for direct payments.
- Independence is a key reason for applying especially for disabled adults and young people.
- Parents of disabled children cite respite as a reason for applying.
- Some respondents felt forced to apply for direct payments as the quality or quantity of services they needed were not available locally.

Uses of direct payments

- All respondents used direct payments to recruit personal assistants.

- Personal assistants were used in a wide variety of ways including social and leisure activities.
- Some respondents wanted to use direct payments for equipment and housing adaptations, but social services departments had no policy on this.
- Respondents also highlighted that some local authorities imposed limits on what direct payments could purchase, with some restricting it to personal assistance only.
- Only one respondent was using direct payments for health purposes.
- Direct payments can facilitate social inclusion, but barriers to implementation still exist within some social services departments.
- There are examples of positive and negative experiences of support from social services departments in each group.
- All groups appear generally satisfied with local support schemes.
- The community care assessment was felt to be the crucial stage in the process of applying for direct payments as it determines the scope of the care package. Some respondents stated that the assessment was the most stressful time.
- When social workers are proactive and supportive, the experience has been very positive.
- The experience of respondents suggests an over-emphasis on the knowledge and commitment of individual social service staff and not enough emphasis on putting structures in place to ensure individuals are able to access direct payments.

Information and support

- Respondents from all groups, especially parents of disabled children, had difficulty getting information from social services departments.

Part Two – Managing direct payments

As employers, most direct payment recipients have to deal with a range of responsibilities such as taxation, national insurance payments and holidays. For many respondents these challenges were significant. This section of the report looks at these experiences and how social service departments monitor direct payments.

The financial side of direct payments

- The majority of adults and young people managed their own payroll albeit that some found this to be a challenge.
- Respondents from all three groups experienced delays in the receipt of payments.
- Internal procedures within social services departments sometimes hindered the efficient management of direct payments.
- Ineffective liaison between health and social service departments caused problems for some adult and young respondents.
- The opening and managing of dedicated bank accounts presented problems.
- There is no recognition or compensation for users who self-manage the system, rather than using agents.
- The notional hourly pay rates for personal assistants used to determine levels of direct payment varied greatly.

Employing and managing personal assistants

- Both young people and adults highlighted the fine line between a personal assistant being an employee and a friend.
- In addition these two groups mentioned the need for training in employment law, producing contracts and job descriptions and the disciplinary process.
- Many people were not fully aware of their employer status and the regulatory responsibilities associated with the role.
- In all respondent groups some individuals were recruited that had already been checked by the police but the majority had not been subject to Criminal Record Bureau scrutiny. Personal assistants recruited directly by direct payments recipients currently fall outside this system.
- There seemed to be suitable support schemes available to help people recruit personal assistants and to share the burden of managing and administering the provision.
- Some social service departments were found to be more relaxed than others in allowing the employment of family members and friends.
- The ability to call on agency staff as well as being able to recruit directly gave added reassurance especially in times of crisis.
- Respondents experienced difficulties in recruiting and retaining staff reporting low pay as a contributory factor.
- There was little evidence of structured training for people applying for direct payments or on how to access suitable training for personal assistants.

Support around managing direct payments

- Generally respondents perceived there to be a lack of suitable support to underpin the system of direct payments.
- The most consistent and valued support appeared to come from support schemes which were contracted out by social services and provided by local voluntary organisations.
- The support schemes were perceived to be user-friendly, accessible and non-statutory.
- Ideas for improving the range and nature of support included peer-support groups, accredited pools of carers and emergency back-up services.
- The commitment, knowledge and availability of the social worker seems to be important to the perceived level of support.
- Some groups reported significantly lower level of support. Adults, particularly disabled parents and people from minority ethnic communities, appeared to have least support.
- The support being offered by social services does not appear to be robust, widely known about or highly valued.

Monitoring the use of direct payments

- There appears to be little formal monitoring of the quality of the service other than that which is incidental to normal social worker contact.
- Significantly, the more in-depth systems of monitoring, including quality evaluation, were reported by people who had most contact with their social worker.
- The monitoring of direct payments by social services departments appears to be rudimentary with an emphasis on income/expenditure and financial procedures.

Part Three – The impact of direct payments

This section of the report looks at the impact of direct payments on the 31 respondents accessing direct payments.

Meeting need

- For a significant number of respondents direct payments were meeting their needs.
- While direct payments were welcomed almost universally as a better way of meeting need, their ability to meet need fully was, inevitably, determined in large measure by the adequacy, or otherwise, of the user's care assessment.
- For some respondents being able to accumulate hours was key to achieving a more flexible care package, although others suggested the need to save hours up reflected the fact that the original assessment of care was inadequate.
- For young people and children not being able to use siblings as personal assistants appears to be an issue.
- Some direct payment users are clearly enabled to live a better social life as a result of the flexibility that direct payments can bring. Where the direct payment user is able to enjoy a better social life, whatever the user's age, this can in turn provide much needed respite for family carers.
- In some instances the independence of the family unit was felt to be undermined because the impact of disability on the whole family unit had not been adequately taken into account at the care assessment stage.

- Ironically, in some cases direct payments were helping to improve the quality of family life when the original care assessment itself was not considered to have taken proper account of the needs of the family as a whole.
- Some respondents were concerned that the lack of responsive back-up and the unavailability of appropriate support could potentially erode the choice and control that direct payments bring.

Impact of direct payments

- While difficulties with recruitment exist, most of the respondents appeared to be able to secure greater continuity of care with direct payments than they might have expected previously through local authority-arranged provision.
- Direct payments had evidently introduced a level of flexibility for many respondents that had not been enjoyed previously. Even small packages were considered to have introduced enough flexibility to create more of a social life for both user and carer.
- Some parents noted how they were more able to cope with running a family and caring for a disabled child.
- A number of people had found that respite was now something that could be opted for at a time to suit the person and his/her circumstances.

Part Four – Those not accessing direct payments

These seven respondents (three adults, one young person and three parents of disabled children) at the time of the research had not been successful in accessing direct payments.

Finding out about direct payments

- None of the seven respondents heard about direct payments via their local social service department.
- The voluntary sector was a key provider of information.
- The internet was a useful source of direct payments information.

Reasons for wanting direct payments

- It is clear that this group of people want to access direct payments to secure greater control, choice and flexibility.

- It is also evident from their responses that this is because they are not getting their needs met via direct services.

Reasons for not being able to get direct payments

- Individuals saw the social services departments, either in the guise of the social worker, or senior managers who had not set up the necessary systems, as the primary reason why they could not access direct payments.
- The common theme linking respondents was their higher levels of personal care needs.

Report Conclusions

The research identified three main areas:

1. Direct payments as a system for delivering social care services

It is clear from this research that direct payments work. The majority of respondents who are receiving direct payments say the scheme has had a positive impact on their lives and those of their families. However, the road to successfully applying for and receiving direct payments can be difficult and long.

It would appear that to be successful in the direct payments process, the willing participation of the social services department, and in particular the co-operation of the individual's social worker, is

crucial. For many respondents, although not all, getting information, recruiting and managing personal assistants (in short being an employer) and getting the appropriate support was problematic. That is not to say that there is not good practice around the delivery of direct payments. This research demonstrates that there is good practice but that it needs to be available to all applicants regardless of where they live.

For a system that delivers social care the use of direct payments is very narrow. Direct payments are being used almost exclusively to employ personal assistants and very little else. This would mainly seem to be because for those applying for direct payments the availability of

suitable, reliable and high-quality personal carers is their first and foremost need.

However, there is also reluctance on behalf of social service departments to encourage a wider and more imaginative use of direct payments such as to purchase equipment or to develop joint health and social care packages.

NB Scope understands that some of these issues will be addressed in the Department of Health's forthcoming policy and practice guidance on direct payments which is due to be published later this year. This guidance will also illustrate the ways in which direct payments can be used.

2. The push-pull factors affecting the decision to apply for direct payments

The evidence from this research suggests that 'push' rather than 'pull' factors, can often determine decisions about accessing direct payments. Thus respondents were not being pulled towards direct payments because of their intrinsic value, but rather being pushed towards direct payments because they were dissatisfied with the direct service provision they were receiving.

There are two key points which need to be made here. First, for the disabled people in this research project the primary driving force for accessing direct payments was the need to have control over their lives, to have the choice of people who provide care, and the flexibility to organise their lives to reflect their holistic needs. It would seem legitimate to ask why choice,

control and flexibility are not the determining characteristics for all social care services?

The second point relates to the consequences of social service departments running both direct services and direct payment schemes. Will there be a point at which a direct payment scheme impacts negatively on direct services to the detriment of service users? For example, if a day centre loses clients because they prefer to use their direct payments to obtain that service in another way will the service continue to be viable? If not, what happens to the service users of the day centre? In short, direct payments are likely to change the nature of service provision in social care. In which case there must be concerns around the planning of services for all and how resources can follow individual choice.

3. Social and health care needs of disabled people

Finally, it is clear from this research that eligibility for and accessibility of services varies widely. Services are uneven in their availability and quality, being driven by where you live and what is available. More research is needed to establish the extent to which the social and health care needs of disabled people are being met. Direct payments are certainly one way of meeting disabled people's needs, but disabled people need to be assured that services, in whichever form they are delivered, are based on their holistic needs, and those of their carers and families.

Key recommendations

(specific recommendations can be found within the full report)

National Government

- Monitor and review the take-up of direct payments by client group, reviewing the qualitative aspects as well as the levels of uptake.
- Ensure disabled people are eligible for and have access to services which meet their needs regardless of where they live.
- Extend the capacity and responsibilities of the Criminal Records Bureau to cover direct payment employment issues.
- Ensure social service department financial structures are not acting as a barrier to more person-centred arrangements.

Local government – social service departments

- Produce a local authority strategy on direct payments to ensure that all eligible groups are able to access direct payments.
- Make sure all tiers of staff within social service departments and those in overlapping professions, such as health, are fully trained in all aspects of direct payments, and know they have a legal responsibility to offer direct payments to all those who are eligible.
- Produce guidance for disabled people on how they can apply for direct payments and

develop structures within the social service department to ensure everyone who is eligible can access direct payments.

- Scrutinise the reasons why people apply for direct payments and feed these reasons into the planning and commissioning of services.
- Ensure that adequate support schemes are in place to meet the needs of all direct payments applicants and recipients.

Social work practice

- Introduce direct payments as a component of the new social work degree.

Support schemes

- Produce clear guidance on the legal responsibilities of direct payments recipients.
- Produce calculations of the additional costs involved in being an employer to provide individuals with informed choice.
- Produce direct payment starter packs appropriate for all potential direct payment recipients.
- Establish a local strategy, possibly in conjunction with social services, on how to promote direct payments to hard to reach groups.

This summary is available in other formats upon request and can be found on our website: www.scope.org.uk

The full report, *The Direct Approach – disabled people's experience of direct payments*, (ISBN 0 946828 77 6, price £13.00 to organisations and £3.00 to individuals) is available from Scope's Library and Information Unit, 6 Market Road, London, N7 9PW
Telephone 020 7619 7342
email: information@scope.org.uk

Scope is a national disability organisation whose focus is people with cerebral palsy. Scope's aim is that disabled people achieve equality: a society in which they are as valued, and have the same human and civil rights as everyone else.

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