Individual budgets and direct payments:
issues, challenges and future implications
for the strategic management of SEN

Policy Paper 3
6th Series
February 2008
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(completed April 2008)
Chapter 1:

Introduction to Policy Paper

Background to the policy paper

This paper is based on the seminar, held at Regents College, Regents Park in January 2008, which focussed on the current issue about Individual Budgets and Direct Payments for children, young people and families. This seminar addressed some of the current issues concerned with individual budgets. The aims of the seminar were:

1. to explore ways in which individual budgets for families of children with disabilities/SEN have and can be used
2. to consider what implications this system of funding has for strategic planning of services
3. to what extent individual budgets are relevant to education services for children with disabilities

The seminar involved brief presentations based on 3 papers that are included in this policy paper, from Christine Leneham Director, Council of Disabled Children, on Individual Budgets and Direct Payments for children, young people and families; Elaine Hack Educational Psychology Service, Nottinghamshire and Glenys Jones, University of Birmingham on Parent / Carer Involvement in the Commissioning of Services for Children and Young People with Autism Spectrum Disorder in the East Midlands and Sheila Riddell, University of Edinburgh on Direct Payments and Disabled Children and Young People: The Service of the Future? Most of the afternoon involved small group and large group discussions, from which some of the conclusions are recorded in the last chapter of this paper.

SEN Policy Options Steering Group

This policy paper was the third in the 6th series of seminars and conferences to be organised by the SEN Policy Options Steering Group. This group organised the initial ESRC - Cadbury Trust series on policy options for special educational needs in the early 1990s. The success of the first series led to the second series which was supported financially by NASEN. (See the list of these 22 policy papers at the end of this section). The Steering Group has representatives from LEA administrators, head teachers, voluntary organisations, professional associations, universities and research. The further success of the second and third series of policy seminars and papers led to a fourth and fifth round of seminars which has also been organised with further funding from NASEN. These events are intended to consider current and future policy issues in the field in a pro-active way. They are planned to interest all those concerned with policy matters in special educational needs.

Aims for the next 6th series over a 2 year period from 2006-2008:

1. To continue to provide a forum where education policy relevant to the interests of children and young people with SEN/disabilities can be appraised critically and pro-actively in the context of the development of children’s services.
2. To inform and influence policy formulation and implementation, to encourage and support an active and ongoing dialogue on SEN policy and practice between key stakeholders such as NASEN and other professional associations, schools, local authorities, parents and other agencies.
3. To examine and evaluate policy options in terms of current and possible developments and research in order to inform and influence policy formulation and implementation in the field.
4. To organise events where policy-makers, professionals, parents, voluntary associations and academics/researchers analyse and debate significant issues in the field drawing on policy and practice in the countries of the UK, and:
5. To arrange the dissemination of the proceedings and outcomes through publication and summary briefing papers.

**Steering group membership**

The current membership of the SEN Policy Options Steering Group are:

Professor Julie Dockrell, Institute of Education; Professor Alan Dyson, School of Education, University of Manchester; Peter Gray, SEN Policy Consultant; Dr Seamus Hegarty, Claire Lazarus, DfES; Professor Geoff Lindsay, Warwick University; Professor Ingrid Lunt, University of Oxford; Professor Brahm Norwich, School of Education, Exeter University; Linda Redford, Policy consultant; Penny Richardson, Educational Consultant; Philippa Russell, Disability Rights Commission and Adviser DfES; Tom Kelly, Rotherham LA; Philippa Stobbs Council for Disabled Children / DCSF; Susan Twemlow, Notts. CC; Janet Thompson, Ofsted; Professor Klaus Wedell, Institute of Education, London University; Tom Williams EPS, East Ayrshire.

**Current series**

The current series aims to organise four full or half-day events on special education policy and provision over the two years 2006-2008 which are relevant to the context of considerable changes in the education system.

If you have any ideas about possible topics or would like to know more about the events, please do contact a member of the Group or Brahm Norwich, Co-ordinator of Steering Group, at the School of Education, University of Exeter, Heavitree Road, Exeter EX1 2LU (01392 264805; email: b.norwich@exeter.ac.uk)

**i. Policy Options Papers from first seminar series**

1. **Bucking the market**: Peter Housden, Chief Education Officer, Nottinghamshire LEA
2. **Towards effective schools for all**: Mel Ainscow, Cambridge University Institute of Education
3. **Teacher education for special educational needs**: Professor Peter Mittler, Manchester University
5. **Special schools and their alternatives**: Max Hunt, Director of Education, Stockport LEA
6. **Meeting SEN: options for partnership between health, education and social services**: Tony Dessent, Senior Assistant Director, Nottinghamshire LEA
7. **SEN in the 1990s: users' perspectives**: Micheline Mason, Robina Mallet, Colin Low and Philippa Russell

ii. **Policy Options Papers from second seminar series**

8. **Independence and dependence? Responsibilities for SEN in the Unitary and County Authorities**: Roy Atkinson, Michael Peters, Derek Jones, Simon Gardner and Phillipa Russell

9. **Inclusion or exclusion: Educational Policy and Practice for Children and Young People with Emotional and Behavioural Difficulties**: John Bangs, Peter Gray and Greg Richardson

9. **Baseline Assessment and SEN**: Geoff Lindsay, Max Hunt, Sheila Wolfendale, Peter Tymms

10. **Future policy for SEN: Response to the Green Paper**: Brahm Norwich, Ann Lewis, John Moore, Harry Daniels

iii. **Policy Options Papers from third seminar series**

11. **Rethinking support for more inclusive education**: Peter Gray, Clive Danks, Rik Boxer, Barbara Burke, Geoff Frank, Ruth Newbury and Joan Baxter

12. **Developments in additional resource allocation to promote greater inclusion**: John Moore, Cor Meijer, Klaus Wedell, Paul Croll and Diane Moses

13. **Early years and SEN**: Professor Sheila Wolfendale and Philippa Russell

14. **Specialist Teaching for SEN and inclusion**: Annie Grant, Ann Lewis and Brahm Norwich

iv. **Policy Options Papers from fourth seminar series**

15. **The equity dilemma: allocating resources for special educational needs**: Richard Humphries, Sonia Sharpe, David Ruebain, Philippa Russell and Mike Ellis

16. **Standards and effectiveness in special educational needs: questioning conceptual orthodoxy**: Richard Byers, Seamus Hegarty and Carol Fitz Gibbon

17. **Disability, disadvantage, inclusion and social inclusion**: Professor Alan Dyson and Sandra Morrison

18. **Rethinking the 14-19 curriculum: SEN perspectives and implications**: Dr Lesley Dee, Christopher Robertson, Professor Geoff Lindsay, Ann Gross, and Keith Bovair.

v. **Policy Options Papers from fifth seminar series**

19. **Examining key issues underlying the Audit Commission Reports on SEN**: Chris Beek, Penny Richardson and Peter Gray
20. Future schooling that includes children with SEN / disability: Klaus Wedell, Ingrid Lunt and Brahm Norwich

vi. Policy Options Papers from sixth seminar series

21. Taking Stock: Integrated Children’s Services, Improvement and Inclusion: Margaret Doran, Tony Dessent and Professor Chris Husbands

22. Special schools in the new era: how do we go beyond generalities? Chris Wells, Philippa Russell, Peter Gray and Brahm Norwich

Copies of most of these papers can now be downloaded from the NASEN website, look for SEN Policy Options public pages for downloading these past copies.
Chapter 2

Individual Budgets and Direct Payments for children, young people and families

Christine Lenehan

Director of Council for Disabled Children (CDC)

Scoping study
This paper describes the Scoping Study undertaken by the CDC for the Department of Children, Schools and Families (DCSF) (2007). The aim of the study was to understand the current thinking and issues in providing individual budgets (IB) in children’s services; to look at barriers and opportunities and to do this by working with the Children’s Society and Contact a Family.

The study involved 40 disabled young people, aged 15-25, in 7 localities. These young people were asked 3 questions:

• What support would young people like more control over?
• What support would they need to manage an Individual Budget?
• What would they gain from having an Individual Budget?

The findings can be summarized in terms of these questions:

1. What might young people want more control over?
They would like personal care provided to them through the day and night and assistance with housekeeping and maintaining a household. They want to attend and study at school or college and have more control over getting around and accessing different places. They wanted control over social activities that they were involved in and equipment that they have access to or use.

2. What support might they need?
They expressed the need to identify different sources of support, where to recruit from or which services could be used. They wanted support over recruitment and the administrative responsibilities that go with employing someone, e.g. how to get the right staff, people who are trained, how to organise contracts, levels of pay, sick pay, holiday pay, tax and national insurance. They wanted support with banking, budgeting and demonstrating how money had been spent, with understanding entitlements, legislation and regulations and how to audit and regulate the quality of care or service that is provided.

3. What opportunities did young people feel that individual budgets might offer them?
With IBs they felt that they would be able to make more decisions about their lives: to be able to choose what to do, how do it, who could help and to live where they want. They felt that they could be more independent, not be overprotected and gain confidence. Being able to do the things that they enjoy, experience new things and meet more people were also considered important. They wanted to be more in control of the support that they used. When control involved money, then they would deal with the agency or employee. Linked to this was the wish to be confident about the support that they had: so that they would be able to have people they trusted and be able to avoid delays in getting what they wanted or needed. All this involved having a choice about being involved in managing their support and finances, as much as they wanted to.
As regards parents' views the study examined the views of 5 groups across the country, with 10-15 parents per group. Efforts were made to reach out to Black, Minority Ethnic (BME) parents and to cover rural issues. Parental views were approached in terms of these questions:

- What support would families like more control over?
- What support would they need to manage an Individual Budget?
- What would they gain from having an Individual Budget?

1. **What might families want more control over?**
   Parents identified the following needs: short breaks, therapy, education, transport, leisure and transition.

2. **What support would families need?**
   Parents saw that individual budgets can be used (with appropriate costing) for: an independent advisor (not someone with a dual remit of saving money), mentoring from another family, freephone helpline and case studies showing how IBs have been used by others.

3. **What might IBs offer families?**
   Parents felt that IBs could increase control, result in services meeting the needs of their child, offer more flexibility and better quality of life for the family and lead to more consistency of services (e.g. continuing over the school holidays).

However, parents identified potential negative impacts for IBs. There was an expressed concern that IBs may not be flexible enough to cope with emergencies and sudden changes in the levels of care needed by a child. Parents also did not want to get stuck with IBs if they decide they are not happy with them.

**CDC's role in the study**

The role of the CDC was fourfold:
- To look at implications for local authority services,
- To ensure all relevant evidence is collated,
- To explore possible models,
- To compile overview report.

To carry out these aims there needed to be a wide collation of evidence about the Direct Payment initiatives, In Control and Dynamite, (both specific initiatives led by Paradigm working with the Valuing People team), Department of Health transition pilots and the work of budget holding Lead Professionals. The aim was also to look at the implications for local authority services in several ways:

- bringing together a group of local authority managers,
- by developing a control/flexibility continuum and understanding what lessons can be learnt from Direct Payments,
- by looking at what is needed for further DP development.

The key questions to examine providers' perspectives were as follows:

- What would it take to develop Individual Budgets locally and what would they look like?
- How would/could Individual Budgets affect current commissioning and delivery arrangements?
- What are the issues that need to be addressed in terms of equity and complexity?
iv. Does it require an effective Direct Payments service in place to deliver Individual Budgets?

v. What are the lessons we can learn from DP and what makes Individual Budgets different?

Some emerging issues included the following: there was clear evidence of some progress and development of ideas for young people aged 16+, while for children under 16 the issues were still debated at a philosophical level. Further work was needed to identify income streams and there were ongoing issues about equity and sustainability. For younger children and their families, local authorities were keen to give it a go, possibly tied to the development of Early Support Programme; but it was difficult to identify income streams without there being a legal challenge and there were possible issues around 24 hour consistency or continuing care. Legal challenges could be likely because both health and education services have specific income streams which have not, as yet, been made available for individual budget usage.

The study also found evidence of what is working in transition. Coventry were involved as part of the DH Individual Budget Pilot Programme, with a specific focus on transition to adulthood services. Key success factors included ensuring assessments were outcome focussed with the use of trusted assessors, a positive attitude to risk management and a person centred planning approach. The In Control and Dynamite pilots identified key elements as being, an agreed self assessment process, brokerage support, and resource allocation system which was based on identifying needs against an agreed legal framework.

Concluding comments
Following this scoping study, the next steps as part of Aiming High for Disabled Children, the DCSF are issuing a tender to further explore some key questions:

i. How many would need to access individual budgets and/or direct payments?

ii. What is the financial level of these individual budgets and the different income streams that would need to come together?

iii. What added value do individual budgets bring to current practice?

iv. How can we identify the levels of support young people and their families need in order to use an individual budget?

Individual budgets offer an exciting development in children’s services with real opportunities for families and young people to have control over their lives. They are part of a recognised policy shift towards self directed support. However, they are not a panacea and further work is needed to ensure that they deliver on an equitable basis. We have to be absolutely sure we are not just advantaging the advantaged but are delivering fairness for all.
Chapter 3:

Parent and Carer Involvement in the Commissioning of Services for Children and Young People with Autism Spectrum Disorder in the East Midlands

Glenys Jones, University of Birmingham and Elaine Hack Educational Psychology Service, Nottinghamshire

Introduction
This paper summarises the aims, methods and findings of a study commissioned by the East Midlands Regional Partnership. The aims of the study were:

1. To ascertain the extent to which parents are involved in commissioning services,
2. To identify the issues involved for authorities in enabling parents to commission services,
3. To make recommendations on how parents and authorities can be supported in increasing parental involvement in commissioning

The study involved the following methods to collect data:

1. 5 families from each of the 9 Local Authorities (LAs) identified by the LA Parent Partnership Services were interviewed / completed a questionnaire;
2. LA professionals involved in commissioning were also interviewed / completed a questionnaire,
3. There was an analysis of websites and documents produced by the 9 LAs on commissioning and Direct Payments (DP),
4. Literature review of research in this area; in UK and internationally.

There were 43 parents who participated in the study, 6 families had more than one child and the sample overall involved 37 boys and 6 girls. Parents were asked questions that covered these areas: their levels of satisfaction with services, what had most helped their child, what had most helped them as parents, educational history and involvement, breaks away for the child, holiday activities and their views about DP and commissioning.

Main findings
For the 43 parents in the sample it was found that the majority had not heard about DP; 8 had heard about DP but did not use DP while only 2 used DP (1 parent did not respond and 3 children were in residential schools).

The main issues that arose from parent interviews were about professional practice and communication. Though there was a ‘team around the child’ approach, the professionals did not work as a team and there was little or no evidence of keyworker system working. One parent said: ‘We would like honesty, knowledge, competence, cohesion and lots of money.’ Another theme was about there being different practices involved in informing parents about DPs.

Parents reported that the support which they would value would include the following:
1. befrienders in the evenings and weekends, 2. sitting service, 3. holiday activities, 4. overnight stay for child, 5. appropriate social contacts; as parents tend to be their only friend, 6. back up when a crisis; not just the Police and 7. more advice on the help you can get; financial/physical/emotional. When asked about their views about DP, some parents expressed the
view that they would like to be able to pay relatives. However others expressed concerns such as these:

‘SW told us about it (we have 2 boys) – but seemed a mountain of paperwork; interviewing; CRB checks and effort’

‘We understand that because of his exceptional needs and the need for a high staffing ratio – we would need to make up the financial shortfall in funding – Could we find staff willing to put up with his behaviour for £7 an hour?’

Several questions arose in the study that were relevant to commissioners: about the current use of DPs, how DPs were calculated, how DPs were promoted, what support parents had in using DPs, the payment of DPs, the involvement of parents in commissioning and the potential benefits/issues.

The study also pointed to factors about families and the assessment of need. Some parents have ASD or aspects of ASD, so requiring a different style. Parents may also have other demands which affect their ability to manage and live with the child. This raised the question of whether assessment/costing formula reflected this? (e.g. housing; other family demands; finance; support from family members)

The particular issues arose in relation to ASD. The demands of living with children with ASD are harder to assess and appreciate than other conditions, such as physical disability, as demands can change with time. The child can require much higher levels of supervision which can often be emotionally and physically draining. Supervision may not be around self-care, but may involve harm to self or others. Constant verbal challenges may also be the most difficult and tiring for parents and the behaviour of the child may be very much affected by the situation and the people within it. All this may also vary with the tolerance levels of parents and their understanding of their child and family support and resources.

Issues around DPs:
Those who are already advantaged may be more advantaged by this system; thus raising the question of how to protect the interests of ALL parents and children and ensure equity. Professionals may be anxious about involving parents more, as this is time-consuming, challenging and expensive. Resources are finite, thus leading to the question of how to encourage parents to be reasonable in their claims, although services procured by families may be cheaper. For children with ASD, payment may need to be more flexible to address times of crisis, rather than a fixed monthly or yearly amount. There is also the issue of recruiting, training and supporting personal assistants (PAs). There are employment laws / CRB checks, health and safety issues and questions about cover for PA absence to provide continuity for the child and family.

Nevertheless, the study indicated that there are potential benefits of DPs:
1. Support at home may be less expensive than support within a Unit and their home is already customised for the child and the child is familiar with this setting,
2. There are positive aspects of having PAs; they are more flexible when and where families want; they can also link more closely to a child’s needs and interests,
3. Extended schools offer great opportunities which parents can access with DPs.
Some relevant findings from other research:

Parents/carers of children with disability have received DP less often than other groups (along with the elderly and those with mental health problems). Many schemes in Europe have been set up based on an inadequate assessment of demand and set up costs. This has caused problems later and unmet needs are often uncovered, which can ‘overwhelm new systems’.

Other studies show that support is needed by parents/users of DP to access the scheme, to manage the money, budget and accounts, to identify and access the required services and to employ and manage staff. This raises questions about how DPs support and enhance educational provision and outcomes. Do they: 1. reduce parental stress – as physically and emotionally supported, 2. enable parents to attend meetings and training, 3. enrich the child’s life outside of school, 4. give parents a greater circle of support – a listening ear, 5. enable school attendance and 6. benefit siblings who may then become advocates?

Recommendations

It was recommended that:

Planning and commissioning

1. LA and services audit the parent/carer representation on planning and strategy meetings and consider whether parents/carers are adequately represented on these.
2. Regional LA consider the 10 principles of commissioning within the Regional Framework to Support Commissioning and use this as a self-evaluation baseline and planning document, making use of comparative information from other LAs.
3. Authorities work to ensure that ALL families with a child or young person with ASD, including those that are hard to reach, have a voice in relation to their own child and the wider population of parents/carers.

Working together across agencies

1. That those in the public, private and voluntary sectors work together and communicate to ensure what they offer is congruent and avoids repetition and confusion for families.
2. Consider allocating a key person to each family to coordinate the support and services provided for families.

Support out of school hours

1. Create ways to support parents/carers and children and young people with ASD in activities out of school hours during the evenings, weekends and holiday periods. This may reduce the need for other services (eg short breaks, residential placements) and so reduce costs.
2. Schools continue to develop their community role as in the Extended Schools agenda so that children and families are included and not isolated from peers.

Direct Payments

1. Enhance the promotion and dissemination of information on DPs to parents/carers and to provide support in using these.
2. Ensure that the DP information and processes are simple to access and use, with paperwork kept to a minimum.
3. LA consider how information on DPs is disseminated to professionals across all sectors and the information and training that is required on these.
4. There is a role for LAs and others (e.g. schools, voluntary groups) to be involved, directly and/or in a commissioning role, to recruit and train pools of potential PAs,
whilst acknowledging the importance of parents in this process to match suitable
people with their child and to provide specific information and advice on their child.

5. There is a need to find and recruit male PAs for this population to provide appropriate
role models, with PAs who are more likely to share similar interests to those of young
men with ASD. (In the ASD population, the majority are male, yet most carers and PAs
are female)

Engagement and consultation with parents/carers
1. Professionals are trained to develop the skills to genuinely engage and consult with
families and listen to what would make a difference to parents/carers and the
child/young person and other family members.

Demands not recognised/difficulties masked in ASD
1. That professionals, particularly school staff, are helped to understand the particular
strains of living with a child with ASD and work together to support the parents and
siblings so that the whole family remains physically and emotionally healthy.
2. Teaching staff to invite parents to visit school to share information and ideas and to
refer parents/carers to appropriate agencies for help/advice with any matters outside
school.
3. Professionals across all sectors need further guidance on how best to ascertain the
needs of the child or young person with ASD and then to provide appropriate support
for the child and the family.

Costs of increasing parent/carer involvement and providing payments to families
1. LAs calculate the costs of moving towards individualised funding and DPs for
parents/carers.
2. Pilot the results of engaging with a sample group of parents/carers and discussing the
current costs of care and how the money might be better spent to support their child
and family.
Appendix:
Tables taken from main report

Figure 1: Professionals and agencies whom the parents/carers might meet to address the needs arising from ASD

<table>
<thead>
<tr>
<th>Professional (n=21)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Befriender</td>
</tr>
<tr>
<td>Connexions worker</td>
</tr>
<tr>
<td>Classroom support assistant</td>
</tr>
<tr>
<td>Classsteacher</td>
</tr>
<tr>
<td>Clinical Psychologist</td>
</tr>
<tr>
<td>Dietician</td>
</tr>
<tr>
<td>Early years teacher</td>
</tr>
<tr>
<td>Educational Psychologist</td>
</tr>
<tr>
<td>Escort</td>
</tr>
<tr>
<td>GP</td>
</tr>
<tr>
<td>Health Visitor</td>
</tr>
<tr>
<td>Headteacher</td>
</tr>
<tr>
<td>Occupational therapist</td>
</tr>
<tr>
<td>Paediatrician</td>
</tr>
<tr>
<td>Physiotherapist</td>
</tr>
<tr>
<td>Psychiatrist</td>
</tr>
<tr>
<td>SENCo</td>
</tr>
<tr>
<td>Social worker</td>
</tr>
<tr>
<td>Speech and language therapist</td>
</tr>
<tr>
<td>Taxi driver</td>
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<tr>
<td>Voluntary worker</td>
</tr>
</tbody>
</table>

Table 1: Ratings given by parents/carers on satisfaction with current services/support

<table>
<thead>
<tr>
<th>Ratings</th>
<th>Descriptor</th>
<th>Number of parents / carers</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-2</td>
<td>Very dissatisfied</td>
<td>6</td>
<td>14</td>
</tr>
<tr>
<td>3-4</td>
<td>Fairly satisfied</td>
<td>10</td>
<td>23</td>
</tr>
<tr>
<td>5-6</td>
<td>Fairly satisfied</td>
<td>12</td>
<td>28</td>
</tr>
<tr>
<td>7</td>
<td></td>
<td>10</td>
<td>23</td>
</tr>
<tr>
<td>8</td>
<td></td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>9</td>
<td></td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>10</td>
<td>Very satisfied</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>43</td>
<td>100</td>
</tr>
</tbody>
</table>
Table 2: Number of people receiving Direct Payments in England 2001 to 2003 Source: Modified from the table in Leece and Leece, 2006, p. 1382

<table>
<thead>
<tr>
<th></th>
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<tbody>
<tr>
<td>Over 65+</td>
<td>537</td>
<td>1032</td>
<td>1,899 (15%)</td>
</tr>
<tr>
<td>Learning disability</td>
<td>353</td>
<td>736</td>
<td>1,337 (11%)</td>
</tr>
<tr>
<td>Physical disability</td>
<td>4,274</td>
<td>5,459</td>
<td>6,944 (55%)</td>
</tr>
<tr>
<td>Sensory disability</td>
<td>100</td>
<td>159</td>
<td>207 (1%)</td>
</tr>
<tr>
<td>Mental health needs</td>
<td>61</td>
<td>132</td>
<td>229 (1%)</td>
</tr>
<tr>
<td>Young carers</td>
<td>3</td>
<td>3</td>
<td>12</td>
</tr>
<tr>
<td><strong>Carers of disabled children</strong></td>
<td><strong>66 (1%)</strong></td>
<td><strong>228 (3%)</strong></td>
<td><strong>875 (7%)</strong></td>
</tr>
<tr>
<td>Disabled children (16-17 years)</td>
<td>8</td>
<td>38</td>
<td>125 (0.5%)</td>
</tr>
<tr>
<td>Carers (for carers’services)</td>
<td>21</td>
<td>95</td>
<td>957 (8%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>5,423</strong></td>
<td><strong>7,882</strong></td>
<td><strong>12,585</strong></td>
</tr>
</tbody>
</table>
Chapter 4

Direct Payments and Disabled Children and Young People: The Service of the Future?

Sheila Riddell, Centre for Research in Education Inclusion and Diversity, University of Edinburgh

Introduction

This paper presents findings from an ESRC-funded four-country study exploring a relatively new and radical form of welfare provision, direct payments, and the possibilities within direct payments for radically improving services for disabled children and young people. Very little work has been conducted on the use of direct payments by disabled children and young people, although they have been available for about seven years (see JRF, 2003). Direct payments are funds paid by local authorities to disabled individuals and other community care service users to purchase their own support. They may be seen as an important means of empowering those at the social margins to act as ‘co-producers’ of support services (Glasby and Littlechild, 2006), allowing service users to determine what support is needed, where it is delivered and who is involved in its provision. Direct payments may therefore be seen as the perfect means of promoting the personalisation agenda which has been identified by the Government as the overarching principle of welfare provision in the twenty first century. Alternatively, direct payments may be seen as a form of ‘creeping privatisation’ (Pearson, 2006), mistrusted by public sector trades unions and ‘Old Labour’ local administrations who believe that there is no place for the involvement of the private sector in the delivery of publicly-funded services. Questions continue to be raised about whether direct payments are an appropriate form of welfare provision for all disabled people and community care groups, or whether some individuals, for example younger or older disabled people living in socially disadvantaged circumstances, may find it difficult to operate as critical consumers. Particular issues arise in relation to disabled children and young people, who are unlikely to manage the payment themselves, but will rely on a parent or carer to help them do this. The dangers of exploitation by other family members or carers may be particularly acute in relation to younger people, and it is possible that any empowerment achieved may be for the adults surrounding the child or young person, rather than the disabled child.

The data used in this paper are drawn from an ESRC study entitled Disabled People and Direct Payments: a UK Comparative Study (RES-00023-0263), which was carried out by researchers at the Universities of Edinburgh, Glasgow and Leeds between 2003 and 2006. The research delineated national patterns in the use of direct payments across the UK drawing on analysis of official statistics and findings from a questionnaire survey (Davey et al, 2007). We also conducted case studies of local authorities in England, Wales and Scotland and health and social service trusts in Northern Ireland, in order to explore how national policies on the delivery of social care are permeated and subverted by local cultures of welfare, where ‘street level bureaucrats’ may have a profound influence. This paper compares the use of direct payments for disabled children and young people in different parts of the UK and presents a case study of two Scottish local authorities where some progress has been made in expanding direct payments to disabled children and young people. Overall, it is evident that whilst direct payments have been ‘talked up’ by Ministers in England as the future shape of welfare provision, they are still only accessible to a small minority of individuals, with children and young people finding themselves at the back of the queue. In other parts of the UK, where slower progress overall has been made in the development of direct payments, there are a few...
(mainly rural) local authorities where some progress is being made in relation to direct payment access for disabled children and young people.

The development of direct payments policy in the UK

For almost two decades, public policy has promoted the involvement of the private sector in the delivery of public services, drawing on discourses of the market as the means of raising standards and promoting choice. Commentators such as Stephen Ball, however, have urged the need for a cautious approach, questioning the hegemony of both the private and the public sector. Direct payments have been advocated not only by proponents of marketisation, but also by disabled people who regard them as having the potential to further the principles of independent living (Barnes et al, 2001). As a result of pressure from the disability movement, the Community Care (Direct Payments) Act 1996 was passed in the dog days of the Conservative administration, coming into force in April 1997 in England, Wales and Scotland and Northern Ireland a year later. Access was initially restricted to those between 18 and 65 and was then gradually extended to older people and more recently to other groups such as 16 and 17 year-olds and parents of disabled children. In England and Wales, changes in 2000 also allowed carers to receive a direct payment. This change followed shortly afterwards in Northern Ireland but was not implemented in Scotland. In England, the Health and Social Care Act 2001 required local authorities to offer direct payments to all eligible individuals. A year later, the Community Care and Health (Scotland) Act 2002 also made it mandatory for all Scottish local authorities to offer direct payments to eligible client groups and this was implemented throughout the UK during 2003. Recent policy documents and ministerial statements (Department of Health, 2005; Department of Health, 2006) have underlined the commitment to direct payments. In England and Wales, individual budgets have been introduced in thirteen pilot areas and are currently being evaluated (Glendinning et al, 2006; Knapp, 2007). These budgets bring together resources from a number of funding streams, including local authority adult social care budgets, community equipment, housing adaptations, housing related support through the Supporting People programme, the Independent Living Fund and Access to Work from the Department for Work and Pensions. There has not been a major push as yet to develop individual budgets for disabled children and young people, although they are eligible. In Scotland and Northern Ireland, whilst there is a commitment to the delivery of more personalised and flexible services, direct payments is seen as only one of a number of means of achieving this goal (Scottish Executive, 2006). Individual budgets have so far gained little political support north of the Border.

Joined-up services for disabled children and young people: a role for direct payments?

As noted above, direct payments clearly fit within the modernisation of welfare agenda, which draws on discourses of the market and of social justice, emphasising the need for flexible and individualised services which are delivered by a range of providers in a mixed economy of welfare. Direct payments also reflect the view that there needs to be a focus on the individual, their family and all domains of their life so that the same pot of money can be used to advance social, educational and employment-related goals. Providing holistic services may involve breaking down existing agency boundaries (Riddell and Tett, 2004) and their associated budgetary delineations, and organisations such as Care Co-ordination UK have been at the forefront of promoting such developments. Whilst joined-up working is often justified in terms of delivering improved services to those at the margins, Clarke and Newman (1997) and Newman (2001) have pointed out that, for those experiencing social disadvantage, the role of service consumer may fit uneasily with their resources and identity. Decisions on the allocation of resources may be passed from one agency to another, leaving the service user embroiled in complex negotiations.
The need for tighter inter-agency working underlies recent policy on services for disabled children in Scotland, as elsewhere in the UK. For example, the *Getting it Right for Every Child* (Scotland) and the *Every Child Matters* (England and Wales) initiatives, set out the agenda for change and the practical adjustments which are required, such as a common assessment framework and the sharing of electronic records by health, education, social work and the voluntary sector. In the policy document *Aiming High for Disabled Children: Better Support for Families*, the DfEs and the Treasury made a commitment to the development of individual budgets for disabled children and young people. In Scotland, new education legislation is also based on the principle of joined-up working. The Education (Additional Support for Learning) (Scotland) Act 2004 placed a duty on local authorities to identify and meet children’s additional support needs. Children with enduring difficulties arising from one or more complex factors or multiple factors and requiring significant additional support from education and other agencies qualify for a Co-ordinated Support Plan (CSP). This plan specifies the services to be provided by a range of agencies and has statutory status. Health and social work have a duty to assist education in making provision to meet additional support needs. Early evidence suggests that a relatively small proportion of children are deemed to meet the tightly specified criteria for a CSP, far fewer than the number who had a Record of Needs (see Figure 1 drawn from an evaluation of the legislation conducted by Her Majesty’s Inspectorate of Education (HMIe, 2007).

### National and local differences in the use of direct payments across the UK

The questionnaire survey conducted by Davey et al (2007) provides a fine grained comparison of use of direct payments by country, type of authority and user group (although the low response rate from Scotland, Wales and Northern Ireland means that the findings for these countries are not necessarily representative).

As illustrated by table 1, England makes much greater use of direct payments than other parts of the UK, partly because it was the first UK country to make it mandatory to offer direct payments to community care users. In addition, in line with its commitment to the modernisation of welfare through the use of manageralist strategies (Clarke and Newman, 1997; Newman, 2001), England was much more proactive in setting targets for local authorities, and the proportion of community care users in receipt of direct payments contributes to local authorities’ ‘star rating’ (Priestley et al, 2006). Furthermore, there appears to have been a longer history of disability activism in England. Table 1 indicates particularly high use in parts of England where disabled people have engaged in a long struggle for independent living. For example, they are used most extensively in the East, South East and North West regions, where Essex, Hampshire and Cheshire were in the vanguard of the development of direct payments. By way of contrast, the North East and Yorkshire and Humberside, with less vibrant traditions of disability activism, have been much less proactive in extending the use of direct payments.
Table 1: Average number of direct payments per local authority, per million inhabitants, 2003-04

<table>
<thead>
<tr>
<th></th>
<th>Valid (n)</th>
<th>Older people</th>
<th>Mental health</th>
<th>Learning disability</th>
<th>Physical disability &amp; sensory impairment</th>
<th>Disabled children</th>
<th>Carers</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td>England (regions)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>East</td>
<td>6</td>
<td>91</td>
<td>32</td>
<td>55</td>
<td>287</td>
<td>69</td>
<td>24</td>
<td>558</td>
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<tr>
<td>East Midlands</td>
<td>7</td>
<td>74</td>
<td>7</td>
<td>41</td>
<td>194</td>
<td>18</td>
<td>9</td>
<td>343</td>
</tr>
<tr>
<td>London</td>
<td>27</td>
<td>67</td>
<td>9</td>
<td>33</td>
<td>181</td>
<td>38</td>
<td>21</td>
<td>349</td>
</tr>
<tr>
<td>North East</td>
<td>9</td>
<td>44</td>
<td>11</td>
<td>42</td>
<td>149</td>
<td>35</td>
<td>4</td>
<td>285</td>
</tr>
<tr>
<td>North West</td>
<td>17</td>
<td>74</td>
<td>11</td>
<td>89</td>
<td>208</td>
<td>109</td>
<td>9</td>
<td>500</td>
</tr>
<tr>
<td>South West</td>
<td>14</td>
<td>90</td>
<td>19</td>
<td>42</td>
<td>238</td>
<td>39</td>
<td>27</td>
<td>455</td>
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<tr>
<td>South East</td>
<td>7</td>
<td>66</td>
<td>5</td>
<td>51</td>
<td>238</td>
<td>42</td>
<td>6</td>
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<td>West Midlands</td>
<td>11</td>
<td>63</td>
<td>6</td>
<td>43</td>
<td>189</td>
<td>32</td>
<td>64</td>
<td>397</td>
</tr>
<tr>
<td>Yorkshire &amp; the Humber</td>
<td>12</td>
<td>52</td>
<td>6</td>
<td>35</td>
<td>139</td>
<td>44</td>
<td>6</td>
<td>282</td>
</tr>
<tr>
<td>England (LA type)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unitary authority</td>
<td>29</td>
<td>82</td>
<td>10</td>
<td>51</td>
<td>231</td>
<td>42</td>
<td>28</td>
<td>444</td>
</tr>
<tr>
<td>London borough</td>
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<td>67</td>
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<td>33</td>
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<tr>
<td>Shire county</td>
<td>24</td>
<td>79</td>
<td>15</td>
<td>52</td>
<td>226</td>
<td>53</td>
<td>23</td>
<td>448</td>
</tr>
<tr>
<td>Metropolitan District</td>
<td>30</td>
<td>56</td>
<td>9</td>
<td>50</td>
<td>165</td>
<td>55</td>
<td>11</td>
<td>346</td>
</tr>
<tr>
<td>UK country/Province</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Northern Ireland</td>
<td>3</td>
<td>7</td>
<td>1</td>
<td>2</td>
<td>11</td>
<td>2</td>
<td>0</td>
<td>23</td>
</tr>
<tr>
<td>Scotland</td>
<td>8</td>
<td>21</td>
<td>1</td>
<td>8</td>
<td>36</td>
<td>7</td>
<td>0</td>
<td>73</td>
</tr>
<tr>
<td>Wales</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>12</td>
<td>1</td>
<td>0</td>
<td>17</td>
</tr>
<tr>
<td>England (regions)</td>
<td>110</td>
<td>71</td>
<td>12</td>
<td>48</td>
<td>205</td>
<td>50</td>
<td>20</td>
<td>406</td>
</tr>
</tbody>
</table>

Source: Davey et al, 2007-08-30

Whilst the survey underlines the national differences noted by Riddell et al (2005), it is evident from tables 2 and 3 below that, even in England, direct payments account for only a very small proportion of community care provision. For example, people with physical disability in the 18-64 age group are the largest group of community care users, but even among this group only 7.1 per cent of all community care users are receiving direct payments. For people with mental health difficulties, a larger user group, the proportion of direct payments recipients is almost negligible (0.4 per cent). Disabled children and young people represent a very small proportion of all those receiving direct payments across the UK. Given English health ministers’ commitment to making direct payments the preferred mode of community care delivery for the future (Pearson, 2006), it is perhaps surprising that implementation on the ground appears to be at such an early stage.
Table 2: Proportion and total numbers of community care service users in England receiving direct payments, per user group, 2003-04

<table>
<thead>
<tr>
<th></th>
<th>Older people (65+)</th>
<th>Mental health (18-64)</th>
<th>Learning disability (18-64)</th>
<th>Physical disability (18-64)</th>
<th>Sensory impairment (18-64)</th>
<th>Disabled children &amp; carers of disabled children</th>
<th>Carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of DP users</td>
<td>5,700</td>
<td>400</td>
<td>1,800</td>
<td>6,800</td>
<td>370</td>
<td>Not known</td>
<td>Not known</td>
</tr>
<tr>
<td>Total number of service users for the client group</td>
<td>631,500</td>
<td>105,000</td>
<td>84,000</td>
<td>96,000</td>
<td>9,600</td>
<td>Not known</td>
<td>Not known</td>
</tr>
<tr>
<td>% service users receiving DP</td>
<td>0.9%</td>
<td>0.4%</td>
<td>2.1%</td>
<td>7.1%</td>
<td>3.9%</td>
<td>Not known</td>
<td>Not known</td>
</tr>
</tbody>
</table>

Having briefly reviewed the statistical data on direct payments across the UK, we present brief case studies of two Scottish local authorities to illustrate the local factors which either promote or inhibit their development. Table 3 provides summary data in relation to the two case studies considered in this paper.

Local Area Case Studies
Case studies were selected to reflect a number of dimensions, including their geographical location, rate of direct payments use and political control. Each case study was intended to shed light on the nature of the local micro-politics which either promoted or inhibited the development of direct payments. The case studies reflect a spread of practice, with Green City effectively blocking the use of direct payments, whilst Rowanshire was supporting their use by disabled children and other groups for whom mainstream services were absent or of poor quality. The fieldwork was conducted in 2004-05, and although there have been year on year increases in the number of direct payment users in each authority, their relative position has not significantly altered. Rather, they illuminate the tensions and contradictions, as well as the opportunities for future development, which appear to transcend national boundaries. A brief overview of each area is presented before considering their key similarities and differences.
<table>
<thead>
<tr>
<th>Characteristics of Authority</th>
<th>Overview of Direct Payments</th>
<th>Financial Management</th>
<th>Views of Social Workers</th>
<th>Views of Direct Payments Users</th>
<th>Support Organisation Perspective</th>
</tr>
</thead>
<tbody>
<tr>
<td>Green City, Scottish Local Authority</td>
<td>Urban area with very high levels of deprivation. Below UK &amp; Scottish average use of DPs. Old Labour council.</td>
<td>Lack of synergy between LA &amp; support organisation. Official support from management but many problems recognised. Managers believed more funds would be released for DPs once demand demonstrated. Historical resistance from UNISON. DPs seen as ‘creeping privatisation’.</td>
<td>Resources tied up in home care and day services. Separate budget for DPs which was overspent.</td>
<td>Generally resistant. Complaints about lack of training – denied by management. Many concerns: accountability for public money; risk of abuse of vulnerable children &amp; adults; substandard care; practitioners’ loss of control; LA liability; users’ ability to manage funds; unfair treatment of PAs.</td>
<td>Centre for Independent Living. Difficulty negotiating contract with LA. Believed LA lacked resources for and commitment to DPs.</td>
</tr>
<tr>
<td>Rowanshire, Scottish Local Authority</td>
<td>Rural area, some pockets of deprivation but mainly affluent. Below median UK use of direct payments. No overall political control.</td>
<td>Positive synergy between LA &amp; support organisation. Broad support from senior managers because DPs helpful for meeting needs in rural area. Desire for future expansion.</td>
<td>Devolved care management – widespread use of spot contracting.</td>
<td>Families of disabled children and young people beginning to push for direct payments, particularly because of poor post-school provision.</td>
<td>User-led management committee. Major support for DP users and social workers. Undertakes financial monitoring on behalf of LA.</td>
</tr>
</tbody>
</table>

Notes: DP use by LA refers to whether above or below UK average use per 10,000 population in 2003.
Green City (Scottish Local Authority)

Green City was a Scottish local authority with an industrial base in long term decline, associated with high levels of poverty, long-term limiting illness and economic inactivity. The social services budget was tightly stretched and a high proportion was tied up in existing services such as day centres. The city was a relatively low user of direct payments and the budget was ring fenced, so that when all funds were committed people wishing to receive a direct payment were placed on a waiting list. Ways had not been found of diverting funds from existing services to meet the growing demand for direct payments.

The city was aware of its limited use of direct payments, and different explanations were given by various groups. Social work team leaders expressed support for the concept of direct payments, suggesting that it encouraged people to ‘take ownership of the solution to their difficulties as well as their problem…I think people can be more innovative if they have the money and then can secure the service themselves’. However, they also realised the challenging nature of this view of the world:

The whole idea of service users having control I think brought people out in a rash (Team leader)

Grassroots social workers tended to be much less positive, believing that there was no point in raising client expectations and using up time and energy setting up a direct payment, when there was a strong likelihood that it would be turned down:

We’re not naïve, we realised that it would be based on budgets and stuff as well. And that’s where the frustration is coming in. Because in some respects we feel perhaps there just isn’t the money in the system for it. And I would much rather they just said that. (Social worker)

Social workers also complained about the lack of training and the difficulty in accessing reliable advice. In relation to accountability and monitoring, some managers and social workers had doubts about clients’ ability to manage, particularly when family poverty might tempt people to subvert funds intended to support the disabled person:

I think one of the biggest difficulties occurs when carers really are quite desperate for the direct payment. Your assessment may be that there’s ulterior motives for it. I work in an area – a very poor area, the North of Glasgow, there’s very few owner occupiers. Poverty is rife. And there’s quite a few cases where it’s an income to the family and in those cases we will say no. (Manager)

Such concerns could of course be construed as legitimate concerns about fulfilling the local authority’s duty of care to the disabled person, or as misplaced paternalism. A team manager expressed the view that the city had created a ‘culture of dependency’, in which people had become used to directly provided services, even if these were of rather low quality. Despite worries about misuse of public money, social workers also expressed the view that direct payment users might emerge as a privileged group receiving a superior service. This, they believed, would be fundamentally unfair:

You shouldn’t be advantaged by getting a direct payment. To me that person’s getting advantage over somebody else that goes to the day centre, because they’re getting one to one. (Manager)
Social workers with reservations about the administrative demands of direct payments had been supported by their trades union, which voiced concerns about the increased workload. In addition, the union representative spoke of the ‘suspicion and hostility to direct payments as a concept’, which might be regarded as a form of ‘creeping privatisation’.

The support organisation, led by disabled people, had considerable experience of supporting both indirect and direct payments, and offered a range of support services including payroll management. However, they were in ongoing discussion with the local authority about the amount of money they needed to support new service users, and they also had a waiting list of those requiring support. Given this array of difficulties within the authority, it is hardly surprising that direct payment users felt inadequately supported. One commented: ‘We’re all getting the different stories…nobody seems to be giving us the right information’ (Direct payment user). Others users commented: ‘the social work department wants direct payments to fail’ and ‘they’re no wanting direct payments’.

Given the reluctance of this local authority to develop direct payments at all, it is not surprising that disabled children and young people were seen as a very low priority group.

*Rowanshire (Scottish Local Authority)*
Scottish Local Authority 1 was predominantly rural, with a dispersed population. The LA included some of the richest neighbourhoods in Scotland, as well as some very deprived areas experiencing long-term decline as a result of the collapse of the fishing industry. The Council was ‘hung’ and members’ main concern was to achieve financial stability. They were broadly in favour of the modernisation of welfare principles and spot purchasing was commonly used. The council tended to be one of the more conservative in Scotland and, partly as a result of its size and rurality, had never invested heavily in local social care services. It did not, therefore, have the problem of dismantling existing provision in order to invest in direct payments, as was the case in Green City.

According to managers and practitioners, the main benefit of direct payments was the potential for user empowerment, however, there were also a number of downsides. The main disadvantage for service users was the responsibility involved in managing the payment and organising services individually, rather than receiving a directly provided service.

Managers and practitioners believed that direct payments could, in the long run, work out to be more expensive for the local authority, since there were a number of hidden costs including funding an independent support organisation and monitoring the payment in terms of financial accountability and fulfilling the authority’s duty of care. This form of service provision was also likely to prove attractive to people who had simply managed by themselves in the past.

Disabled children and younger adults had been identified as a group who could benefit from the expansion of direct payments, and a local voluntary organisation working with families with severely disabled children had encouraged their uptake. Disabled children had often had a positive experience of education, and the paucity of provision by social services in poorly-run day centres prompted some parents to seek direct payments. Parents who were interviewed described how they had looked after their son themselves for two years after he left school, until this was no longer a feasible option:
We were both very stressed, you know, physically and mentally with caring. By the time it [the direct payment] was set up, we had been two years care 24/7… we were quite desperate. (Parent of physically disabled adult son)

His mother felt strongly that direct payments were the only acceptable option but she would not have tried them had the day centre been better. Another parent reported that direct payments were offered to her as a last resort after her daughter’s care package changed. She had previously received payments through the Independent Living Fund (ILF) for her daughter, but the number of respite hours went over the ILF limit so this money was no longer available. At this point her social worker suggested direct payments to avoid her daughter having to move into residential care and because there were few services available in their rural location.

Another parent who managed the payment for her son wanted a direct payment as she felt that this would offer the best way of ensuring her son’s complex package of care could be continued when he moved from child to adult services:

I was told that, quite bluntly,… I should be having a direct payment… that it would be too difficult for, you know, an organisation, that particular care organisation to be able to look at my needs and the complex package I had. (Mother of disabled son)

She reported being shocked initially at the thought of having to manage a direct payment, but felt more reassured when she discovered that support was available.

Overall, parents of disabled children felt direct payments enabled their son or daughter to receive personalised services in the family home, although these were almost always to do with care rather than education. They were mistrustful of externally provided services for vulnerable children and adults and wanted to retain control of the quality of care:

There’s good practice everywhere which I’m delighted about but I just don’t want to take that risk with my son. I couldn’t. So I feel I want him to live independently as possible but within the family home. (Parent of disabled adult)

I’m certain that his mental wellbeing and health have been protected through this and… he’s not been admitted to hospital,… it’s kept him at home because as soon as he’s not well, we’re able to get in there, get the carer in for him and, you know, it’s kept him out of hospital basically. (Parent of disabled adult)

Dissatisfaction with agency workers provided by social services was also a motivating factor:

She really wasn’t doing things properly, the way that I wanted them done. (Parent of disabled child)

It makes it all worth while, going through all this, because you get to choose all the carers. (Parent of disabled child)

However, there were also downsides, particularly in terms of sacrificing privacy:

I mean, it’s not easy. There’s no way you can say that it’s easy having people in and out of your home, sleeping in your home overnight, you know, coming in at 10 o’clock… but I’ve accepted that if my son was going to have an independent life away from us and
really helping his normal development as much as I could that was the price that we must pay; to lose our privacy, if you like. (Parent of disabled adult)

All the parents to whom we spoke were either fully or largely responsible for managing the funds and they had all taken the decision to use a direct payment. Direct payments were largely seen as the means of meeting care needs rather than enabling social inclusion or delivering education. Any choice or control that they might offer was mainly of benefit to the parents, who derived comfort from directly managing their children's care. This raises interesting questions about the ownership and control of the direct payment, as its purpose has been recast as a tool to be employed by carers rather than an aide to independent living, although of course a better quality of care for the user may also result.

The support organisation operating in Rowanshire was very much in tune with the local authority's ethos. Although it was managed by disabled people, it lacked the campaigning style of the support organisation in Green City. The organisation willingly took on many of the training and accounting roles which were reluctantly undertaken by social workers elsewhere, thus fostering the view that direct payments did not necessarily intensify work for frontline staff. They also worked closely with voluntary organisations who were also encouraging parents to consider opting for direct payments.

**Conclusion**

Direct payments have become extremely popular in the UK at least at the level of political rhetoric, but analysis of official statistics shows that they are very much a minority form of provision at the present time. Most direct payments are made to adults with physical disabilities, the original user group, although they are becoming more popular with parents of disabled children and young people. Despite the expansive rhetoric of enabling people to purchase services flexibly to meet their needs, funds are almost exclusively used for personal care rather than, for example, education or employment support. Certain regions in England have been at the forefront of the development of direct payments, and in general Scotland, Wales and Northern Ireland lag behind, continuing to be attached to traditional forms of service delivery. The two case studies of local authorities presented above provide insight into why direct payments have failed to become a mainstream form of welfare provision. Local authorities find it difficult to dismantle existing services even if these are rather poor in quality, and there are also fears about ‘dead weight’ and increasing costs, as people discover the benefits of direct payments. If poor services are delivered through direct payments, or parents expect to be paid for caring work which was previously carried out without payment, then escalating costs may ensue.

Particular anxieties exist in relation to the use of direct payments for disabled children and young people. Managers and social workers fear that poor care may be provided or that relatives may exploit a child's disability to gain additional income for themselves. Ambiguity about who counts as the employer in law has fuelled fears that the local authority might find itself liable to pay large amounts of compensation if a carer or personal assistant were found guilty of abuse. In addition, there is confusion about whether Police Disclosure checks are necessary, and if so, whose responsibility it is to carry these out. Finally, parents of disabled children who decide to seek a direct payment find themselves with considerable amounts of paperwork to contend with, in addition to the pressures of supporting the disabled child and the family.
It is also evident that attempts to introduce a mixed economy of welfare into different spheres of social welfare meet with very different receptions as a result of complex historical and cultural factors. Since the early 1990s, the idea of a market in social care, with a range of services provided by the private, voluntary and public sectors, has been widely accepted, despite the disapproval of public sector trades unions who continue to defend the principle of public sector provision as inherently superior to the values pervading private sector provision. The principle of competition between a range of providers has also been generally accepted in the pre-school sector. In the compulsory school sector, on the other hand, the idea of direct payments or individual budgets is regarded as analogous with the policy of education vouchers, which has traditionally been promoted by the right as a means of challenging the hegemony of state provision. In order to avoid a very defensive reaction from teachers’ trade unions, it might be important for the Government to be clear about which groups of children might be regarded as eligible for individual budgets. If the mixed economy of welfare were to develop only in relation to the small group of children with severe impairments, for whom the boundary between health, social care and education is particularly fuzzy, then there might well be little opposition. However, if the group were defined broadly, to include all children with additional support needs (possibly 20% of the population), then there would be fears of large-scale raids on education budgets and opposition from local authorities, schools and teachers would be intense. Clearly, these are areas where clarification is needed.

Finally, the central rationale of direct payments and individual budgets is to provide the individual disabled person with the means of achieving social inclusion and self determination. However, for disabled adults these goals have been only partially achieved, since straitened local authority circumstances, particularly in authorities like Green City, mean that direct payments have only been made available to those whose needs are most acute in order to purchase personal care services. Overall, it is evident that direct payments have great potential to usher in new forms of welfare provision, but at the present time there is a large gap between aspiration and reality. There is a need for much greater reflection on who should receive a direct payment or hold an individual budget, and the policy goals which are to be achieved. At a more practical level, there is a need for a body of evidence to be developed on the conditions which are necessary for direct payments and individual budgets to work effectively for disabled children and young people.

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References


CHILDREN WITH RECORD OF NEEDS AND WITH CO-ORDINATED SUPPORT PLAN NOVEMBER 2005

No. of Children

- Aberdeen City Council
- Aberdeenshire Council
- Angus Council
- Argyll & Bute Council
- Clackmannanshire Council
- Dumfries & Galloway Council
- Dundee City Council
- East Ayrshire Council
- East Dunbartonshire Council
- East Lothian Council
- East Renfrewshire Council
- Edinburgh City Council
- Eilean Star (western isles) Council
- Falkirk Council
- Fife Council
- Glasgow City Council
- Highland Council
- Inverclyde Council
- Midlothian Council
- Moray Council
- North Ayrshire Council
- North Lanarkshire Council
- Orkney Islands Council
- Perth & Kinross Council
- Renfrewshire Council
- Scottish Borders Council
- Shetland Islands Council
- South Ayrshire Council
- South Lanarkshire Council
- Stirling Council
- West Dunbartonshire Council
- West Lothian Council

- Number of children/young people with a Record of Needs at 14 November 2005
- Number of children/young people with a Record of Needs and who have a co-ordinated support plan
Chapter 5

Summary of discussion and conclusions

Brahm Norwich

With 40 participants in the seminar, small group discussions were organised into 3 groups. What follows is a summary of what these groups reported back to the plenary discussion at the end of the seminar. The steering group set out some questions for these groups to consider in their discussions:

1. What is the rationale for broad concept of direct payments?
2. How do direct payments address questions about equity of allocation to all disabilities?
3. When are direct payments relevant to education services?
4. How would the child and young person’s voice be responded to through using direct payments?
5. How would the quality and effectiveness of arrangements made by parents be monitored?

Group 1
Discussion in this group centred on how direct payments arose from adult services. Some wanted evidence that transferring this system to children’s services would be effective. An officer from Coventry reported that there were 30 children receiving direct payments in that LA and that there was evidence of parental satisfaction in these cases. However, other LAs ignored direct payment systems. In this regard there was discussion about the boundaries between care and education and whether extended schools could be considered as care. Others referred to the need for a mindset change if direct payments were going to be introduced. The benefits of direct payments were explained by some in terms of how the payments could be used in a person-centred way – e.g. the same assistant could be employed for support before school in the mornings and during school day, facilitating continuity of support. There was also some criticism of how Government came to adopt systems like direct payments without evaluation evidence that it could work effectively; where as one participant explained, the political process was such that evidence played an intermittent role in policy formation. The discussion also identified that not all services for children with SEN / disabilities are one to one services; some involve social experiences. It was also explained that any evaluation of a direct payment system needed to take account of whether there would be a loss of economies of scale in service delivery. One of the topics discussed in this group was that with the users having controls of funding, some of the services might be relabelled as care; an example given was respite care coming to be seen as short breaks. Some members of this group also wondered whether the personalisation agenda in service delivery actually required user budgetary control in the form of direct payments. This had to be demonstrated in evaluation rather than just assumed as it is in Government policy justifications. A final observation was that the individualisation and use of market approaches had been accepted more in care than education services.

Group 2:
This group thought around the question of what direct payments meant for education. Local authorities were seen as having a responsibility to use public funds equitably. There were some concerns expressed in this group that direct payments may be a backward step as regards
inclusive education, if parents were moving away from inclusion. There was a rich discussion around these themes and issues, but no consensus emerged in this group.

Group 3:
This group discussed the question of finding evidence to support a direct payments system. Local authorities were said to want more evidence on which to base service delivery. If direct payments were all right for pre-school services and adult services, why were they an issue for schooling? There was no clear explanation for this that emerged from this group. One proposal was that funds for short breaks could be a suitable test case for direct payments. This was something that could be tried out. The group also considered whether the benefits of direct payments might also be for siblings, not just the child with disability. The group considered whether the use of direct payments was best seen in terms of market led flexibilities versus the local authority leviathan, where the former was good and the latter bad. This group also considered the question of how to evaluate services funded by direct payments. How would we know if the services provided were of appropriate quality; do we rely on professional judgements for this? It was argued that parents need to know about the restrictions on their use of the budgets in direct payments; local authorities could be more honest with parents about the restrictions on their use of these funds. The question of commissioning of services in children’s services was also said to need addressing. Lessons about commissioning could be learned from its use for Sure Start and extended schools provision; this was relevant to the significant increase in funding to be made available for short breaks. The Department of Health wanted to use direct payments, but how far did the DCSF want to go with direct payments?

Concluding comments:
It is interesting that the recent review of market suitability for individual budgets conducted for the DCSF by Price Waterhouse Cooper (2007) concluded that there were few markets that are currently suitable for the introduction of individual budgets. In their analysis there are some markets that require limited development to be suitable for individual budgets, e.g. provision of additional tutoring, transport and equipment. Markets that require, in their analysis, further development to be suitable for individual budgets included extended school activities, play, sports, leisure, half term opportunities and cultural activities, therapeutic Care Services, childcare provision and short breaks. Markets that require considerable development to be suitable for individual budgets covered some of the areas relating to educational support, e.g. provision of additional support in schools, special schools, residential care homes. This analysis shows how far special education provision is from being seen as ready for individual budgets.

The seminar discussion raised many of the underlying issues about the introduction of direct payments that had been discussed in the seminar and how far this system of funding would be beneficial in relation to children with SEN / disabilities. Direct payments had been tried and many thought they had been accepted in pre-school provision, but vouchers for schooling has been a politically sensitive matter. Is it likely to remain one or will this change in the years to come? The seminar also raised some differences of views between those who call for more evidence of how direct payments would work in education services (researchers, some LA officers) and those who advocated this approach as offering children with SEN/ disabilities and their parents benefits (from the voluntary sector). This is a topic which touches on fundamental questions about resource allocation and the balance between individual user’s decision making and the decisions of officers/professionals responding to the collective wishes of parents and users. It is one that produces tensions in a field rife with contradictions.
Reference: