Royal College of Nursing

RCN Policy Unit

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Individual Budgets

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Introduction

This briefing will provide details of Individual Budgets (IBs) and their implications for nurses, people needing care and their carers. It also contains a number of references for those wishing to know more about the scheme.

In general terms, Individual Budgets build upon earlier experiences with Direct Payments which were developed in the 1990's. A pilot project was set up with 13 local authority areas in England, with a commitment from central government to roll it out nationally should the pilot prove to be successful.

Individual budgets have been referred to in various Dept Health documents such as Commissioning for Well Being and the Operating Framework. In December 2007 ministers signed a 'concordat' with local government, the sector's professional leadership, providers and the regulator pledging to create 'a high quality, personalised system which offers people the highest standards of professional expertise, care, dignity, maximum control and self determination' (Department of Health 2007). Individual budgets for those living with Long Term Condition (LTCs) featured highly in the presentations.

If you are involved in the IB pilot sites and wish to contribute to RCN policy in this area, please contact us at policycontacts@rcn.org.uk or 0207 647 3754.

What is an individual budget?

An IB is essentially an individually allocated fund which allows the recipient to purchase services to meet any assessed needs. These budgets are pulled together from several sources of funding in addition to adult social care resources, such as supporting people and the independent living fund. Where as direct payments are solely from adult social care funding.

This currently involves a three-way agreement between:

- The local authority
- The individual IB holder
- A third party - this could be a provider, a trust, or a specialist broker. The third party undertakes to carry out the support plan in accordance with the wishes of the IB holder.

The main idea behind individual budgets is to put the person who is supported, or given services, in control of deciding what support or services they get, rather then more traditional service models where the workforce make decisions on what they believe people need and want .

Two of the pilot sites repeatedly identified the potential value of including NHS resources, particularly in respect of supporting people with long term conditions and for those meeting the criteria for NHS continuing care in the community, but this has been repeatedly ruled out by the government.

The system as set out in the concordat is described as a commitment to the objectives of personalisation and independence, at least at the level of principle and support for the broad objectives of choice, control and flexibility.

Currently the use of IB's being tested through the pilot sites are being reviewed by the Individual Budgets Evaluation Network (IBsEN) who will report back in the summer 2008. However the Sec of State for Health the Rt Hon Alan Johnson has already announced that he intends to roll out their use in health for people suffering long term conditions such as diabetes or chronic pulmonary disease[1].

What should they do?

Individual Budgets:

- Should give people a clear idea about how much money there is for their support.
- Make assessment quicker and easier and mean people have to give out information fewer times.
- Bring together different kinds of support or funding from more than one agency thus providing a more streamlined commissioning process
- Let people use the money in a way that best suits their own needs and situation
- Give individuals support to plan what they want and to organise it with help from a broker or advocate, family or friends, as the individual desires.
- Not cost the Local Authority any more.

[1] Speech by Alan Johnson at the Kings Fund (Dec 2007)

- Individual budgets should put people in the centre of the planning process, and recognise they are the person best placed to understand their own needs and how to meet them.

- Individual budgets should be flexible enough to allow people who are satisfied with existing services to keep these, and also give people a range of options for building up more individually tailored support (CSIP, 2006)[2]

The DH document, 'commissioning for health and well being'[3] offered a number of examples where individuals and families could have their lives transformed through the use of individual budgets for example:

- Purchasing of respite care – allowing carers to take a break particularly families of children with a disability, or when patients with a terminal illness need more intensive nursing for a fixed period of time.

- Supporting carers of terminally ill patients so that people with a terminal illness can choose to stay and die at home.

- Supporting greater independence for people with long-term conditions – This could include provision of self-monitoring equipment (e.g. to measure blood pressure) and self-care educational programmes.

However the public and professional responses to the consultation pointed out many anxieties with pursuing IBs, for example problems of insufficient data on the individual to accurately assess the resource/budget needs of the patient. This introduces the problem of misallocating resources.

In addition there is a lack of legal certainty around whether NHS funds can be used to pay for what is currently considered Social Care[4]. Some of these issues are dealt with below.

Eligibility

There appears to be large differences in what service users are entitled to according to their income and their assets. Along with poor information about the options available, CSCI identified 'a real tension between the

[2] M Henwood & B Hudson (2007) '*Evaluation of the self-directed support network: An overview of key messages: a review for the Department of Health*'. Melanie Henwood Associates – health and social care consultancy.
[3] Dept of Health (2007) '*Commissioning framework for health and well-being*' 6 March. Gateway reference: 7361
[4] Dept of Health (2007) '*Commissioning framework for health and well-being - response to consultation*' 6 July. Gateway number: 8906

hierarchical, narrowing interpretation of social care'[5] dictated by eligibility thresholds.

They also found there is little consistency within and between councils on who is eligible for services as staff interpret the national fair access to care services (FACS) guidance on eligibility differently in practice[6].

There seems to be many potential service users who are unable to access social care funding or support due to current local authority social services approaches to rationing[7] or because their needs do not correspond with local eligibility criteria. Consideration also needs to be made for those who are self funding their own care because they have assets that put them above the means-testing threshold for social care. It is unclear whether IBs will be a suitable policy platform to address these issues of eligibility but there are clear opportunities to make criteria more accessible and clear to service users through the IB scheme.

As far as IBs are concerned, they are aimed at three distinct groups of users: the older person; those with mental health conditions and the disabled - all of whom have very different needs regarding their understanding of and the support they require to manage an IB appropriately. It is very clear, therefore, that it is not a case of 'one size fits all'.

What are the pilot sites doing?

Some nurses may feel that social care and individual budgets will have very little impact on their day to day practice. However a review of the details of the each pilot site's work reveals there are several areas where the interface between health and social care will be challenged for e.g. around learning disabilities, mental health and care of the older person. In this respect, nurses should be examining how IBs will impact the profession, its practice, and its relationship with the public. Ministers have agreed that the pilot programme includes the following income streams:

- Council-provided Social Care services for adults
- Supporting People funding
- Independent Living Fund
- Disabled Facilities Grant

[5] Lovell, C. (2008) 'Services gap imperils care-all-plan' *Community Care* 1708 pp10-11, February
[6] Lovell, C. (2008) 'Services gap imperils care-all-plan' *Community Care* 1708 pp10-11, February
[7] Henwood M. Hudson B. (2008) 'Checking the FACS' www.guardian.co.uk/society

- Integrated Community Equipment Services
- Access to Work

The table below summarises what each of the sites is trying out in respect of IBs

Site	**Who will they be trying Individual Budgets for?**
Gateshead	People with learning disabilities, people with physical disabilities, people with sensory impairments and people who use mental health services at times of transition from children's services to adult services, and from adult services to older peoples services.
Coventry	People with learning disabilities, people with physical disabilities, people with sensory impairments and people who use mental health services. They will all be people who are going through big changes in their lives - e.g. growing up, moving from education to employment, leaving a family or other 'supervised' home to live more independently, moving from hospital or rehab to living in the community or at home, and people who are coming home from living in an 'out of city' placement.
West Sussex	Older people.
Manchester	Older people - people with neurological illness, renal patients.
Oldham	All adults including older adults.
Barnsley	All adults including older adults and young people in transition.
Lincolnshire	Starting with older people, but later to include all adults.

Barking and Dagenham	Older people, people with learning disabilities and people with physical disabilities, and people who use mental health services.
Kensington and Chelsea	Older people and people with physical disabilities.
Leicester	People with learning disabilities, people with physical disabilities and people with sensory impairments. May include other people later in the pilot.
Bath and North East Somerset	People with a learning difficulty, older people and younger people with a physical or sensory impairment.
Essex	People with learning disabilities, people with physical disabilities, family carers.
Norfolk	People with mental health problems.

Source: CSIP (2006)

What are the challenges?

Developing IBs is not just about changing who spends the money. The following section summarises the key challenges for nursing and for the whole health and social care system in implementing IBs based on numerous reviews and reports on the progress of the pilot projects so far.

Public perception

There is already a well established public dialogue around the issue of patient choice and becoming the recipient of personalised services. However on first reading of IBs, members of the public might be put off by the idea of administering a fund of any kind – there may be a misunderstanding that some kind of financial skills may be required. In addition, there might be considerable anxiety around changing the way services are delivered when they have previously proven to be reliable. Changing something which has "always worked" in the past can be

challenging, particularly if the experience of setting these services up in the first place was complex.

However early user experiences show that "freedom" and "independence" were terms most commonly associated with Individual Budgets[8] (although that was in comparison with another scheme, direct payments). There is clearly a right time to raise the issue of changing from one system of service provision and commissioning to another. There will also be, at least initially, a range of people for whom this change is appropriate given their needs.

Each member of the public will need time and space to consider the options. Despite the relatively positive feedback shown above, participants in the pilots also felt that support networks for IB holders and their families would be essential in order to help advise and develop understanding around IBs[9]. Some pilot sites have used patient stories to great effect in helping potential IB holders understand the potential benefits and issues that they bring.

For a range of case studies and real examples of IBs in action, you can refer to the joint newsletter published by the DH[10] or go to the main IB website run by the CSIP[11]

Staff involvement and participation

The IB scheme process starts with a potential recipient filling in a Single Assessment Questionnaire. Given that IBs are supposed to reduce the amount of form filling and administration, the SAQ is quite a large document that has to cover a range of eventualities.

However, it provides an opportunity for a comprehensive assessment of the recipient's needs and can be a useful starting point for a constructive relationship.

IB pilot participants and various reviews of the scheme so far have all recommended that a high level of support be available for members of the public going through this process[12]. As with all assessments, staff offering

[8] ISBEN (2007) '*Individual Budgets Evaluation: A Summary of Early Findings*' Individual Budgets Evaluation Network. This research is funded by the Department of Health. More information on the
IB evaluation is available at www.ibsen.org.uk

[9] Rabiee, P and Moran, N. (2008) '*Interviews with early Individual Budget Holders*' Social Policy Research Unit, University of York

[10] The National Centre for Independent Living has published a joint newsletter at www.ncil.org.uk/uploads/pdf/ib_newsletter_july_07_final%5B1%5D.pdf

[11] Click on the news section at www.individualbudgets.csip.org.uk/index.jsp for the latest newsletter

[12] CSIP (May 2007) '*Older People's Services and Individual Budgets - Good Practice Examples and Ideas*' This paper was commissioned by Judith Whittam, Individual Budget Pilot advisor for the Care Services Improvement Partnership.

this kind of support will need time to allow an unhurried assessment and particular skill in eliciting the most accurate and useful information.

Once the scheme is up and running, it is not simply a matter of leaving the service IB holder to get on with it. They are likely to need considerable advice in the early stages of holding an IB, in particular around legal and employment issues.

Despite the potential for technical and financial issues to arise, social care staff involved in a similar scheme, Direct Payments, reported that this kind of partnership with the public can act as an opportunity for staff to take part in genuine 'care' rather than be immersed in running or working for a service. In a sense, putting the patient in charge of the commissioning process has reduced confusion over roles and provides more clarity around the recipients 'actual' needs.

Technical issues

As the pilots have rolled, there have been a range of technical issues which have arisen where the IB scheme rules have had to be clarified in respect of existing funding schemes or legislation.

As an example of one of the issues raised during the pilot, IB holders have chosen to give some of their IB to a family member in lieu of the care and support they have previously given for free. IB holders were unaware that this may have implications for the family members NI and Tax payments (payments made to carers under IB will be treated as a taxable income[13]) or may affect the level of benefits a family member can receive. In this situation the Government response was inconclusive other than to recommend the individuals seek an assessment from HMRC. Whilst this may be appropriate for a small number of cases, at some point, Government may have to consider amending legislation to clarify responsibilities and ensure that the IB scheme doesn't adversely impact on the financial security of IB recipients and their carers.

In addition to the technical issues and given the transfer of spending decisions from a large authority to individuals, governance also has to take on a new character which allows spending decisions to be monitored without giving the IB recipient a feeling of being controlled or disempowered.

[13] CSIP (2007) Financial matters issues log. Advice from DH is that "…most equipment designed specifically for use by disabled people is VAT exempt (VAT relief for disabled people, HMRC reference 701/7, August 2002) and personal care services e.g. PA s, home care, are VAT exempt (Welfare, HMRC reference 701/2, February 2007)…". However "People being paid by IB holders are not exempt from income tax and national insurance requirements. Vouchers or other benefits given to employees may or may not be subject to income tax dependent on circumstances. Individual cases should be referred to HMRC for individual ruling."

Outcomes from the care given also need to be tracked to ensure that value for money is being obtained from the perspective of the recipient, the LA and the provider or broker. Agreeing what a quality outcome looks like, how it is measured and by whom will be an essential part of the contractual conversation between commissioners and providers.

Impact on service markets

Moving from volume contracts to a more flexible source of income is likely to create some anxiety for providers not used to such variations. On one hand it could create powerful incentives for providers to improve service quality and ensure a high level of satisfaction from service users.

On the other hand, the roll out of IBs could destabilise the market leading to merger and acquisition (therefore a reduction of market choice for service users) or provider withdrawal from the market altogether either by choice or through financial failure.

For some speciality areas of need, it is unlikely that a real market for different forms of provision will emerge and so standards of service in such markets will need to be carefully monitored.

In some of the pilot sites, IB holders have chosen to pool their budgets to give them greater buying power. Whilst sounding attractive, this is an added layer of complexity for managing IB the governance and probity.

IBs and Nursing – issues to consider

At this stage of the pilot, it is too early to tell to what extent IBs impact upon staff of any profession least of all nursing. It is unclear from pilot site feedback to what extent nursing has been involved or impacted, however, it is clear from recent ministerial announcements that IBs are likely to figure highly in future policy to deliver services to people with LTCs – an area characterised by a high population of nurses and nursing care support workers.

Crudely, the main issues might be categorised under two headings 'professional' and 'employment' issues:

Employment Issues

Changing the nature of commissioning and provision will have a fundamental effect of organisational structure and culture.

Under the Direct Payments scheme, there has been a mixed reception but common concerns raised about employment stability, variations in pay for workers employed by users, and complicated regulatory and professional

issues arising out of direct employment by members of the public[14]. Regarding over night care there are also concerns of breaching the European Working time Directives and the Statutory Minimum Wage.

Professional Issues

In terms of professional or practice issues, in a number of articles around the development of direct payments, staff commonly cited concerns around issues of consent, control and management of direct payments, all of which have been implicated as factors contributing to reluctance amongst certain groups of staff (and users) to embrace direct payments. Whilst IBs are different in some respects, lessons should be learnt from this experience and built into roll out processes.

Staff development needs should be carefully identified and met in a timely fashion. Consultation over changes to team structures and job roles should be as inclusive as possible with generous time given for full discussions and a frank exchange of views.

Another consideration is the role of voluntary care agencies such as Age Concern and Friends and Family. Caring Choices state that 'the government has acknowledged the important contribution made by unpaid carers such as friends and family but there is great scope for development here'. They often play a dual role of carer and advocate and some sites are actively working to extend the range of options and support available. The accountability relationships between patients, employees, volunteers and carers will have to be carefully thought through to make clear who is responsible for which part of the care package.

Clearly a high degree of leadership is required during the implementation and roll out of any such scheme in order to assure staff that such issues are covered but also to provide a useful focus for handling problems when they arise and championing the project.

Finally, this represents a new frontier for regulators to contend with. Guidance from regulators like the NMC will have to be made available to members of the public in an accessible manner and staff will need clear guidance from the NMC about the possible conflicts of interest that may arise whilst working in such close proximity to patients, their families and their carers.

It is clear that moving the nurse/patient relationship from one where the patient is a passive recipient of services to one in which they are more akin to an active consumer is going to create new dynamics. As a profession,

[14] For a full account of the impact of Direct Payments, read '*The national survey of Direct Payments: Policy and Practice*' produced by the Personal Social Services Research Unit and the London School of Economics (May 2007)

nursing will have to consider the impact of that change on pre and post registration education as well as in clinical practice.

Conclusion

IBs offer an opportunity for the public and for nursing staff to develop a new relationship and one which is more personalised and underpinned by true partnership rather than institutional and dictatorial.

However we should ask critically if giving such financial controls to members of the public is the only way to deliver personalised services, as suggested by some,[15] or are there other ways of releasing members of the public to take an active, leading role in commissioning services that we have not explored?

There is a need for:

1. A clearer central government definition of the national guidelines for eligibility for both the service users and the commissioners

2. Appropriate training for the providers, commissioners and the advocates to maintain a fair and consistent provision of care packages nationwide

3. A central cross departmental effort to identify all the technical implications of IBs for staff, carers and patients

In a policy environment in which it is increasingly assumed that our preferences are expressed solely through how we spend our money, IBs should not be a surprising development to nursing, particularly in services where there is an on-going and sometimes changing need for support (for e.g. mental health, physical and learning disabilities.)

However, whether it has been sufficiently thought through that the Government can boldly announce the extension of IBs to people currently receiving what is essentially free NHS care remains to be seen.

When the pilot scheme report is launched in the Summer of 2008, we will be developing our policy further. If you are involved in the pilot scheme or have other experiences which you think will be useful in developing RCN policy, please contact us at policycontacts@rcn.org.uk

[15] Vidhya Alakeson (2007) 'Direct Dollars' *Mental Health Today*; Mar 2007; ProQuest Nursing & Allied Health Source: RCN Edition pg. 16

Appendix I

The following case studies give an illustration of how an individual budget can work to give greater control over care delivery and help secure lower cost provision. The case studies have been provided by RCN members and have been anonymised to protect the identity of the service users and their families

Clients A & B

A is18 years old and B is 21 years old, both young people live with their parents at home. There are no other siblings and the family home has been fully adapted and financed by the family.

Both young people need ground floor accommodation that is fully accessible with enough space to accommodate specialist medical equipment, seating, beds, aids and adaptations plus room for additional people to care for A and B.

Mum is unable to work because of her caring responsibilities therefore Dad is the sole breadwinner. Mum spends most of her time filling gaps in the current support system, negotiating social and health care systems, identifying risks, navigating health care appointments and contact with numerous health care professionals and managing crisis, this is not an exaggeration as both young people have such complex needs that within a short space of time either young person could have developed life threatening circumstances.

Nature of impairment and needs.

Both A and B have significant, complex and unstable health needs associated with their disabilities. Their impairments are caused by a genetic condition that is life limiting, meaning that the older they get the more complex their impairments are becoming and, as a consequence, the greater the dependency on medical and technological support and the competency of support staff around them becomes.

A has recently had a tracheostomy fitted and needs regular intra-tracheal suction. This followed a sudden recent deterioration, which has subsequently been further complicated by respiratory pseudomonas.

A also needs 24 hour constant support with a variety of other chronic conditions such as seizure management including emergency rescue

treatment, management of Percutaneous Endoscopic Gastrostomy (PEG), continence support and so on.

One cannot overestimate the complexity of care arrangements needed in this situation, having two young people in the same household increases the risks and variables tremendously

Mum's health is now beginning to fail.

Current services

Adult learning disability services, from pooled budgets, commission a local voluntary organisation to provide 24hour support, they in turn commission qualified staff via a nursing agency or the PCT and provide unqualified staff support directly.

The complexity of health needs cannot be met by untrained staff support.

Total current cost of package is about £350,000 for both young persons.

A local nursing agency provides a number of qualified nurses but there is no consistency and little chance to develop meaningful relationships.

Both A and B need support staff around them who are clinically competent, know, understand and can interpret changes in behaviour and condition and act accordingly and swiftly.

Neither young person can communicate easily therefore the quality of relationships and the competency of support staff is pivotal.

Responsibility for overseeing the support in theory lies with services but in reality stays constantly with the parents, usually Mum. The family are deeply unhappy with the current arrangements but have no opportunities or authority to change the current service provision.

How could things be done differently? / How are things done differently now?

A learning disability pooled budget of £254,000 has been identified as an 'indicative' individualised budget (representing a saving to services of £100,000). The family are now, for the first time, clear in terms of the financial constraints and are able to begin a planning process that will lead to the development of person centred and family directed support teams.

It is envisaged that the family may recruit a personal facilitator to co-ordinate and oversee the support system and begin to take some of the responsibilities from the parents, who are wanting to develop longer term plans to secure appropriate support for their children for the future.

Having a personalised budget means that the family gain more control and therefore, potentially, removes one of the biggest stressors i.e. Having all the responsibility without any power to change things

What is getting in the way of doing things differently?

Current NHS legislation prevents continuing care / NHS funding being included in an individualised budget therefore preventing the family constructing a personalised support system, in reality this means care options open to A and B under current conditions translate into either nursing home provision, community nursing teams or agency nurse staffing.

An absence of ability and willingness from services to harness the capacity, competency and goodwill of families and work in partnership gets in the way.

The most competent people in both A and B's life are their parents…not to recognise this and invest in their capacity and capability to construct sensible support doesn't make financial or moral sense.

Client C

C is 14 years old and lives at home with his parents and younger brother. The family home has been extended to include a fully adapted ground floor living space for C; this was financed by the family re mortgaging their current property.

C has a diagnosis of 'neuronal migration disorder' this means that his brain didn't develop properly and as a result he has many associated complex health needs such as requiring constant care for a Tracheostomy, a Gastrostomy, severe visual impairment, complex epilepsy (allergic to diazepam) and digestive and elimination problems

Current services

The PCT commission services via the local acute trust who then provide a 24 hour community based nursing team of qualified and unqualified healthcare assistants who carry a small 'caseload' of 4 to 6 children (overall cost of team is unknown) at an estimated cost of £200,000 for C's support. The team is managed by a number of qualified nurses with direct care to C provided by an ever changing team of Healthcare Assistants who are trained to meet his medical needs by the qualified nurses.

Although there is round the clock support for C, the model of care provided is very medical / nursing orientated with 'clinical risk' uppermost in the perceived hierarchy of needs. This translates as C being seen as a series

of medical conditions that have to be met rather than a child with additional complex needs.

The family have no control over staff appointments and this often brings them into unnecessary conflict with the qualified nurses and causes great anxiety in the family.

Mum has to be able to trust the appointed staff, who in turn have to be able to establish a long term relationship with C – the nature of the team means that staff turnover is high, with health care assistants shared between several families rather than bespoke wrap around support teams for each individual child.

C is also approaching transition into adult services, which, if the situation is not addressed, will mean the existing 'children's' service will stop and a new service will have to be constructed from adult services (this does not exist at the moment).

In the long term this is disastrous as potentially relationships and competencies that have taken years to develop are dumped because of service splits between adult and children's teams and funding.

How could things be done differently? / How are things done differently now?

Family are working in partnership with the local PCT to establish an individualized budget and from this a bespoke wrap around staff team within which the family can have control over the finance, staff appointed and quality of care given and at the same time the PCT stay within current NHS legislation and retain clinical governance responsibilities.

The PCT are about to commission an independent review and options appraisal and family and PCT have established a steering group to oversee the process this is made up of the family, PCT director of nursing, independent consultant advising family.

An individual budget will provide the family with an actual amount of money that they can spend according to the felt needs of the client. The role of the PCT shifts from being the designer/purchaser or services to one of advocate, adviser and contractor on behalf of the client.