

## Personalised Budgets Consultation

### *A Submission to the Department of Health*

The Citizens Information Board (CIB) is a statutory body under the aegis of the Department of Employment Affairs and Social Protection with responsibility for the delivery of information, advice and advocacy services to the public and with a specific remit in respect of people with disabilities. The CIB funds and supports Citizens Information Services (CISs), the Citizens Information Phone Service (CIPS), the Money Advice and Budgeting Services (MABS) and the National Advocacy Service for People with Disabilities (NAS). The Board also supports the Sign Language Interpreting Service (SLIS) and runs the Assist Ireland website and helpline which provides information on assistive technology (aids and appliances) for older people and people with disabilities.

### **In your opinion, what should personalised budgets be used for?**

We believe that this question can only be answered by first fully and clearly defining the target group for personalised budgets, i.e., people with disabilities. The term is typically used generically to refer to a broad spectrum of people, including those with a physical, sensory, intellectual disability and those experiencing mental health difficulties. There is also clearly a wide range of ability/disability within each of these groupings. Individuals will both need and want different supports. The 2012 New Directions Report<sup>1</sup>, for example, noted that people want flexible supports suited to their needs, for example, some need assistive technology, others would benefit from a 24/7 helpline at weekends, staffed by experienced community nurses.

Personalised budgets should, therefore, be used primarily to give people a greater amount of choice over the service they receive on the basis that different people will want different things from different providers.

In determining what personalised budgets should be used for, it is also necessary to take full cognisance of the core characteristics of a personalised budget approach:

- Determined by the person (in collaboration with their family/advocate as required and in consultation with an independent assessor) and not the service provider or other experts
- Directed by the person (with their family/advocate as required)

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<sup>1</sup> <http://www.hse.ie/eng/services/publications/Disability/newdirections2012.pdf>

- Provided on a one-to-one basis to the person and not in group settings (unless that is the specific choice of the person or a natural group activity)
- Flexible and responsive, adapting to the person's changing needs and wishes
- Encompassing a wide range of sources and types of support so that very specific needs and wishes can be met
- Not limited by what a single service provider can provide

Taking all of the above factors into account, the following are likely areas of usage of a personalised budget:

- Supports for independent living, including, in particular, *Personal Assistants* and essential transport costs
- Home care support services
- Psychological services
- Therapies – physiotherapy, occupational therapy, speech and language therapy
- Treatments such as chiropody
- Respite care (in-home and outside the home)
- Residential care services for those who have been deemed to require such on the basis of a comprehensive and integrated assessment of their needs

The focus of the present consultation is on a personalised budgets approach in respect of HSE funded services and introducing the model initially for these services clearly has merit and is pragmatic. However, in the longer-term the concept of personalised budgets must be extended to include other aspects of living, in particular, housing supports, education/training and engagement in social and cultural activities across the life-cycle.

**With reference to the supports and services available for this phase of implementing personalised budgets (Section 4), what are the top 3 things you think people would spend a personalised budget on (e.g. personal assistance services, home support, residential services, adult days services in line with New Directions, respite services, etc)?**

Assuming that living independently or semi-independently in the community would be the preferred option, people would be likely to spend a personalised budget on:

1. Personal Assistance services
2. Home supports
3. Day services and transport

People with more severe forms of disability who are being supported and cared for by family members, would be likely to spend their personalised budget on:

1. Home care assistance
2. Respite care
3. Therapies
4. Psychological support for family carers

For people who cannot live independently and require a residential facility a key question is how the personalised budget approach will relate to the current system of long stay contributions towards maintenance and accommodation costs in HSE facilities or Section 38 funded settings.

### **What are the key advantages in having a personal budget?**

It is widely acknowledged that people with disabilities and their families, more than anything else, are looking for more choice in the services they receive and more control over how they access them.

The personalised budgets approach is based essentially on the concept of Consumer Directed Care (CDC) which is a model of service delivery designed to give more choice and flexibility to consumers. Consumer-directed services are aimed at empowering clients and family carers, giving them maximum control over the *what*, *who* and *when* of needed care.

Under the CDC approach, care recipient's own needs assessment and care planning are based on there being a 'basket of services' available from which individuals can select services to meet their needs rather than a one size fits all approach. User choice as an ideal is implemented through choice of services, choice of funding approach (personal budget or service provision) and choice of provider. In the case of the latter, publicly available quality reports on service providers would obviously be of value to consumers.

The Personalised Budgets approach provides a necessary platform for implementing the provisions of the UN Convention on the Rights of Persons with Disabilities, in particular, maximising individual potential; supported decision-making; independent living choices and options; consumer choice; community/neighbourhood integration; information and advocacy support; individually-tailored health and social services and equality of educational and training opportunities. Article 19 of the Convention is particularly relevant in the context of the personalised budgets approach in that it requires States parties to recognise the equal right of all persons with disabilities to live in the community with choices equal to others, and to take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community.

The Personalised Budget model offers scope for greater convergence between social inclusion measures (equality of access to health, housing, employment and welfare supports) and human rights and equality measures. Giving individuals more control over their lives clearly enhances their ability to shape and direct their own particular living context.

### **From your perspective, what would be the biggest challenges in administering personal budgets?**

The transition from block-funded services to individualised supports is a complex task which is not simply a case of replacing one set of mechanisms with another. A key consideration in

a successful transition is the adoption of a vision and a strategy for addressing needs which includes embedding the voice of people with disabilities in the service delivery system. This presents significant challenges in respect of people with more complex support needs.

Access to independent advocacy support may be necessary to ensure that provision is made for the full exploration of choices and options by or on behalf of each individual, e.g., people who require support in exercising their will and preferences in accordance with the provisions of the Assisted Decision-making (Capacity) Act 2015.

Crucial to the successful implementation of a personalised budgets approach will be an objective, independent, comprehensive, consistent, integrated and nationally standardised needs assessment process to determine the nature and scale of assistance required. The purpose of needs assessment should be to help determine an individual's eligibility for or entitlement to benefits or services on the basis of agreed and transparent criteria. Such criteria should include the following essential components:

- The level of dependency and/or needs of individuals in respect of health, housing, social care and transport needs
- Establishing the will and preferences of individuals as to how the care and support they require should be provided
- Using a multi-disciplinary approach to assess needs and design appropriate responses
- Identification of the role of different State agencies in meeting identified needs relating to accommodation, home care supports and nursing requirements
- Establishing in a realistic and transparent manner the respective potential contribution of family members, community/neighbourhood networks and voluntary/community organisations
- Providing for choice of provider where the services required have to be purchased from private providers to enable people to choose those that best suit their preferences

The Law Reform Commission<sup>2</sup> has recommended that care needs should be assessed under the following range of headings in respect of the care recipient:

- Companionship needs
- Care needs
- Advanced home care needs

The Commission also recommended that the level of care should be appropriately attuned to the actual needs of the person, thereby promoting the autonomy and independence of the care recipient to the fullest degree (2.19). The Commission concluded that examining a person's needs under companionship needs, home care needs and advanced home care

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<sup>2</sup> Law Reform Commission (2011), <http://www.lawreform.ie/fileupload/Reports/r105.htm>

needs would ensure that their needs are adequately assessed and the appropriate level of care provided.

“It is important that the level of care should be appropriately attuned to the actual needs of the person and that special care is taken to ensure that the level of care provided is not too high because to do so may negatively impact on a person’s independence ...” (2.17).

### **What supports do you think would need to be put in place to help people to use a personalised budget?**

- Supports for individual self-assessment of needs should be included as part of the process
- A regulatory and quality monitoring framework must be in place that can ensure that people are not exploited and that people are helped to manage risk
- Opportunities and forums for sharing innovations and best practice should be promoted
- Transparent and staged transition arrangements need to be put in place
- Service providers need to be given time to prepare for the implementation of a personalised budgets approach in order to enable them to tailor their services accordingly
- Personalised budgets should be managed and administered in a variety of flexible ways and a range of options should be available that reflects the diverse and changing needs of service users and their carers – this should build on international experience and related best practice
- There is a need to further develop an empowering service provision ethos based on person-centred practice, thinking and planning and on promoting service user choice and control – this will require an attitudinal shift on the part of both service users and service providers
- People with disabilities accessing personal budgets should be supported in their decision making through the provision of capacity-building programmes, including information and education
- There should be provision for people availing of a personalised budget to have access to an independent advocate particularly in cases where there is conflict with a service provider, a member of the person’s circle of support or where there is an issue around the level of personal funding that the person is receiving
- Independent advisory, support and broker services should be available to service users wishing to access personalised budgets

On the latter point, it would be essential that a planning support mechanism and brokerage support is available to individuals, families and support networks. This is required in order to facilitate people in identifying needs, strengths and goals. It is also necessary to help people explore the potential of community and family supports.

Other necessary aspects of such a mechanism would be costing supports, applying for funding, negotiating agreements, arranging support providers, funding management, and ongoing planning and support management. This planning support mechanism needs to be independent from service providers and funders while allowing for maximum collaboration between individuals, funders (the State) and service providers.

Since individuals with disabilities often require support from trusted others (family, friends and professionals) it is important that the development and maintenance of such personal support networks is facilitated and enhanced as far as possible in the personalised budgets model.

### **What changes do you think having a personalised budget would make to the life of a person with a disability?**

People with disabilities and those experiencing mental health difficulties require the same level of choice and control in everyday life that most people take for granted. In this regard, it is almost certain that a personalised budgets approach would radically change the landscape for this population sub-group. In particular, people would be enabled to explore new ways of using and developing their abilities and maximising their capacity while at the same time choosing the way they receive support.

In addition, the personalised budgets approach would over time result in a move away from the traditional approach in Ireland where funding has been allocated to service providers who then offer a set menu of services to people and families. Increasingly, people are seeking greater choice and control over how their funding is used and the personalised budgets approach can significantly support this. Services can also be enhanced through greater dialogue about what individuals and families want in terms of support and services.

It is also likely that giving service users a stronger voice will result in more appropriate policy decisions and support programmes. This is particularly important in the case of young adults with an intellectual disability for whom current post- second level education options are extremely limited.

### **What is one important change you would make to the way you use services and supports provided if you had a personalised budget?**

This question is targeted at individual service users rather than organisations, but in our view, self-direction and user (rather than provider) definitions of need should become central to the service delivery ethos.

The added value that can come from using an approach that does not start with a standardised model of service or support, but rather with the question of what can be done to enable a given person to obtain and enjoy the rich possibilities embedded in normal lives in the community, would, we believe, transform fundamentally the lives of people with disabilities.

### **People using a personalised budget will have to provide some information on how it is being spent by them. What type of information would you expect a person to have to provide? How often would you expect them to have to provide this information?**

It would be reasonable that people be expected to provide some overview of how they spend their allocated budget and how this relates to their needs assessment. Where

contracts for care are entered into a breakdown of hourly costs for service and the terms of supply should be included to ensure visibility around the kinds of charges being incurred for similar types of provision. Provision should be made in any reporting template for people to identify their changing needs.

It is important, however that reporting would not be overly burdensome or require minute spending details if the principle of a personalised budget where the individual has control and choice is not to be undermined. The concept of reporting by exception and on a changing needs basis rather than routine administrative reporting should be considered.

There would be a requirement to have in place support structures at local level to enable individuals and families to fulfil any reporting requirements. Such support could be provided by an NGO or by a broker.

### **Do you have any other ideas on personalised budgets that you would like to include?**

The basic premise of the personalised budgets approach is that personalised lifestyles, largely directed by people themselves, are both feasible and desirable. This means keeping the person and their search for a way of living and being that suits them at the centre of all decisions and funding allocation.

There is a particular challenge in including people with more severe intellectual disability in the personalised budget approach. A personalised budget may become meaningless if a person does not have legal capacity to enter necessary agreements. Therefore, it is crucially important that this aspect of any personalised budgets mechanism introduced is clarified and the necessary legal provisions, including supported decision-making in accordance with Assisted Decision-making (Capacity) Act 2015, are put in place to protect individuals who are deemed not to have the required capacity to enter into contractual service arrangements.

The personalised budgets approach must be governed by the presumption of legal capacity. This means that everyone has legal capacity but some people need more support than others in exercising that capacity. Capacity should be assessed in accordance with the provisions of the Assisted Decision-making (Capacity) Act 2015.

A personalised budget should be based on an individually-tailored plan which addresses the disability-related support needs of the person, includes individual goals across the life-cycle, identifies least costly alternatives consistent with principles of social and community inclusion and maximises the potential of personal and community support networks.

Care needs to be exercised to ensure that those who do not have personal or community support networks are treated equitably. Ensuring fairness in allocations on the basis of striving for equality of outcomes should be the guiding norm.

Personalised budgets should be provided in a manner that allows people (with support as required) to purchase supports in ways that are accountable to and manageable by an individual or network and in a manner that can be monitored. Provision should, therefore,

be made for support for individuals to help them to manage individual support arrangements and to revise their supports as required.

Community-capacity building (which has been regarded as a weak link in some other jurisdictions) would be an essential component of any personalised funding approach. The focus would be both on creating the capacity of communities to develop a supply of specialised supports and on enabling access to community-based services (e.g., recreation, transportation). This would require an investment in community capacity building in order to allow natural support systems to evolve. In this regard, the CIB notes the view of the National Disability Authority that better outcomes for people with disabilities can be achieved through aligning services with the policy goals of promoting community integration, independent living, choice and participation.<sup>3</sup>

The challenge is to optimise (from both a resource efficiency and an individual needs perspective) the potential respective and complementary contributions of family and community supports and mainstream services as well as the more specialised disability services.

The respective roles of the individual, his/her family and the responsible service professionals in the planning and organising of services must be clarified in the new model. There is a need for clear guidance on how the family is to be included in decision-making in cases where the family is a significant provider of care and support and/or where a person's capacity may be impaired.

To be economically sustainable into the future, and to fulfil the expectation that care requirements in the future will be honoured, the personalised budgets model needs to coordinate care resources and set eligibility criteria to deliver the appropriate level of service to a variety of different categories of people.

While increasing choice to people with disabilities almost certainly improves their sense of well-being, it should be borne in mind that, for some, the additional burden of decisions and administration can lead to apprehension and worry. Care must also be taken to ensure that any attempt at cost saving through the use of a personalised budgets approach does not result in unregulated, unskilled workers replacing qualified and protected workers. On this point, there continues to be an absence of a regulatory structure for the delivery of professional care in the home -- this issue was addressed in a 2011 Law Reform Commission report, *Legal Aspects of Professional Home Care*.

It is essential that there be clarity of definition and understanding of the term 'personalised budget' which is essentially an amount of funding allocated to a person to enable him/her to determine which services they wish to purchase to meet their expressed needs. There also needs to be clarity in relation to how a personalised budget may be paid -- directly to a service user in the form of a direct payment or paid indirectly through another person, broker or agency or a combination of both and clear criteria in this regard.

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<sup>3</sup> <http://nda.ie/nda-files/Advice-paper-to-the-Value-for-Money-and-Policy-Review-of-Disability-Services-Programme1.pdf>