



INCLUSION IRELAND

National Association for People with an Intellectual Disability



NUI Galway

**CENTRE *for* DISABILITY
LAW & POLICY**

Essential Principles of Personal Budgets

Introduction

'Essential Principles of Personal Budgets' aims to establish what the key ingredients are for effective operation of a personal budgets system in Ireland.

In October 2016, The Minister for Disabilities established a Taskforce to make recommendations on a personalised budgets model which will give people with disabilities more control in accessing health-funded personal social services.

The Taskforce on Personal Budgets proposed two goals, underpinned by principles and values. Goal 1 - Full inclusion and self-determination underpinned by the principles and values of citizenship, control, informed choice, self-determination, responsibility, inclusion and participation.

Goal 2 - The creation of a cost-effective and responsive and accountable system which will support the full inclusion and self-determination of people with disabilities underpinned by the principles and values.

In this document, we set out what we believe the key elements of any personal budgets system should be.

Language

We are using the term 'personal budgets' throughout this document. We believe that this centres the process on the individual and that the budget is centred with the person.

We further believe that this is a more easy to understand term.

The preferred term by government is 'personalised budgets', which uses the verb of 'to personalise', which could be interpreted as being personalised for a person instead of by them and for them.

The term 'individualised funding' is also commonly used.

Essential Principles of Personal Budgets

1. Personal budgets should be available to all persons with disabilities

1.1 Personal budgets should be available to all persons with a disability regardless of age or nature of disability.

1.2 A person should have access to a personal budget regardless of services they are already receiving including people in residential settings.

1.3 Access to personal budgets for all persons with disabilities is necessary for equality and fairness.

1.4 A person's right to control what services they want to avail of should not be determined by an upper or lower age threshold.

1.5 A person's right to control what services they want to avail of should not be determined by the nature of their disability.

2. Personal Budgets should be cross-departmental and joined-up

2.1 The provision of personal budgets must be approached from a cross - departmental perspective with a solid commitment to co-ordination between the appropriate departments within the government.

2.2 Each department should develop a unit to co-ordinate that department's personal budget responsibilities.

2.3 A focal point for the co-ordination of personal budgets must be established and to act as a mechanism for all stakeholders to cut down on the burdensome administrative requirements.¹

¹ Based again on the experience of the UK, if the NHS and the social care services provide services to an individual they can do this through a joint funding mechanism while also having one reporting and oversight structure in place. This is a system that could be adapted to the Irish context also.

3. Personal Budgets should focus on achieving personal outcomes

3.1 A focus on outcomes should be one of the key principles underpinning a personal budgets model.

3.2 Examples of outcomes might include where a person is

- Living in their own home in the community,
- Making choices and exercising control over their everyday lives,
- Participating in social and civic life,
- Having meaningful personal relationships,
- Working or performing another meaningful social role.

3.3 Using an outcomes approach, accountability is achieved by measuring whether people are living an everyday or good life.

3.4 An outcomes approach requires starting from a position of trust with the focus on supporting the person to make good decisions rather than controlling them.

3.5 A balanced approach to risk that prioritises choice and control over safety is important whilst ensuring each individual is supported.

3.6 Education and capacity building for budget holders or their family supporter is important. Training on how to imagine a good life and practical skills building must be available.

3.7 Good quality, accessible information and advice must be widely from independent sources.

4. Values should underpin a Personal Budgets system

4.1 The concept of independent living is an essential part of the individual's **autonomy**. Person-centred is not enough if the individual is not the one expressing their will and preference. Freedom to choose the supports and services that best suit one's individual support needs is central to autonomy.

4.2 Personal Budgets should be administered in a **democratic** fashion and this involves persons with disabilities having an equal say and having their voice heard. Systems that are put in place must ensure accountability but they must also be reflective of the voices of persons with disabilities and their needs.

4.3 The value of **social justice** requires a personal budget to be sufficient to meet the agreed need of the individual in order to live a good life.

4.4 The accessibility, availability and adaptability of publicly-funded services is core to **dignity**. A one-size-fits-all approach does not foster dignity. Personal budgets allows a person to choose the supports that best reflect their personhood.

4.5 Personal Budgets are a practical step towards removing institutionalised barriers and towards the full **inclusion**, visibility and participation of persons with disability in society. Inclusion involves a person taking part equally, being positively valued in an environment typical of their age, peers and culture.

5. A Human Rights and Equality Based Approach should be adopted

5.1 Self-determination is enshrined in the Universal Declaration of Human Rights and a personal budget model should encompass self-determination.

5.2 Personal budgets should reflect the principles of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

5.3 Persons with disabilities should have access to services, including personal assistance, necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community. (Article 19)

5.4 All persons with disabilities should be entitled to access personal budgets irrespective of their age, sex, ethnic background, language, social condition, migrant, asylum-seeking or refugee status. (UNCRPD Committee)

5.5 Personal budgets should take into account and address the challenges that persons with disabilities face when living in rural and or urban areas. (UNCRPD Committee)

5.6 Equal recognition before the law is essential for the operation of personal budgets and should be consistent with the requirements of the Assisted Decision-Making (Capacity) Act 2015.

6. People should have choice about how they receive a Personal Budget

6.1 The personal budget should be sufficient to live a good life.

6.2 The individual should make or be supported to make a choice in accordance with their will and preference.

6.3 A personal budget can be administered as a direct payment (cash payments are given to people in lieu of directly provided services) or through a broker (a service that holds and manages a person's fund and provides support and information)

6.4 Individuals using traditional services should have the option of unbundling funds from that service.

7. Personal Budgets should be flexible and responsive

7.1 Personal budgets should allow for creativity and be portable and flexible as a person's circumstances change or as they age.

7.2 A personal budget may increase or decrease in amount, depending on a number of factors.

7.3 The personal budget holder should have flexibility in how they spend that budget to meet their identified outcomes.

7.4 Persons can change their mind about availing of a personal budget or how it is allocated.

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