



**ACQUIRED
BRAIN INJURY**
IRELAND

**Submission on Personalised
Budgets for People with a Disability**

**Department of Health
Task Force on Personalised Budgets**

October 2017



Introduction

Acquired Brain Injury Ireland (ABI Ireland) welcomes the opportunity to make a submission to the Task Force on Personalised Budgets.

The submission highlights the particular issues that need to be considered specifically in relation to the population of people with acquired brain injury (ABI).

ABI Ireland firmly supports the principle of promoting choice and control in the lives of people with ABI and welcomes initiatives that promote these principles. In addition, ABI Ireland recognises that people with ABI need specialist inputs and services as part of the ABI pathway. **Emerging policy discourse on personalisation of services for people with disabilities must recognise the role of specialist services, where and when they are needed.**

Insight into the condition and nature of ABI

Brain injury is a complex condition. It affects the person's ability to negotiate one's way through life, work and relationships.

Lack of insight into their disability, is a significant issue for some people with ABI and therefore the model of personalisation must be able to respond. People with ABI will require high levels of supports in the process of gaining access to and sustaining a personalised budget in the long term.

Difficulties with cognitive and executive impairments, particularly reduced insight, may preclude people with ABI from easily developing and communicating knowledge of their own situations and needs. This can be further exacerbated when people with ABI receive limited or non-specialist supports. Effective and accurate assessment of need following brain injury is a skilled and complex task requiring specialist knowledge. (Holloway and Fryson, 2016).

People with ABI may have difficulties with decision making and applying everyday judgement. They also may have impulsive responses as well as being vulnerable to abuse by those around them. A model of personalisation that works well for cognitively able people with physical impairments is unlikely to work for people with ABI. Holloway and Fryson (2016) note that there are mixed results in relation to the personalisation delivery mechanism in England. They conclude that people of working age with physical impairments are most likely to benefit. They also note that none of the major evaluations of personalisation have included people with ABI so there is no evidence to support the effectiveness of self-directed support and personalised budgets with this group.

Consent and capacity

As indicated, following an ABI, the person may have little or no awareness about their physical, cognitive, personality or behaviour changes and they may fail to see how acquired impairments impact their ability to effectively execute activities of daily living. Lack of insight can be caused by impaired self-monitoring, reasoning, attention and concentration, learning and memory, and reduced emotional coping or acceptance (denial). A person with impaired insight or self-awareness may not appreciate the implications of their impairments for decision-making or life planning. **The**

Task Force must take into consideration the practical elements of how the lack of insight into their condition impacts on the person’s capacity to make decisions and ability to consent.

Also, in relation to insight, it would be helpful to disambiguate an issue that constantly arises in disability services, namely, that making a choice to do a thing is not the same as being able to do that thing. For example, a person may make the choice to move out of a nursing home, but this is not the same thing as being able to live independently in the community, particularly where the requisite community supports are not available.

The National Disability Authority (NDA) (2012) report provides a very comprehensive analysis of the personalised budget models. They describe three types of models that have emerged internationally (See Table 1). For people with ABI, a range of models will be essential and specialist input from ABI clinical experts in each model is critical when the Task Force is considering a move towards personalisation for this population.

Table 1: Summary of Models of Personalisation (NDA, 2012: 21)

Model	Key features
Professionally monitored model	In this model, service users receive mandated guidance from care managers or co-ordinators, who are also responsible for monitoring services over time according to an approved care plan. Health professionals such as social workers and nurses tend to play a key role in the assessment and care planning processes.
Professionally assisted model	Here, service users receive assistance from care managers/co-ordinators/brokers to access funding and co-ordinate support and care. The professional/agency/broker may also assist with the determination of decisions regarding hiring, scheduling, supervision and terminating of workers.
Service user directed model	In the service user directed model, service users receive periodic cash allocations based on an assessment of needs and subsequent care plan. They have wide discretion with respect to purchasing virtually any services or goods they deem appropriate to meet their needs and the objectives of the care plan. Optional independent professional counselling and advice may be available, separately from the funding, to assist the service user.

In its analysis, the NDA (2012) also weighed up the strengths and weaknesses of each model (See Table 2). This is very useful analysis and should be given careful consideration by the Task Force in terms of determining the models that will be presented to the Minister. **The issues of capacity, consent, insight for those with acquired brain injury and the nature of their disability as a result must be understood in terms of generating the detailed models.**

Table 2: Strengths and limitations of personal budget models (NDA, 2012: 24)

Professionally monitored	Professionally assisted	Service user directed
Strengths: assessment, clear eligibility and entitlement, advice and support, monitoring, accountability, quality control	Strengths: person-centred, capacity building (family, community), access to mainstream services, advocacy	Strengths: choice, control, independence, flexibility, access to support and care services
Limitations: restrictive, intrusive, less flexible, level of professional involvement, limited access to different sources of funding	Limitations: availability of professional services and resources, extent of professional involvement	Limitations: fiscal accountability, support, advocacy, mental capacity and ability, responsiveness of care professionals and market, quality control

Final comments

Information and support

People with ABI and their families will need significant levels of information and support if they chose a personalised budget option. At present, people with ABI face enormous challenges to navigating the current health and social care system. So any additional layer of complexity must be avoided by the introduction of personalised budgets. **In such scenarios there is very strong evidence to suggest that where a person with ABI is assigned an ABI case manager to work with them to navigate the system the outcomes are much better.** (British Society for Rehabilitation Medicine, 2012). International best practice guidelines (British Society of Rehabilitation Medicine 2009 Standards for Rehabilitation Services, 2009:9) recommends that people living in the community (with ABI) should have timely and on-going access to a case manager/team to take responsibility for their rehabilitation and for their continuing care and support, who has knowledge of the various specialist and local services available and who works across the range of statutory, voluntary and other independent services to meet the person's needs.

Entitlement, eligibility and assessment

There needs to be a policy and legal framework devised and an understanding reached in terms of what people are *eligible for* and *entitled to* under the personalisation model.

What will the assessment for service look like? Who will carry out the assessment? How will the changing and evolving needs be included?

According to Holloway and Fyson (2016: 8) **effective and accurate assessments of need following a brain injury are a skilled and complex task requiring specialist knowledge.** An effective assessment needs to incorporate what is said by the brain-injured person, take account of third part information and take place over time. Only when these conditions are met can the impacts of an injury be meaningfully identified, by generating knowledge regarding the gaps between what is said and what is done. **A once-off assessment by non-specialists followed by an expectation to self-direct ones' own services are unlikely to deliver good outcomes for people with ABI.** (IBID)

Unbundling of the disability budget

There are implications for all publicly funded disability service providers when the unbundling of the funding for an individual takes place. How will the unbundling aspect be calculated? How will it be deducted from the service provider? How will this impact on the Service Agreement process currently in place with the HSE? In certain services there are economies of scale in operation (s.a. residential) and if a resident leaves then the economies of scale may no longer be applicable.

Careful consideration of the implications of the unbundling process for the service provider is needed. Equally, if a service provider agency is involved in delivering a service for a personalised budget holder, what are the processes in place to make sure that it is streamlined and the full costs of the service provision are covered? (for e.g. on-going specialised input). How easily will the budget holder be able to move between providers? What is the envisaged timeframe for moving from one provider to the next? What types of contracts will exist between the service provider and the budget holder?

How will the service be monitored and regulated? Issues of quality standards, risk assessment, safeguarding, legal and financial oversight are all issues that will arise for the personalisation models of service provision too.

Basket of services

ABI Ireland recommends that the Rehabilitation Assistant role be included in the basket of services.

Service availability

There is currently a gap in the levels of service provision for people with disabilities and specifically for people with ABI. There are significant waiting lists for basic services such as home care, personal assistance and home help. There are also massive waiting lists for the range of primary care services. Specific/specialised services for people with ABI are underdeveloped, sparse and in some instances non-existent. For those that do exist, there are long waiting times. A major concern therefore is that if the services that are to be in the “basket” are not readily available to people with disabilities in their current format, then moving towards personalisation is almost a moot point. The capacity is not there in the system at the present time to be able to meet the level of service demand. This lack of capacity in the system is a fundamental problem that must be addressed before personalised budgets are introduced.

References

British Society for Rehabilitation Medicine (2009) *Standards for Rehabilitation Services Mapped on to the National Service Framework for Long-Term Conditions*. London: BSRM.

British Society for Rehabilitation Medicine (2012) *Specialist Neuro-rehabilitation Service Standards*, Updated 30.04.2015. London: BSRM.

National Disability Authority (2012) *The Transition to Personal Budgets for People with Disabilities: A Review of Practice in Specified Jurisdictions*, A National Disability Authority Working Paper, Dublin: November 2012

Holloway, M and Fyson, R. (2016) *Acquired Brain Injury, Social Work and the Challenges of Personalisation*, British Journal of Social Work, 2016 Jul: 46 (5) 1301-1317

Supporting Information

About ABI Ireland

ABI Ireland is a dedicated provider of community-based neuro-rehabilitation services for people with an acquired brain injury (ABI) and their families. As a brain injury can affect a person's ability to manage their own life, ABI Ireland works in communities across Ireland to support and empower people to rebuild their lives. ABI Ireland also campaigns, educates and advocates for the rights and needs of this hidden group in society.

ABI Ireland Services

ABI Ireland provides a diverse range of accredited neuro-rehabilitation services. The core services include:

- Clinical neuro-rehabilitation team
- Residential rehabilitation
- Transitional living
- Day resource/clubhouse
- Home and community rehabilitation
- Case management

Additional support services are also provided and include ABI information, family support and carer training.

Key Facts on ABI

- There are many ways in which a person can acquire a brain injury. These include, among others, a fall, assault, accident, infection, stroke or tumour.
- Depending on what part of the brain is injured, and the extent of the injury, the person will have to live with different consequences.
- Many of the consequences of brain injury may be hidden, others not. They range from physical and sensory to cognitive and psychological affecting how a person feels, thinks, acts and relates to others.
- Each year it is estimated that 13,000 people in Ireland acquire a brain injury. However, there are no official statistics on ABI in Ireland.
- ABI is one of the leading causes of disability and can have life-long consequences
- Neuro-rehabilitation is a clinical and social process to aid recovery after a brain injury. It is about relearning, compensating and regrowth so the person lives a life of their own choosing. It supports the person to live a meaningful everyday life.

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