

## Personalised Budgets Consultation Questions

### YOUR DETAILS

In this section, we ask you to tell us a little about yourself so we can look at the responses received from different points of view. This is the only reason for collecting this information.

(Note: If you are making a submission on behalf of an organisation or representative body, please complete Part B.)

**PART B – This section only needs to be completed by organisations or representative bodies (you do not need to fill in the section below if you are responding as an individual)**

### Organisation

I am the authorised representative on behalf of an organisation/body.

Please state **name and address of organisation:**

Care Alliance Ireland,  
Coleraine House,  
Coleraine St,  
Dublin 7

**Title**

Ms

**First Name**

Zoe

**Surname**

Hughes

**Job Title**

Policy & Research Officer

**Please state category of organisation:**

- |   |                                     |                      |                                     |
|---|-------------------------------------|----------------------|-------------------------------------|
| Regulatory Body                             | <input type="checkbox"/>            | Representative Body  | <input checked="" type="checkbox"/> |
| Public Interest Group                       | <input type="checkbox"/>            | Academic institution | <input type="checkbox"/>            |
| Advocacy Body                               | <input checked="" type="checkbox"/> | S.38/S.39            | <input type="checkbox"/>            |
| Private Service Provider                    | <input type="checkbox"/>            |                      |                                     |
| Voluntary/Not for Profit Home Care Provider |                                     |                      | <input type="checkbox"/>            |
| Other, please specify:                      | <hr/>                               |                      |                                     |

## **PART C: YOUR VIEWS – To be completed by everyone.**

After reading the above outline of personalised budgets, please answer the questions below with any views you/or your organisation may have on the proposed model. If necessary, please feel free to include additional points on your submission at the end of this document.

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

Care Alliance Ireland is the National Network of Voluntary Organisations supporting Family Carers. Our vision is that the role of Family Carers is fully recognised and valued by society in Ireland. As such, it is important to note that the focus of this submission will be the impact upon families as a whole, and in particular, Family Carers of those seeking to access personalised budgets.

We understand, of course, that personalised budgets are a way to encourage and ensure that people with disabilities can live as independent a life as is their choosing, and appropriate for them. The focus of this submission is not to minimise that in any way, however the introduction of any form of personalised budget must also take into account a holistic view of the family, and in particular any Family Carer who has had significant responsibility for the care and support of their loved one.

To this end, we see two main foci for personalised budgets for people with disabilities. These are summarised below.

#### **1) Accessing the correct services needed in the right format**

There are many Family Carers who are of the opinion that their loved ones are currently inappropriately placed in their current support situation. These inappropriate supports are not in place through any deliberate negligence in any way. However due to the need for many service providers to accommodate a range of service users with different needs and abilities, it is impossible to ensure that all the personal needs of all services users are adequately addressed within the budgets provided by the HSE.

The freedom to ensure that their loved one is accessing the correct supports and opportunities would be, for many families, highly positive. In addition the knowledge that changes can be made quickly and new opportunities can be

taken advantage of in a more flexible manner within the correct personalised budget framework would be greatly appreciated by families.

## 2) Homecare/medical care if needed to ensure a high quality of life

A significant concern for many families of adults with significant health and support needs is that their children are being “left behind” in the progress towards deinstitutionalisation and decongregation. For these families, access to work placement and educational training opportunities is simply not the priority- ensuring that their children have access to the nursing, home care and other supports they need is.

We would direct readers of this submission to our Discussion Document published earlier this year for more of this discussion in detail, and it is highly relevant to this discussion. The document can be found at <http://bit.ly/2o0J51K>. A copy is also included with this submission.

## **2. 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)?**

It is very difficult to pinpoint a list of things that individuals and families accessing personalised budgets would spend their money on, let alone rank them in order. Each individual and family situation is unique.

However, it is important to highlight that there is a small but significant number of families where the individual requiring care needs constant medical care in order to ensure a quality of life acceptable to them and to their loved ones. In those instances, appropriate residential and home support services will likely be at the top of the list for an allocation of funds from any personalised budget.

With regards to how individuals might spend their funding in a personalised budget model, it is important to look at the effects of these programmes on the Family Carer. Whilst we acknowledge the particular focus of recent disability policy (and do not challenge the overall promotion of independence and choice for people with disabilities), there is a significant disconnect

between current disability policy and current Family Carer policy. The National Carers Strategy (2012) stresses that Family Carers should be increasingly seen as “key partners” in care- disability policy advocates for almost the complete opposite. This disconnect at policy level makes it increasingly difficult for service providers to adequately include family members- where appropriate- in the care and support of their service users. Again, we would direct readers to our recent Discussion Document on this topic, available at <http://bit.ly/2o0J51K>.

We would like to see the possibility of people with disabilities who access a personalised budget be given the option to receive services and support- in particular when the support required includes a focus on home care support as outlined, or significant medical support- from family members. We appreciate that this has the potential to be controversial, especially as it is vital that families do not “take advantage” of the system. The outcomes for the person with a disability should, and must, always remain the focus of the budget system. However it can be argued that in some cases, those best outcomes will come from those Family carers who wish to continue to support their loved ones at home can continue to do so with the correct supports. An example of this is The Netherlands, where the majority of personal budget holders choose to employ family members as their carers within a service user directed model.

### **3. From your perspective what are the key advantages in having a personal budget?**

For Family Carers, there are a number of advantages in assisting their loved ones to access a personalised budget.

First and foremost, Family Carers want the best for their loved ones, and so having the opportunity to access the best supports in the most appropriate manner, in the most flexible fashion is positive.

There is a level of mistrust on the behalf of some families- in particular where the services which they feel best support their loved ones are withdrawn for reasons such as lack of funding, interest, or indeed the process of decongregation. This should not be ignored. Seeing their loved ones gain control over who supplies their supports, where and when they are provided, will again provide security to those families in knowing that their loved one is

in receipt of services which, given that they are in control of these supports, are less likely to be removed without warning.

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

##### Ensuring families are included

As we have previously discussed in this submission, there is a significant disparity between current disability policy, and current Family Carer policy. Given that a significant majority of people with disability live in the family home, it is not unreasonable to suggest that accessing a personalised budget, and therefore reframing how supports are received by a person with a disability is something which will impact upon the whole family. In particular, ensuring that the families are included in the process is vital to ensure that the outcomes for the person accessing the personalised budget are positive.

##### Ensuring right of people with advanced medical needs to access the budgeting system

We note with concern that Section 4 of the accompanying briefing notes for this consultation did not specifically mentioning nursing or high intensity home care assistant support as part of the suite of services accessible via the proposed system. As many of these individuals rely on such significant measures as part of their daily lives, ensuring their continued access to them as part of a range of services is critical.

##### Ensure it does not become a "2-tier" system

Many families are concerned that current disability policy does not adequately address the specific needs of those people with significant medical needs as part of their condition. The focus is on education, training, independent living and related issues. In no way is this a bad thing, however it is important that these personalised budgets are accessible by ALL individuals with disabilities. This means that those with the ability to manage such a system on their own (with appropriate supports where necessary) do not become the only ones accessing personalised budgets. There may be more work involved, and more administrative costs, however ensuring there are mechanisms for families to become involved will alleviate that- and is in line with current Family Carer policy.

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

In keeping with the focus of this submission, we outline below some of the key training around personalised budgets which would minimise some of the concerns which families, services and people with a disability may have when accessing personal budgets.

- Understanding the rights and responsibilities of all members of a budgeting “team”;
- Education for families on recent capacity legislation as it pertains to this particular issue;
- Training for people with disabilities to advocate for themselves;
- Training for family members regarding risk and their reactions to possible risk for their loved ones;
- Money management

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

As with all significant changes to how systems are organised, there will likely be both positive and negative changes possible for those choosing to access a personal budget. In keeping with the rest of this submission, this section will also take into consideration the wider family implications.

*More choice/ appropriate service*

The main positive change for those accessing personal budgets is the increased freedom to craft their own support environment, utilising their own choices and their own particular individual needs to ensure the best possible fit.

*Challenge for family members*

There is no doubt that occasionally family members of people with a disability can act in a paternalistic fashion to their loved ones. Usually, these actions are

acted upon out of concern and love. However, there is much literature which asserts that some families face difficulty acknowledging the changes in policy which dominate our social discourse on disability, and who infantilise their adult children with intellectual disabilities in particular. This is a challenge for all support staff and services who work with families in these situations. Accessing personalised budgets and supporting their family members to take control of their own supports will be seen as a major challenge by some families. In particular due to the clear contrast between established disability policy and Family Carer policy, this needs to be treated sensitively for all parties involved. It is important that family relationships are not allowed to break down, just as it's important that families are supported to be involved in the process of personalised budgets for their loved ones.

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

N/A

**8. 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?**

Upon initial purchase of a particular service:

- How the decision was made to access a particular service (e.g. consultation, use of a mediating team if necessary)

Regular administration:

- Receipts for payment of fees to service providers etc.
- Progress reports (satisfaction with service, changes to be made etc.)



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

Not at this time.

**Please ensure that you have filled out the above survey in full.**

**Please email your submissions to [Budgets\\_Taskforce@health.gov.ie](mailto:Budgets_Taskforce@health.gov.ie) by 20 October 2017.**

**Thank you for your input.**