



INDEPENDENT LIVING  
MOVEMENT IRELAND

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[www.ilmi.ie](http://www.ilmi.ie)

## **ILMI Position Paper on the HSE Personalised Budgets Demonstration Models**

**July 2021**

### **Introduction to ILMI**

Independent Living Movement Ireland (ILMI) is a campaigning, national representative cross-impairment Disabled Persons Organisation (DPO) that promotes the philosophy of independent living and seeks to build an inclusive society. Central to the way we work is to ensure that policy decisions that impact on the lives of disabled people have to be directly influenced by those whose lives are directly affected. Our philosophy can be summed up as: ‘Nothing about us without us!’ and ‘Rights Not Charity’. Our vision is an Ireland where disabled persons have freedom, choice and control over all aspects of their lives and can fully participate in an inclusive society as equals.

### **Personalised Budgets and Independent Living**

Independent Living is the right of all persons regardless of age or impairment to live in the community; to have the same range of choices as everybody else in housing, transportation, education and employment; to participate in the social, economic and political life of their own communities; to have a family; to realise their own potential and have the freedom to live the lives they wish to in an inclusive society.

Ultimately Independent Living is about empowerment, options, choice and control, and the logical extension of independent living is for disabled people to be in control of all aspects of their lives, including the resources they need to do the things they need to do.

Therefore pathways for disabled people to manage their own budgets, with appropriate supports, are hugely important to the lives of disabled people.

Based on this principle and also based on the recommendations of the Taskforce, ILMI has always recognised the importance of the demonstration models and their potential to explore the process of transition towards a person-centred budget to inform future best practice.

From an ILMI perspective, the demonstration models need to be informed by what works best for disabled people to give them control in their lives and to ensure that the bureaucratic burden placed on disabled people, especially those applying for a person-managed fund (direct payment) be kept to a minimum in order that paperwork, governance and reporting doesn't become overwhelming.

### **Policy Context**

The Programme for Partnership Government in 2016 included a commitment to the establishment of a task force on personalised budgets for people with disabilities. The Task Force was established by Minister Finian McGrath, TD on 20th September 2016.

*“Towards Personalised Budgets for People with a Disability in Ireland: Report of the Task Force on Personalised Budgets”* was published in 2018 and outlined three possible models for personalised budgets:

1. Person-managed fund, often referred to as Direct payments
2. Co-Managed with the service provider
3. Broker managed fund

The Task Force report recommended that each of these models be tested and evaluated within two years of the publication of the Task Force Report to inform a wider roll out of personalised budgets in Ireland.

In August 2019, the HSE announced the first stage of the Demonstration models and invited expressions of interest from disabled people already in receipt of some form of disability support service which is funded by the HSE. The launch stated 90 people will be selected to take part in the first phase, which would be followed by a second call for expressions of interest will go out on April 2020 for a further 90 people. It was also noted that the demonstration models will explore the development of a standardised assessment tool for all CHO areas based on two proposed models for assessment.

In a written response to a Parliamentary Question (PQ) asked by: Pauline Tully T.D. that as of November 2020, “there are currently 32 participants in the various stages of Phase 1 of the Personalised Budget Pilot Demonstration. This means that the pilot is running behind schedule. This is due to the COVID-19 pandemic, which as I'm sure the Deputy is aware, resulted in the closure of disability services. The current Level 5 restrictions are also severely impacting with the Health Service Executive's (HSE) ability to meet with individuals and progress.”

The written response to Deputy Tully also stated “Phase 2 of the pilot commenced on 27th July with a call for Expressions of Interest. The Expressions of Interest application deadline for Phase 2 closed on 7th September, with the HSE receiving 136 applications. As there was a pause in processing applications, due to COVID-19, applications are still being processed.”

## **ILMI Space to assess the progress for applicants in the HSE Demonstration Models**

Recognising the significance of the demonstration models, ILMI has maintained contact with the HSE on this issue. ILMI acknowledges that the impact of Covid-19 on the rollout of the demonstration model, but through many of our online discussions the lack of clarity on the project prompted ILMI to create a specific discussion space on May 25<sup>th</sup> to capture the experiences of people who have applied to be part of the demonstration models to build a collective shared sense of how the project is progressing. The meeting was predominately disabled people who had applied themselves and also some parents who had applied on behalf of their disabled children. These were children who were about to leave school and there was a real concern that delays in accessing a personalised budget might limit their immediate life choices.

### **Overarching themes were:**

#### **Frustration about lack of progress**

A huge amount of frustration was evident from all the participants. People were frustrated about the lack of contact, the lack of clarity or the lack of a clear sense of a plan on how the demonstration models were to be delivered.

Many had signed up in September 2019 and have sent emails and made calls which were never returned.

Some had more recent contact but there was no update on when the demonstration model was starting, or what supports were available. One participant was contacted to say her child had been accepted on the

programme and that it was starting in September and to “get ready”. However, there was no sense of support on what the parent needed to do- did it mean form a company, and what did that entail? Again there was frustration about the lack of communication, supports and pathway for people to work towards a personalised budget.

There was considerable anger that even accounting for Covid-19 delays that the two year pilot phase is almost been reached and no one has progressed on their journey towards a personalised budget. People voiced concerns that of the €1.5 million allocated to delivering the project how much of that funding is left and how little things have progressed.

People spoke of anecdotal issues relating to recruiting staff to the personalised budgets project but again there was a total lack of communication or clarity.

### **Barriers from service providers**

Many people spoke about when they raised the issue of participating on the demonstration model they were told by their service provider that they “would not be unbundling funding”. In one instance, a person was offered money not to participate in the project by their service provider.

There was frustration about any information on what options there would be for people to participate in. No one had heard anything about possible brokerages or a tender to support this. At present there are two brokerages who are at capacity, so how are people going to be able to access this option?

One participant who attended the meeting who already has a personalised budget found it hard to understand why there was such a lack of progress. He could demonstrate that it can be done and that disabled people can be accountable but it can be done and people can control their own budgets.

## **Recommendations from ILMI to advance the Demonstration models for Personalised Budgets**

- A webinar for all disabled people who have registered for the demonstration to clearly outline the process of when and how personalised budgets will be delivered.
- This would include details of future webinars dealing with specifics in relation to personalised budgets, such as training on HR, employment, accounts, company law and so on. There would also be clarity on specific issues such as insurance for disabled people employing PAs directly which places a large financial burden on leaders.
- Clear timelines of how models will be delivered, how they will be delivered (online / blended) and by which staff.
- A clear commitment from the HSE, Department of Health and the Department of Children, Equality, Disability, Integration and Youth to the demonstration models as a pathway to personalised budgets for disabled people.
- A clear message from the HSE, Department of Health and the Department of Children, Equality, Disability, Integration and Youth to service providers that where Exchequer Funding is being used to provide services to disabled people that these hours must be unbundled without delay when a disabled person signs up the demonstration models.

- An update on the tendering process for brokerages and when this option will be made available.