



Áiseanna Tacaíochta's response to Taskforce Report on Personalised Budgets

Overview:

Áiseanna Tacaíochta (ÁT) have issued a qualified welcome for the **Taskforce Report on Personalised Budgets** and urge the Minister to put the necessary infrastructures in place without delay in order to hasten the development of a truly universally available direct payment for all.

Whilst ÁT hold the view that there is much that is lacking within the report, we must not run the risk of delaying any positive momentum in the development of a model that ultimately offers the option of a personalised budget to everyone who wishes to avail of it.

On behalf of all the Leaders at ÁT we welcome in particular the opportunity for Leaders to finally, albeit under a demonstration project, obtain a genuinely direct payment, directly to their bank and not via a third party.

ÁT believe that the Taskforce have missed an opportunity by not exploring further more imaginative methods to remove the need for the huge levels of bureaucracy and governance (three levels) that is being placed upon the individual. The taskforce appear to have forgotten that the individual does not, should not and can not implement the level of policies, procedures, guidelines, and governance that HSE impose on itself and its licensed agencies.

The report begins by putting the individual at the centre of the taskforce review, and proceeds, (necessarily to a large extent) to focus on the detailed infrastructure of any potential system and the governance requirements. However great care needs to be taken to ensure that the person does not get lost in the overall process. We must remember that we are dealing with individuals, not organisations, who do not have any infrastructure at their disposal to accommodate these requirements.

The taskforce have not achieved one of their stated guiding principles of being "universal" as they are restricting the opportunity for a direct payment to adults only, which is not universal. ÁT do not agree with this restriction and would call on the minister to reject this aspect of the proposal.

The taskforce proposes a two year demonstration project period from the date of publication of the report. Following that initial two years (2020/2021) there are a further four stages proposed:

- Evaluation
- Agreement of final design
- Implementation planning
- National roll out

There are no timescales given for these phases and ÁT would have a concern that the state agencies and policy makers are "kicking the can down the road" in order to prolong the introduction of a national and universally available direct payments.

Despite the shortcomings in the report from ÁT's perspective, we welcome the publication of the report and impress upon the Minister to immediately task the appropriate agencies with developing, funding and engaging with the demonstration projects as soon as possible.

END

19th July 2018

Discussion points for consideration in respect of the way forward:

1. Restriction of spending:

The recommendations are not consistent with the vision as set out which is “Personalised budgets will enable a person with disabilities to have choice and control over individualised supports **in all aspects of their lives**, to enjoy an independent life and to be an active participant in their community” because it restricts the personal budget to HSE / health funded budgets .. It is ÁT’s view that there really ought to be a cross departmental approach.

However, it must be accepted that this was the terms of reference from the start so can there really be any surprise? The focus was always *HSE Disability Service-funded personal social services and supports*.

The idea was that the model that emerged would do so in such a way so as it could be developed over time” The Task Force adopted an approach to the development of personalised budgets which could be shared with other State-funded services for people with disabilities in the future.”

There does need to be clarity in terms of allowing leaders to use a proportion of their budget on the administration costs of running their entity, within certain guidelines ... if they become an employer they may very well set up a company and with that comes administration costs.

2. Emphasis on fraud risk and governance:

Word fraud mentioned 9 times in the report. The context would seem to be “fraud in other jurisdictions were low” and regulation do not lead to lower levels of fraud.

We would welcome the tiered approach to required levels of governance depending on the funding option and on the amount of the personal budget approved, though we feel that it still falls significantly short of what is desirable for the individual with a disability. It is a significant and potentially discriminatory barrier, to insist that recipients of a personal budget should have to complete the levels of training required, (*“Training should include a focus on HR law, finance, employment relations etc.”*) and have to go through the process of establishing a company, etc. etc. We would have hoped for a proposal with more imagination than that. For example why can’t the state alleviate the “employer” burden by coming up with some new form of employee class for tax / USC purposes... who don’t pay tax where it is an employment funded directly by a state disability budget, where perhaps the rate per hour is x% below min wage to reflect the fact that they do not pay tax.

Alleviate that requirement, and you alleviate the need for a company to be set up and then the governance might be as simple as returning an income and expenditure account monthly / quarterly to account for the funds. Also PA’s could be trained to a high level in Health and Safety and take the burden of responsibility away from the leader by being “an expert” or advisor in the area of H&S. The PA would perhaps complete a service agreement with the Leader as opposed to a contract of employment.

These are simply “blue-sky ideas” that perhaps could have and should have been explored. ÁT feels that this report falls short of a more imaginative approach where the tax aspect of this employment class could be removed from the leader.



3. Age restriction:

The taskforce have not achieved one of their stated guiding principles of being “universal” as they are restricting the opportunity for a direct payment to adults only, which is not universal. ÁT do not agree with this restriction and would call on the minister to reject this aspect of the proposal.

As a side comment for internal discussion regarding the point on exclusion of under 18’s... it can’t be viewed as a surprise as the remit from the outset is stated as “Government agreed that the Task Force should focus on services for **adults with disabilities** funded by HSE Disability Services i.e. health and social care.” This is reflected in the Task Force’s Strategy Group’s Terms of Reference, which clearly outline the objectives of the Task Force.

4. Timescales:

In terms of the assessment of the demonstration projects we would not be at all happy with a formal evaluation of the Demonstration Projects being completed and submitted to the Department of Health **at the end of the two year period**. There needs to be resource dedicated within HSE / DOH, at the appropriate level, to engage on an ongoing basis throughout the two years so that the demonstration projects can be refined on an ongoing basis ... to accommodate a more finished product emerging at the end of two years.

We are somewhat disappointed that we are entering yet another demonstration period which moves the national roll out of any model out a further two years **and more**. ÁT has been in existence since 2010 in various forms, initially as a “pilot” project and more recently as a “demonstration” project. There have been many learnings which we have shared with the taskforce BUT these learnings should have been captured with HSE / DOH by way of a formally agreed and established evaluation team.....

- The administrative and governance burden placed on individuals is unacceptably high
- There needs to be a proper and professional level of funding provided for demonstration projects in order to facilitate the full and robust development of a model.
- There needs to be meaningful and regular engagement with the agency of the state that will ultimately have the decision making power about the future shape of any model
- There needs to be a national training framework developed via a national training provider that can provide a consistent level of training and support to all leaders

The taskforce proposes a two year demonstration project period. There are four stages proposed after completion of the demonstration project phase:

- Evaluation
- Agreement of final design
- Implementation planning
- National roll out

There are no timescales given for these phases and ÁT would have a concern that the state agencies and policy makers are “kicking the can down the road” in order to prolong the introduction of a national and universally available direct payments.

5. Funding for the demonstration projects:

We welcome the allocation of €1.3m in funding for the demonstration projects. In order to conduct a meaningful demonstration project there needs to be sufficient resourcing of the project in order to



develop all of the identified recommendations AND there needs to be an interactive process of engagement on an ongoing basis with HSE / DOH to inform and facilitate a collaborative evolution of the process during the two year period.

There is a considerable level of alignment with the recommendations of the taskforce and what ÁT currently does / aspires to do. It is regrettable that the experience of the ÁT project has to a large degree been a wasted opportunity because of the fact that the learnings were not being captured OR the process was not being systematically reviewed and developed during that time. That is why there must be ongoing review and evaluation and not just at the end of the period and also there must be proper resourcing and an agreed framework for consistent capture of data.

6. Individuals level of funding:

We welcome the spectrum of options proposed by the Taskforce which attempts to cater to the level of bureaucracy that the individual is willing or able to absorb. We welcome recommendation 15 in that regard that *this should include specific provisions to support the introduction of a direct payment model of personalised budgets and graded levels of accountability. (Recommendation 15)*

We would absolutely welcome the introduction of a standardised assessment tool to identify the person's needs and desired outcomes through a person-centred planning process. Focus on outcomes is key to long term success

We would welcome the outline of a six stage programme to the establishment of an individual's personal budget.

We would have difficulty with the support plan having to take into account the supports that are provided through family or community. The state cannot rely on family / community in order to taper its funding proposal to an individual... this is a form of means testing.

We welcome the Department of Health In conjunction with the Department of Employment Affairs and Social Protection, the Department of Public Expenditure and Reform and the Department of Finance, examining whether legislative change may be required to ensure that a personalised budget is not subject to assessment as income or means-tested for the purposes of the Finance Acts or Social Welfare Acts, or for other income tested schemes.

Training should be provided in a standardised and centralised way. This should cover PA's and leaders. PA's could be trained to a high level in Health and Safety and take the burden of responsibility away from the leader by being "an expert" or advisor in the area of H&S.

7. Family members:

The taskforce did not reach a consensus on the matter of hiring of family members and have as a consequence excluded it as a permissible option for the impending demonstration projects. Clarification will be required as to how this will effect someone who is currently has an approved arrangement with a family member who wishes to participate in the new demonstration project phase. Will exemptions be made for pre-existing arrangements?

END