

## **Opening statement from Áiseanna Tacaíochta, to the Joint Oireachtas Committee on Disability Matters Thursday 8<sup>th</sup> July 2021**

Cathaoirleach,

I, along with my colleagues present here today, wish to thank the Committee for this opportunity to make our representation to you.

I now make a number of points to give some background to our previous submission.

Áiseanna Tacaíochta's (ÁT's) mission statement is "to provide leadership and support in Ireland to empower disabled people to direct our own lives and enjoy the same freedoms, choices and opportunities which their nondisabled counterparts take for granted".

As disabled people, we need daily personal support to carry out all of the daily activities and routines necessary to live an ordinary life in our own homes. To do this, we need the support and assistance of other people – we call them our Personal Assistants and we call ourselves Leaders. We employ our own Personal Assistant's and direct their work through the independent Companies that we set up for this purpose. Áiseanna Tacaíochta acts as an intermediary (or Broker) between each of our Leaders Companies and our funders (the HSE) to set up a Direct Payment to the Leaders Company. This broker model enables us to move from a service delivery model, such as residential care, to choosing and managing our own services, which is a Personal Assistant service.

Everything we do is underpinned by the philosophy of Independent Living and the Social Model of Disability. True Independent Living allows individuals to custom-design their supports, based on their individual needs, capabilities and aspirations and, in doing so, to contribute to the development of a more equal and just society for everyone. We believe that Leaders are the best experts of their own lives, and it's important that their expertise is listened to and valued.

The availability of a Direct Payments option in this country is a hugely important step in having our rights to independence and equality recognised as disabled people. ÁT commissioned NUI Galway to conduct research into our model and the overwhelming conclusion was that it was quite literally "life changing" for those who were able to avail of it.

<https://www.theatnetwork.com/publications/nuig-research/>

One of our strategic objectives as a peer led organisation is to "lobby appropriate stakeholders to make this model more readily available nationally and to ensure that Leaders who undertake the ÁT process will be facilitated by Government to move to full independence".

As this committee is very well aware, Article 19 UNCRPD – Living Independently and being included in the community: **States** that parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right .and their full inclusion and participation in the community.



# ÁISEANNA TACAÍOCHTA

**Working towards universal availability:** ÁT have demonstrated to HSE the benefits of this model; which has been accepted at national level within HSE; and on that basis we have requested additional funding for the creation of more places, to support new Leaders all over the country in gaining a direct payment. This request has been denied in the context of the ongoing Personalised Budgets Demonstration Projects. However, these projects are now significantly behind schedule by over 3 years, having initially been intended to report in June 2020.

**Achieving full independence:** ÁT provides training and support to Leaders to establish and manage their own support service. Once a Leader is experienced and proficient in same, it is our view that they should be facilitated to move to complete independence and sign their own service agreement with HSE rather than through a brokership arrangement. This facility is currently denied to them.

## **Recommendations:**

- We call for the immediate removal of the restriction on leaders from moving to full independence, entitling them to leave the broker and be in receipt of their funding directly from HSE. This could be accommodated via the current demonstration project structure. This would require the immediate implementation of the demonstration projects in a much more comprehensive manner than is currently the case.
- We call for immediate action to make Direct Payment available to all Leaders who would desire to choose it. We have been waiting too long for the HSE demonstration projects to complete their evaluation. There are Leaders in situations today where their freedom to choose is denied, which is an infringement of their basic human rights under article 19 of UNCRPD. An interim solution is to make more funding available immediately to organisations such as ÁT who can in the short to medium term begin to increase capacity to support more Leaders. This can be done against the backdrop of the continuing demonstration projects with some form of agreement that Leaders will migrate to one of the approved models which emerge from the demonstration projects.
- Incorporate capacity building in the form of a “peer support group” , Independent Living training and its principles into the demonstration projects to empower less able leaders or potential leaders to become more self-confident to succeed as a user of a direct payment.
- Lately: Change terminology in all of your communications from “people with a disability” to “disabled people”.

Thank you for listening.