Exploring Direct Payments and Government Policy



"I have so much more independence now and so many more goals to achieve and so much more understanding of my own worth and my own abilities"

- Áiseanna Tacaíochta Leader

Government has committed to promoting community inclusion for people with disabilities and establishing individualised funding models which support this. At Áiseanna Tacaíochta (ÁT), we believe that our work and innovation is pushing these initiatives forward and demonstrating the significant impact that they can make in the real, everyday lives of people with disabilities.

ÁT is the first organisation in Ireland to offer a Direct Payments model to people with disabilities and their families. A Direct Payment is a cash payment made directly to an eligible person to enable them to purchase and manage their own care and support services.

This represents an innovative and progressive approach, which drives the shift towards personalised models of support that give power back to the person, in line with Government policy and Health Service Executive (HSE) commitments. Our model holds huge potential to achieve Government's vision of inclusive, progressive disability policy.

How do Direct Payments support the vision of Government policy?

The *Programme for Government 2011-2016* clearly sets out a move "to a personal budget model so that people with disabilities or their families have the flexibility to make choices that suit their needs best". It notes that "personal budgets also introduce greater transparency and efficiency in funding services". This grounds our model of Direct Payments in Government policy and vision.

Numerous Health Service Executive (HSE) policies add further weight and obligation to that commitment. For example, the *New Directions* report states that individuals with disabilities should have access to supports which enable him or her to "make choices and plans to support personal goals; have influence over the decisions that affect his or her life; achieve personal goals and aspirations; and be an active, independent member of his or her community and society".ⁱⁱ

It advocates that people are supported to maximise independence; access employment, education and training opportunities; enjoy health and wellbeing; strengthen personal and social development; participate in normal, everyday community activities; and influence service policy and practice. Our model of Direct Payments delivers on each of these outcomes.

Equally, *Time to Move on from Congregated Settings* recommends that people with disabilities have access to new models of support "based on the principles of personcentredness"ⁱⁱⁱ, and, crucially, that "the scope for introducing forms of the individualised budgets giving people as much control as possible over their choice of supports should be examined by the HSE" for both individual and family-governed supports.^{iv}

The *Final Report of the Disability Policy Review*, conducted by the Department of Health and the HSE in 2011, also defines individualised services and supports as the "range of assistance and interventions required to enable the individual to live a fully

included life in the community". It includes supports and services "in the form of personal care, communication or advocacy support, learning support, therapeutic interventions, aids and equipment, adaptations to the physical environment, and so on".

The report proposes that such supports are used to "identify an individualised budget, which is a sum of money that attaches to the person and is used to provide the supports and services they need within existing funding limitations", and distinctly names Direct Payments as a mechanism to achieve this. Again, this not only authenticates the use of our model within Government and HSE policy, but indicates the great range of supports that can be opened to people with disabilities through Direct Payments.

Are Direct Payments recognised by Government?

The vision and success of our model of Direct Payments is recognised by the HSE, which supports us as a demonstration project under the Value for Money (VfM)

Review of Disability Services. Our work strongly reflects its vision statement, which is:

"To contribute to the realisation of a society where people with disabilities are supported, as far as possible, to participate to their full potential in economic and social life and have access to a range of quality personal social supports and services to enhance their quality of life and well-being."

This vision is fortified by two key goals which embrace the full inclusion and self-determination of people with disabilities "through access to individualised personal social supports and services needed to live a fully included life in the community" and "the creation of a cost-effective, responsive and accountable system".

Implementation of the VfM Review means a seismic shift in how disability services are funded and provided, moving choice and control from professionals and service providers to people and families with disabilities themselves. This will advance delivery of services and supports with much greater efficiency, transparency and accountability.

Recommendation 7.11 of the VfM Review, in particular, seeks to identify the precise features of individualised support models, taking into account that it should be multi-form and multi-faceted.^{vii}

We are leading the way in achieving this vision. As well as empowering people with disabilities to participate equally in their communities and to pursue their life goals, our model offers true cost-effectiveness as Leaders and families work with a customised budget, removing administration costs and offering opportunities to maximise the number of Personal Assistant (PA) hours they receive. In this way, we believe that we are setting a precedent for the future of disability policy in Ireland.

Does international policy support Direct Payments?

Each of the values underpinning disability policy decisions is enshrined under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which Ireland signed in 2007 and has yet to ratify, one of just three European Union (EU) countries - along with the Netherlands and Finland - not to have done so. Its general principles promote respect for the dignity and "individual autonomy, including the freedom to make one's own choices, and independence" of people with disabilities.

Article 19 further supports the right of people with disabilities to live independently and to be included in their own communities, with access to a range of services, including Personal Assistant (PA). Once ratified, Government – along with all of its

bodies and agencies – will be obliged to adopt all the appropriate legislative, administrative and other measures necessary to fully implement the rights recognised within the Convention. viii

At our *Realising Equality through Active Participation* event in December 2014, Minister for Equality, Aodhán O'Ríordáin TD, stated that Ireland should be in position to ratify the Convention "within twelve months". Furthermore, in a meeting with disability activists organised during a three-day campaign in September 2015, the Taoiseach, Enda Kenny, committed to ratify the UNCRPD by the end of the year. It is therefore crucial that the steps - such as the evaluation and adoption of our model of Direct Payments and other forms of individualised and self-directed living supports - are taken now to prepare for this imminent progression, and to ensure that the rights of people with disabilities in Ireland are fully protected and realised.

Why is now the time to support Direct Payments?

Apart from the need to implement policy, it is crucial that models like Direct Payments are explored and enacted now.

Almost 600,000 people in Ireland live with a disability.^{xi} Disability can happen to anyone at any time; our chances of acquiring a disability increase with age. It is an enduring, societal matter affecting every area of life, not just our health. It will always be necessary to provide help and support; at ÁT, we have created a truly empowering way of doing so.

A historical cycle of dependency on providers has left an indelible mark both on people with disabilities and on our culture as a whole; the result sees too many people with disabilities becoming passive service users with no say in the decisions affecting them, isolated in their communities and facing limited opportunities. For example, just one in five people with disabilities over the age of 15 are in

employment, compared to one in two for the general population of the same age. Equally, the numbers of people aged 15-49 who have completed no further than primary education are three times higher for people with disabilities, at 16%, than for the general population, at 5%. By empowering people with disabilities, giving them the say in their own lives, and thus opening new avenues to education, employment and so many other social opportunities, our model is changing this.

Not only is the impact being felt and recognised now, but it is on track to prepare most effectively for the future. Today, just over 22% of people aged 60 to 64 live with a disability. If that rate continues, the number of older people with disabilities is set to increase by 18% until 2021, and by a further 11.6% until 2031. Equally, just over 72% of people aged 85 or over live with a disability; their numbers are expected to increase by 19% until 2021, and by a further 22% in the following ten years to 2031. Before taking into account the number of people who will be born with disabilities and disabling conditions, as well as those who acquire them at different stages in their lives, it is clear that people with disabilities will represent an increasingly significant demographic within a very short period. Indisputably, the right supports must be explored and put in place now to ensure that these people enjoy their rights and can access the services that they are entitled to in a fair, efficient and cost-effective way. Our work clearly demonstrates the possibilities to achieve this.

Here at ÁT, our model of Direct Payments breaks the cycle of dependency on service providers and empowers people with disabilities and their families to take the support they're entitled to and build on it through their own communities, in line with every aspect of Government and HSE policy.

The time has never been better to make the final push for the status, rights, resources, supports and funding models that can make Ireland the best place to live as a person with a disability. Recovery is finally on the horizon and now we have the opportunity to shape a new Ireland that acknowledges and supports diversity.



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