ÁISEANNA TACAÍOCHTA

Annual Report of Áiseanna Tacaíochta

October 2010 to December 2011

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To provide leadership and support in Ireland to empower those of us who have disabilities to direct our own lives and enjoy the same equality and freedoms as non-disabled citizens

Mission Statement of Áiseanna Tacaíochta

Chairman's Report

Martin Naughton signing the Service Agreement for the release of funding for Gordon Ryan, Owen Collumb and himself with Geraldine Murphy (HSE Dublin North East) on the 5th of October 2011

Dia Dhaoibh,

I am pleased to present our first annual report on the first year of activity of Áiseanna Tacaíochta. As Chairperson I have certain duties that I have not yet fully learnt but I am reminded of a World Champion boxer, in fact and Irish World Champion boxer that used to say – "Thank you very much, thank you very much Mr Eastwood!".

Thank you very much 'Mr' Genio, Irish Wheelchair Association Cheshire Ireland, Citizens Information Board, our glorious Stakeholder Group, HSE, Department of Health, Disability Federation of Ireland, Sean Gardiner and his Circle of Support, Owen Collumb and his Circle of Support, my own, Anseo Arís's, Circle of Support, Gordon Ryan and his Circle of Support and Niamh Quinn and her Circle of Support.

I could name a lot of individuals at this stage, but I could forget an important person. Instead I will say what is commonly said nowadays, "thank you very much, you know who you are"! If only Dermot Morgan was still about he might consider putting the above to verse.

The last two years (the first year in operation and our pre-operational year) have been wonderful. We have had lots of learning, lots of debate, sometimes too much hard work but it's really great to get to this point. But we are only just at this point. The next two to three years will be at least if not more challenging than the past two

years. If we can succeed however, we will have achieved a giant step forward in the development of Direct Payments in Ireland.

When we think of this as a possible accomplishment, we can see that Áiseanna Tacaíochta is about more than just having Direct Payments for a small number of individuals; it is for benefit of the hundreds of Leaders, any individual with a disability, that will come after us who will gain a much more flexible cost effective response to their needs. This shift brings with it a confidence for Leaders that comes from being in control of the planning in one's life to simply living like everybody else.

Slán,
Martin Naughton

Chairperson
Áiseanna Tacaíochta

Background to Áiseanna Tacaíochta

Áiseanna Tacaíochta (ÁT) is a user-led organisation that was founded by Leaders[1]. We received seeding funding from Genio in October 2010 to develop our pilot of a model of Direct Payments, a first attempt of its kind in Ireland. We believe that we, the individual, should have the right to choice as to how our service is delivered.

There are vast amounts of knowledge, research and experiences in Ireland and internationally about Direct Payments. The strong recommendation from all Leaders is that systems of Direct Payment are feasible and should be available to all to choose if they so wish.

We aim to be innovative and advocate for a person centred approach as to how Personal Assistant services operate for us in Ireland. We have developed as an organisation as a result of the wishes expressed by Leaders for such a programme of Direct Payments to exist in Ireland.

► Research

This identified need to test a Direct Payment approach in Ireland has existed for a considerable amount of time. Reviews have been undertaken by many national disability organisations about systems of Direct Payments and the viability of applying them in Ireland. In the National Disability Strategy (2004) comments suggested that a system of Direct Payments is a necessary development. Discussions prior to the publication of the Review of Disability Services under the Value for Money and Policy Review Initiative 2008-2011, have also resulted in the growing support for a pilot of a model of Direct Payments.

► Direct Payments

Áiseanna Tacaíochta is the first attempt in Ireland of practicing something which has become a norm in many European Union countries. For the past 20 years Direct Payments in different forms has been available to Leaders in many European countries such as Austria, Britain, Finland and Germany. Direct Payments has also been available to Leaders in Northern Ireland since 1998.

[1] A Leader is commonly known in Ireland as a person with a disability who supervises their Personal Assistants

►The Áiseanna Tacaíochta model

As a result of the lack of specific legislation in this area we are working within the current legislative framework so as to allow individuals receive a Direct Payment. There are certain legal concerns for an individual with a disability receiving HSE funding directly and managing it locally outside the traditional setting. That is why each Leader is supported by ÁT to set up a company limited by guarantee to manage and account for funding.

► Mainstreaming

By looking to the mainstream suppliers of services, maximum choice can be facilitated and exercised by Leaders. Leaders managing their own services do not have to feel excluded from the freedom to 'shop around'. Leaders can personalise their services without restriction.

► A Circle of Support

Each member is responsible for setting up their own Circle of Support, which is personal to them and separate from the Network. Each member is setting up their service to function like any other Company Limited by Guarantee and it is important that their Circle of Support is in place to help shoulder the legal responsibilities. A Circle of Support can be drawn from friends, family, volunteers and citizen advocates. It is advisable that the following interests are held by individual circle members; Accountancy, counselling, life coaching, legal expertise, employee management, advocacy and maintenance of equipment.

► Áiseanna Tacaíochta Support Network

Áiseanna Tacaíochta guarantees that with its Support Network no member will ever feel or be isolated. The Áiseanna Tacaíochta Support Network encompasses a diverse group of Leaders, with different disabilities, united by a common desire to direct our own lives. This Network has been designed by us to support ourselves and each other in managing our own Personal Assistant Services. The aim of the Network is to ensure that those supports are readily available when we need them.

►Áiseanna Tacaíochta's role

ÁT negotiates the release of funding on behalf of the individual and then empowers and supports the individual to set up their company which allows them to recruit and manage their PA's in a way that is personal to them. We offer reassurance to the HSE, as we ensure statutory measures attached to funding are guaranteed. We also link with service providers and other disability organisations to ensure that all that we learn and our experiences are shared so as to ensure a greater understanding of this model of Direct Payments.

Establishing a pilot of Direct Payments

We identified four Leaders who agreed to participate in our pilot to see how a system of Direct Payments would work for them individually. Each of them began the process of recruiting their Circles of Support and establishing their own companies by early 2011. It had been anticipated that each of the participants would receive their funding in the first quarter of 2011.

However it became apparent in early 2011 that there was to be some unforeseen delays to be resolved in order to allow the rerouting of Personal Assistant funding to our Leader participants. As this was the first attempt of unbundling funding by Áiseanna Tacaíochta it was anticipated that there was a certain amount that was unknown until the negotiation process began. The commitment of key personnel in both the HSE and the Irish Wheelchair Association with the facilitation of negotiations by Genio ensured that by mid 2011 a compromise had been reached. A Service Agreement for the funding for the Leader participants was drawn up by August 2011 and signed in early October 2011.

Throughout this period of negotiation the Leader participants had to remain patient and optimistic that the outcome of the discussions would result in them receiving their budget for their Personal Assistant service. During this time they offered peer support to one another, regularly meeting, sharing ideas and concerns of the practicality of managing their Personal Assistant services.

The Leaders progress has been monitored by Áiseanna Tacaíochta and by the ongoing evaluation of the progress of our project by the Genio team who we met regularly throughout the year. It was and will continue to be important to record feedback of Leaders so that the approach and support we offer is suitable and effective. The HSE are also keenly interested in the progress of our project. We are now a part of a Monitoring Group with the HSE which will regularly meet for the first year that Leaders are in control of their funding for their Personal Assistant service.

Meetings with our Stakeholders Group

From the outset we understood the critical importance of open communication with the current service providers of our Leader participants and members of the HSE and other stakeholders. One of the earliest measures undertaken by Áiseanna Tacaíochta was to form a Stakeholders Group to foster a partner relationship with some of the organisations that are conscious of the need for Direct Payments in Ireland. The inaugural meeting of Áiseanna Tacaíochta Stakeholder's Group was held in the Citizens' Information Board offices on the 24th of January 2010.

L-R:Breda Mulvihill (HSE), Mark Blake Knox (Cheshire Ireland), Claire Crehan Dowdall (Irish Wheelchair Association), Helen Lahert (Citizens Information Board), Aisling Jones (Áiseanna Tacaíochta), Owen Collumb (Áiseanna Tacaíochta participant), Martin Naughton (Director of Áiseanna Tacaíochta)

This group met on three occasions throughout our first year. The purpose of this group was to share what we were learning, receive their advice and feedback. They also assisted us with planning an event to share the developments of the project with Leaders, other organisation and statutory bodies with a working interest in the area of Direct Payments for October 2011.

Recruitment of the Group

We identified and recruited members of the Stakeholders Group in December 2010 and January 2011. The members of this group are; Mark Blake Knox (CEO Cheshire Ireland) who was to chair the group, Claire Crehan Dowdall (National Development

Officer Assisted Living Service Irish Wheelchair Association (IWA) and Michael Doyle's IWA representative), Breda Mulvihill (National Disability Unit Health Service Executive, HSE), Joan O'Donnell (Support Officer Disability Federation of Ireland, DFI),Jackie Barron's HSE A/Area Manager Louth Disability Service and Helen Lahert (National Advocacy Director Citizens Information Board, CIB).

Meetings of the group

This group first met on the 24th of January 2011 in the Citizens information Offices in Dublin. They were introduced to the project, to each other and approved the Terms of Reference for the group. Their initial reaction to the project was one of interest and enthusiasm.

The next meeting of the group was on the 11th of April in the Citizens Information Board office in Dublin. In preparation for this meeting all members were given a copy of the 'Introduction to the ÁT Network' information pack in order to understand fully the process that we advocate and to give additional input.

The problems we were experiencing regarding Transfer of Undertaking for the Protection of Employees (TUPE) were also explained. The meetings we had to that stage to progress the situation were outlined. The Stakeholders fully engaged with what they were shown and guaranteed their support in relation to the situation with TUPE.

The third Stakeholders Group meeting was held on the 27th of June in the Citizens Information Board offices. Each member was asked to play a role in our October shared learning event in the National Disability Authority. The group was also given an update about our progress in relation to the situation regarding TUPE and the project as a whole. All members were encouraged by the developments and were very positive about the project and its progress. They are all very eager to see our project succeed and are very forthcoming in their support to us.

Future of the Group

In 2012 we will continue to link with all of these individuals and the organisations they represent. The support of this group was very important to us in our first year as we learnt so much and benefited from their collective experience and their individual working knowledge.

Pilot Participant's Story – Owen Collumb

Owen Collumb, Director of Collumb's Personal Assistant Services Dublin Ltd. (the company Owen established to receive his budget for his Personal Assistant Service

"As I move to the rerouting of funding for the Irish Wheelchair Association to my own personal company, over the past two months I have come to realise that there have been many new challenges presented to me.

However, as I reflect on my time managing a Personal Assistant (PA) service I remember that, when I began receiving a PA Service ten years ago, it also represented a life changing event for me.

Since our conference on the 4th of October 2011 many people have approached me and asked 'Do I not find this model of direct payments difficult to operate?' My honest response would be that this model is no more or less difficult than operating the self-directed service which I had previously received. When a person becomes competent at doing a particular task they find it quite easy and feel like they are in control. After completing the documentation and registering my company the other tasks became repetitive and have to be done on a monthly basis.

At the seminar I realised that they are still many people 'passively' receiving services that they have been ascribed with. A lady told me about her mother receiving a package of hours from a private health care provider when she became immobile. This lady, for her previous years, had always been involved in the political and social life in the community. Now she is told when someone will come to her home at a

fixed time of 6pm to provide her with assistance to go to bed and in the morning someone will arrive at 9am to assist her with getting up and preparing her for that day. This is when I realised how much our project has to offer people. If she was in control of her own service, she could organise where and when she wanted assistance.

I have learnt a great deal during the process of setting up my company. This was a new experience for me and the other guys (Martin and Gordon) as none of us have done something like this before. We are, in a way, pioneers' trying something that has never been done before in Ireland. We did this to open up the different options of how a PA service could be delivered to people. Although, there have been challenges in setting up my own company, it has been a learning experience more than anything else. I know how funding is distributed to individuals and the process involved in receiving a PA service. I am currently recording my own individual experience for anyone who wants to come on board with the ÁT project.

It has been almost two months since my company has received funding in order to run my service and for the most part it has been a positive experience. My Personal Assistants understood and were involved in this process and they still continue to provide a PA service underpinned by the Philosophy of Independent Living. Through the peer networking group with ÁT we can use our own knowledge to provide new individuals with training and support in managing their own service".

Sharing the learning Event 4th of October 2011

Some of those who attended

The morning panel

On the 4th of October we held a Learning Event in the National Disability Authority. At this event we had representatives from key stakeholder organisations and many Leaders who were eager to hear more about Áiseanna Tacaíochta (ÁT). The day was broken up into 3 sessions.

Morning Session

The event was opened by Madeline Clarke, Director of Genio, and was chaired by Sara Burke, health policy analyst and journalist. Aisling Jones, Project Assistant Coordinator explained where the idea of Áiseanna Tacaíochta came from and how it as a pilot fits into the changes in disability policy in Ireland today. Owen Collumb, a participant, spoke about his experience of the project. Owen also volunteered some of his time helping to develop the peer network of ÁT and the information material for setting up a company that will be used for future members. Helen LaHert is a Circle of Support member for Gordon Ryan who is also a participant. She spoke to attendees of how much work was involved in the start up of Gordon's company. Gordon then shared his motivations in setting up his own company and his founding role in Áiseanna Tacaíochta.

Coming to us live from Sweden

A lively question and answer session followed that was chaired by Sara Burke with some concerns and interest expressed in the approach that we are taking. Bairbre Nic Aongusa, Director of the Office for Disability and Mental Health Department of Health and Children (ODMH), then described some of the current work her department was engaged in and spoke very positively of the work of ÁT. She introduced Eugene Callan, a Leader. Eugene hosted a webinar session with Erik Ljungberg a Swedish Leader who founded and developed his company AiAi. Erik, in Stockholm, demonstrated his company's simplified tool of managing PA's hours and

pay that is used by some Leaders receiving a Direct Payment in Sweden. This is an area that ÁT is looking to develop in the coming year.

Afternoon Session

After a quick lunch and a slice of birthday cake, the last section of the event focused on contributions by Stakeholders. Claire Crehan Dowdall, National Development Officer with the Assisted Living Service in the Irish Wheelchair Association (IWA). Claire was a part of our Stakeholders Group that helped to advise us as we began our work. She spoke of her background knowledge of Direct Payments, her role in IWA and the implications of Áiseanna Tacaíochta for those wishing to choose this option. Jackie Barron, acting Area Manager Louth Disability Services HSE, outlined her personal experience of assisting one of our participants in receiving his funding and how it was rerouted from the original service provider. Joan O' Donnell, Support Officer Disability Federation of Ireland reflected on all that had been outlined in the day. Martin Naughton, Project Coordinator of Áiseanna Tacaíochta, spoke about Áiseanna Tacaíochta's plan for the both the immediate and distant future. Sara Burke then brought the afternoon to a close making remarks on what she had learnt and wished us well as we continued with our work.

Those present expressed concerns and some were very complementary of how far we had come in a year. Some Leaders felt that the amount of work involved was too much. In response to the concerns expressed, we have decided that we will reassess our approach in the coming year to simplify our current model. We will also test out other models of individualised payment so as to make choice available.

The afternoon panel

Don Bailey asking the panel a question

Bairbre Nic Aongusa ODMH and Patricia Mc Larty HSE

Achievements to date and future targets

At the outset we had drawn up eleven targets for our first year of operation. We were extremely happy with our progress in achieveing nine of these key areas.

Targets Achieved

- ✓ A Direct Payment project was developed
- ✓ A Peer Support Network for individuals was created
- ✓ 4 individuals who have significant disabilities and who use Personal Assistants (PA's) directly were supported and empowered to manage their PA service
- ✓ A Stakeholders group was established to ensure the Irish Wheelchair Association, Cheshire Ireland, the Health Services Executive and other organisations were made aware of how our project was operating
- ✓ An 18 month leeway for pilot participants to return to their former service provider arrangements has been made available
- ✓ Individuals with disabilities have demonstrated that they have the capacity to direct their own lives by managing direct payments with support from the Peer Support Network
- ✓ A new model of Direct Payment Service delivery in Ireland has been created that can be emulated by other service providers and utilised by policy makers
- ✓ Advice materials and training for self-advocacy and for circles of support have been created
- ✓ The organisation has the capacity to enable others to manage their own service.

As we approach our second phase of expanding our pilot the remaining two areas must be worked on.

Original targets that need to be addressed in Phase Two of Áiseanna Tacaíochta

1. Work with an additional 17 identified individuals who have expressed interest in moving to this model of service, with the support of their current service provider
2. Develop access to mainstream training for individuals with disabilities

As we approach our second year we are working towards the broader aim of expanding the model of Direct Payment delivery with the ongoing commitment of two of the main service providers; Irish Wheelchair Association, Cheshire Ireland with the guidance of Disability Federation of Ireland. We intend to achieve this by using a timetabled action plan for the next three years that will target the previous two unresolved aims and an additional seven.

Additional key aims of Áiseanna Tacaíochta

1. Strengthen the existing board of management structure of Áiseanna Tacaíochta
2. Streamline the current company model of Direct Payments
3. Broaden the choice of model of receiving funding for services directly
4. Develop policies that are relevant to individuals managing their service as opposed to those which are currently adapted from those used by larger organisations
5. Support the growth of a Cooperative model which will assist those who require extra support or the involvement of their family in order to manage their support services
6. Ensure evaluations take place on the work of Áiseanna Tacaíochta
7. Continue to share the learning by hosting seminars and annual events

Martin Naughton on behalf of Áiseanna Tacaíochta in September 2011 at a national event facilitated by Genio for special recognition of the work completed by grantees of the Genio Trust 2010

Acknowledgment of our supporters

We would like to thank all who have helped us in our first year as a pilot project. As we come to the end of our first year as a pilot, we would like to thank you whether it's just for reading our e-nuacht's, for giving us your time to assist or advise us with pieces of work or engaging with our new approach. We must thank a lot of people whose invaluable support throughout this year helped us to get to the stage we are at now. On the 5th of October 2011 we signed the Service Agreement for release of funding between ÁT and HSE. We can now look back at how we got to where we are now. This was as a result of a lot of hard work and time that was given to us by those we wish to specifically name below.

Participants and Circles of Support

The efforts of participants and their Circles of Support have been tremendous. They have, as Madeline Clarke Director from Genio said, took a chance at high risk and at great difficulty to themselves in order to achieve Direct Payments.

Sean Gardiner and his father Kevin Gardiner

Gordon Ryan, Martin Naughton and Owen Collumb

Staff who have worked for the past year with the project

Aisling Jones, Project Assistant Coordinator (ÁT), and Mladen Tubic Accounting Assistant (ÁT),have worked hard to support participants and their Circles of Support.

We would like to thank Cathy Mc Grath, Disability Federation of Ireland (DFI), who gave us great support early in the year.

Genio who helped fund our project

In particular we would like to thank Madeline Clake, Hugh Kane (not pictured), Tara Doheny and Fiona Murphy.

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The members of the Stakeholders Group

Breda Mulvihill (National Disability Unit, HSE, Mark Blake Knox (CEO Cheshire Ireland), Claire Crehan Dowdall (National Development Officer with the Assisted Living Service, Irish Wheelchair Association, IWA) and Helen LaHert (National Advocacy Director, Citizens Information Board)

Joan O'Donnell, Support Officer, Disability Federation of Ireland, (pictured right) was also a source of support and guidance as we have and will continue to develop.

Jackie Barron (A/Area Manager Louth Disability Services HSE) pictured here (right) with Claire Crehan Dowdall (IWA) was also a very important supporter of our project at the outset.

Cheshire Ireland

We would also like to thank, along with Mark Blake Knox the CEO of Cheshire Ireland, Aoife O' Toole and Ian Quinn for their support during this year.

Irish Wheelchair Association

We would especially like to thank the key staff in the Irish Wheelchair Association that supported us throughout the negotiation process this year, to help us get funding released resolving all of the issues along the way. This includes Kathleen McLoughlin (CEO), Gerry Phelan (HR Director), Chris Hoey (Regional Director) and Michael Doyle (Regional Director).

HSE

We would finally like to thank key personnel in the HSE; Carol Doolan (Disability Manager Dublin North Central), Maebh Reynolds (Disability Services Manager (Dublin Area 6),Geraldine Murphy (Disability Manager, HSE North Dublin) Angela Walsh (Senior Manager, Dublin North),Geraldine Murtagh (Office of the Area Manager North Dublin), Denise Donlon (Case Manager/Liaison Officer, Galway) and Mary O' Donnell (Disability Service Manager).

Statement of Financial Activities

(incorporating Income and Expenditure Account)

For the 16 months 31 December 2011

	16 months 2011 €	€
INCOME	70,213	-
(Continuing operations)		
Adminsitrative expenses	(72,152)	-
Operating (deficit)/surplus	(1,939)	-
Interest receivable and similar income	-	-
(Deficit)/surplus on ordinary Activities before taxation	(1,939)	-
Tax on (deficit)/surplus on ordinary activities	-	-
(Deficit)/surplus on ordinary activities after taxation	(1,939)	-
STATEMENT OF MOVEMENT IN RETAINED INCOME		
(Deficit)/ retained surplus for the 16 months	(1,939)	-
Revenue Movements	-	-
Accumulated (deficit)/surplus carried forward	(1,939)	-

The financial statements were approved by the Board on 16th April 2012 and signed on its behalf by:

Gordon Ryan Director

Martin Naughton Director

Balance Sheet

For the 16 Months ended 31 December 2011

	Notes	2011 €	€
Current Assests			
Debtors	**3**	827	
Cash at the bank and in hand		33,319	
		34,146	
Creditors: amounts falling due within one year	**4**	(36,085)	
Net Current Liabilities			(1,939)
Total Assists Less Current Liabilities			(1,939)
Capital and Reserves			
Income and expenditure account			(1,939)
Equity Funds	**5**		(1,939)

The financial statements were approved by the Board on 16th April 2012 and signed on its behalf by:

Gordon Ryan Director

Martin Naughton Director

ÁISEANNA TACAÍOCHTA

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