

Dublin Leader Forum Newsletter

*Welcome to the Dublin Leader Forum
Newsletter*

Dear Leader,

Welcome to the first edition of your Dublin Leader Forum Newsletter! I hope you will find it informative and entertaining.

The primary aim of the newsletter is to inform Leaders about the work of the Dublin Leader Forum. We also hope that you will use it to air your own views and share your experiences with your peers. We would like to thank those of you who contributed to this newsletter, and to assure everyone else that we are always happy to receive articles, letters and ideas for forthcoming newsletters. The more involved Leaders become with the forum and this newsletter the more representative they will be of you and your experiences as Leaders.

In this edition Sarah Maye will review the Dublin Leader Forum concept, and outline its structures and aims. Those who volunteered to join the DLF Committee Group will introduce themselves, and we also have opinion pieces from Orlaith Humphries and James Brosnan.

Enjoy!

Issue 1

September 2005

Aims of the Dublin Leader Forum

To create a strong network of peer support

To monitor service provision

To advocate for improved conditions for Leaders

To liaise with the National Leader Forum

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Your Guide to the Dublin Leader Forum

As you know, the Dublin Leader Forum is in its very early stages. So here's a quick guide to the concept of the Leader Forum & the principles behind the idea.

The Basic Concepts

Independent Living

In practice **Independent Living** means that a person with a disability employs various services in order to carry out the tasks of daily living. Independent Living does not mean living in isolation, or not asking for help. Instead it means choosing the most appropriate tools to allow yourself to live the way that you want. The most important service available to a person with a significant disability, who wishes to live independently, is the Personal Assistance service.

Leaders

A Leader is somebody who uses a Personal Assistance Service. The term Leader was chosen to reflect the fact that the person with the disability directs or "Leads" his/her own service. A Leader should expect to be treated with respect, and it should be accepted that you Know what is best for you.



Personal Assistant (PA)

A Personal Assistant or PA works for, and in theory is managed by, a Leader. He/she helps the Leader with tasks ranging from personal care to assistance in the school, college or workplace. In theory it is the Leader and not the Service Provider that tells the PA what the Leader requires. This empowers the Leader and allows him/her flexibility and independence. This is a cornerstone of the philosophy of Independent Living.

Service Provider

A Service Provider... provides a service! They are the people who provide your Personal Assistance Service. The Service Provider should inform the Personal Assistant of the philosophy of Independent Living. Unfortunately some Leaders feel this is not always the case and therefore the need has arisen for a Leader Forum.

The Dublin Leader Forum

The Dublin Leader Forum (DLF) is the Dublin branch of the National Leader Forum (NLF). Basically, it is a group of Leaders who have come together to offer each other support and information, and to discuss any problems that may exist within their service. The DLF aims to place the Leader back in control of their PA service, so that the philosophy of Independent Living can be put back into the heart of PA services.

Why do we need a Dublin Leader Forum?

The idea for a Leader Forum was put forward in 2003. A number of Leaders agreed that this would reduce the isolation felt by individual Leaders. It would also place Leaders back in charge of their own PA Service and their own lives.

Put simply, it was felt that a DLF was needed to address the concerns of many Leaders. These concerns included:

- ❖ Both Personal Assistants and Leaders not fully understanding the philosophy of Independent Living.
- ❖ The geographical distance between Leaders makes it difficult for them to come together as a unified group.
- ❖ Some Leaders felt left out of the service provider-Leader-PA relationship
- ❖ Some Leaders felt that they lacked the skills to manage their PA services properly

Who Runs the Dublin Leader Forum?

Dublin Leaders (i.e. You are in charge of the Dublin Leader Forum. The DLF will be independent of any service provider and will be accountable to its members. An independent group like the Dublin Leader Forum will become an effective platform from which to address any issues you may have with your Service Provider.

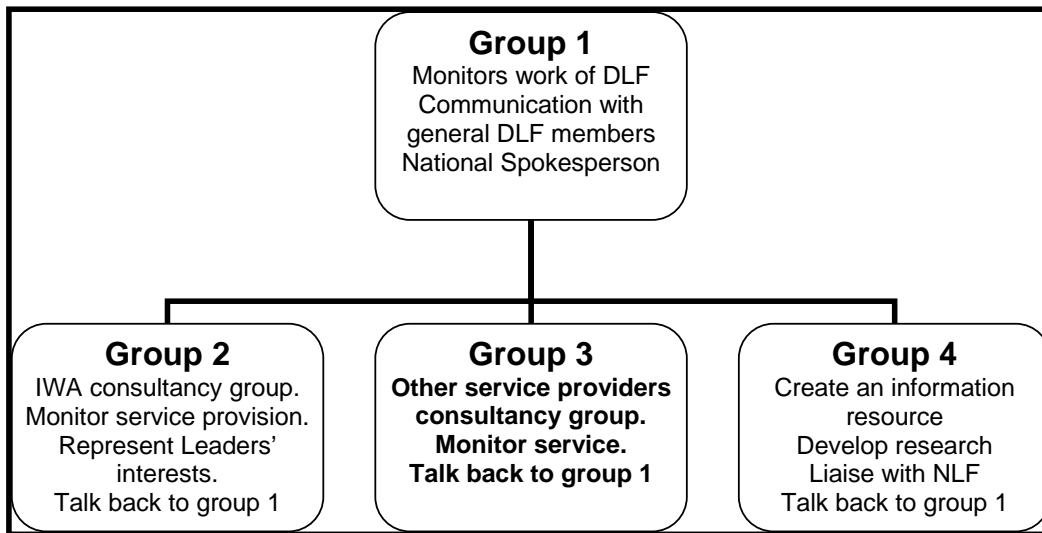


How will the Dublin Leader Forum tie in with the National Leader Forum?

The National Leader Forum will act as an umbrella group for regional Leader Forums like the Dublin Leader Forum. The Dublin Leader Forum committee group will liaise with the National Leader Forum, and will share the concerns, work and progress of the Dublin Leader Forum members with this national body. The National Leader forum will strive to achieve;

- To have a real user say in service provision quality, style and level
- To rally the group for the push to 'mainstream' present PA services being operated through FAS CE.
- To break down the isolation barriers that are weakening individual spirit, resolve and voice.
- To train for and lobby for Direct Payments

The Structure of the Dublin Leader Forum



The Role and Structure of the Dublin Leader Forum Committee

At the first meeting of the Dublin Leader Forum, it was agreed that the DLF should have a definite structure. The purpose of this structure would be to ensure that the forum is accountable and representative and to prevent burnout or apathy on the part of Leaders. Therefore it was proposed that the

Forum should be operated through a committee with four main focuses. The committee will carry out its tasks on behalf of all forum members. There will be an overall spokesperson who can report back to the forum and carry any concerns from the forum to the committee group.



Meet the Dublin Leader Forum Committee Members

Eileen Daly (National Spokesperson for the Dublin Leader Forum)

I'm Eileen, I've been a Leader and involved in CIL since 1994 when I moved from my parents' house in Cork to study in UCD. I live in my own apartment and my PA's assist me in all aspects of my daily life. I work full time with students in further education. I love music and I can be found at many a live gig! I also love the cinema and I like nothing better than going for a few scoops (often a few too many as my PA's can testify!!) on a Saturday night.

I'm excited about the development of the Leader Forum and I believe that is crucial that we Leaders work together and support one another to ensure that independent living is recognised by government and policy makers as a right and a choice for disabled people in Ireland. Being a Leader/line manager enables me to have choice and autonomy in my life and I wouldn't change it for gold but it can sometimes be a frustrating and lonely role, you need to do timesheets, rosters, recruitment, and interviews, organise holiday cover, it sometimes seems never -ending..... this is why a Leader forum is vital.

Orlaith Humphries

My name is Orlaith Humphreys. I am 25 years old and I come from Dublin. I have recently volunteered to become involved with the leaders Consultative Group. I have a BA in History and Politics, a Masters in Equality studies and a Higher Diploma in Woman's studies.

Owen Collumb

My name is Owen Collumb. Originally from Longford, I now live in Chapelizod in Dublin. I have been living at my current address for the past two years and with a personal assistant, I live as independent a life as possible. I have recently completed a Degree in Sociology & Politics in university and would like a new challenge in my life now. I have a particular interest in film production and the politics of foreign countries like ex- Yugoslavia where I have just returned from after a two week visit.

Gordon Ryan

My name is Gordon Ryan. I am 31 years old. I currently work for Comhairle as an accounts assistant; I have been working here for the past two and a half years. I have been a Leader for the past seven years.

My PAs are very important to me, because without them I would not be able to live independently, as I do at present. I currently live in Baldoyle in a one-bedroom apartment. I have 70 PA hours a week, which is funded through IWA. I think the Leader Forum is very important, as we need to emphasise the importance of the philosophy of independent living to as many potential leaders as possible.

Dermot Walsh

Hi I'm Dermot Walsh,

I work mainly for Dublin Bus and the Carers Association. Apart from the Center for Independent Living, I am involved in the I.W.A. and am interested in Sport. I was a member of the Transport Committee of Dublin City Council up to last year. I am a founder member of the Center for Independent Living, and am now a member of the board.

Peter Moore

From the age of five until I was twelve I spent my life in Marino Clinic in Bray. Apart from regimentally of strict bedtimes and meal times for me the most institutionalising experience was that I was put in nappies every time I had diarrhoea. For me this symbolized most strongly the denial that I had a growing intelligence and sensitivity; it was never even suggested to me that it was for the best, it was just done to me.

From Marino I attended St. Brendan's Clinic and school in Sandymount where the education can be described as non-existent except for an overdose of religion. It was only when I joined the Irish Wheelchair Association and was inspired by people like Paddy Crooks, Liam Maguire and Colm O'Doherty that I began to think I did not have to walk to be proud of what I am. However, it was not until the advent of the Center for Independent Living which began the concept of personal assistants that I felt I could reach my full potential and be myself.

Mary Collins

I am a graduate of Trinity College Dublin now working toward a Master's degree. I was responsible for setting up of a special government fund for second and third level students with disabilities now worth several million Euro per year. I am on the Board of the Southside Partnership and a Director of ACTS (Accessible Community Transport Southside) on a voluntary basis

James Brosnan

Hello from Kilbarrack.

I am looking forward to the Dublin Leader Forum coming together. Sure, it takes time to be set up. We have one purpose in mind. That's to be reached by every disabled person in the role of leader. I have made some mistakes which I dare not mention. It's part of growth. We aren't there to judge – we are there to listen.

Nothing about us without us



Attitudinal barriers against the disabled

By Orlaith Humphreys

Why do people stare at us?... Is it because we are different? In the year 2005 where acceptance is common place why are disabled people still looked or stared at! On the buses, Luas and even on planes we are regarded by some people as being freaks let out of the asylum. Do I have two heads? Am I an alien from outer space? I must have something going for me to cause that much interest!!

Here is an example of negative attitudes towards people with a disability: During the summer I was out walking my dog when due to road works I was unable to cross over the footbridge and was forced to cross the dual carriageway. This was scary and extremely dangerous. I was forced to dodge traffic during red lights. I was shouted abuse at by drivers passing by. "Use the ramp" one driver shouted at me while others beeped their horns. I was very upset. I realise that crossing the road this way was unsafe, but what other choice did I have at the time? Is my safety not an issue in this case or did the fact that I was out walking my dog cause the drivers to feel uncomfortable? As a disabled person in Dublin am I meant to stay indoors and not be able to enjoy my dog just as every other able bodied person is entitled to do? Negative attitudes exist in every aspect of our lives. Sometimes I think that it would be easier to be a green, two headed alien living in Dublin than it is for me presently. At least then I would have a reason to be stared at. Negative attitudes surround every aspect of my life as a young disabled woman. This is particularly true as I am not able to enjoy the same freedoms as other able bodied individuals of my age.

As a young disabled individual I really am disgruntled at having to ring ahead to restaurants or bars to make sure that they are accessible. Or, as is often the case, having to hold on to go to the toilet. Because of this I have developed a very strong bladder. It is also true wherever you go in Dublin that you are not guaranteed accessible toilets or even accessibility to a building.

A big pet hate of mine is the fact that in many bars in Dublin the accessible toilet is used as a storing cupboard for the sanitation wares. This is reflecting the negative attitudes that exist towards disability. Recently I heard a story of a disabled person going to a wedding and when the venue was rung up to check if it was accessible, was told "well its not accessible, what

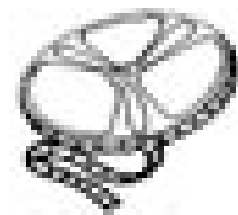
do you expect it's a 17th century castle"!! Why should disabled people have to plan their journeys in advance? In 21st century Ireland the disabled population can not do anything spontaneously. My solution to the problem of bad attitudes and intolerance toward the disabled population is to start educating people when they enter primary school. It would also be important for disabled children to be integrated into mainstream schools so that people begin to get used to seeing disabled children as normal. This is the only way forward. It is important to shape the minds of children when they are young and accepting of most things.

It should also be government policy that all buildings public or private should be accessible and equipped for use of all.

It will take a couple of generations before the effects of this will be felt in society, and if you can't wait this long, it might be easier to be abducted by aliens and come back in a different guise!!!!



Orlaith Humphreys



Inside I'm Dancing – a year on **By James Brosnan**

The film 'Inside I'm Dancing' celebrated its first anniversary in August. The storyline about two disabled lads moving from a residential institution to a flat of their own has been nominated for Best Film in the Irish Film and Television Awards. Based on the original screenplay, by the Personal Assistant to one of the leaders who first established the PA service, it can provide a background behind the early days of CIL. In 1994, CIL had a 24-hour protest for PA funding outside the Dail that lasted for three days. It was seen as a make or break standpoint by many. "It was based on the protest," one of the leader portrayed in the film explains. "The end had Nelson Mandela coming over here after getting released and granting us our freedom". The film depicts two or three true-to-life characters. Some controversy has come up concerning what is referred to as the love story. "The screenplay writer wanted me to go down the road in the script about going to bed with a female PA," one of the leaders depicted in the film remembers. The other Leader depicted in the film says that there should be a fine line with PA's always. "If that did happen, a relationship with a PA - there won't be PA's anymore". The film has grossed \$0.021 million in America. It popped up at number ten in Britain. 'Rory O'Shea Was Here' was the film title in the States. The sister of another leader has come up with an alternative title for the film. It is 'Outside I'm Dancing'. "We came up with the

name because of the way he is,” the sister clarifies. “He’s still dancing – and that’s not happening inside – it’s happening outside as well”. Her brother is living in a residential institution but wants to move out like the characters in the film. “We’ve got the home, we’ve got the liberation, we’ve got the disability,” the film director surmises. “It’s a high-concept movie”. The PA, who wrote the story, is no longer working with the leader. They both want to bring it onto stage eventually. Prior to its release in Ireland, the film won the Best Audience Award in the Edinburgh Festival. Among the other contenders for the Irish Award are ‘Adam and Paul’ and ‘Mickybo and Me’.

James Brosnan

Where to From Here?

Over the coming weeks the committee members will meet to clarify their roles and to talk about the practicalities of running the Dublin Leader Forum. They will discuss how best to carry out their various tasks, and how to communicate with all of the forum members. It is important that a dialogue is open between Forum members and the Forum Committee members, so that the Dublin Leader Forum remains a truly representative organisation. The easiest forms of communication will probably be by email and telephone, as well as by post. It is therefore important that you fill in and return the attached registration form - if you have not already registered - so that your contact details are up to date. It is particularly important to include your email address on this form so that you can be kept informed about

the progress of the Dublin Leader Forum. There are still some places to be filled on the Dublin Leader Forum Committee. It’s important that the people who have already volunteered do not become not overstretched. If you feel that you can volunteer around six hours of your time per month please indicate this on the attached registration form. The Committee is open to any member of the Dublin Leader Forum. In the interim you may direct any queries or suggestions to Sarah Dixon at the Center for Independent Living at Carmichael House, contact details are included opposite. If you have any ideas, letters or articles for the next Dublin Leader Forum Newsletter please feel free to send them in.

Dublin Leader Forum

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sarahdixon@dublincil.org

telephone

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Dublin Leader Forum Registration Form

Center for Independent Living
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Email: sarahdixon@dublincil.org

I WOULD LIKE TO BECOME A MEMBER OF THE DUBLIN LEADER FORUM

NAME _____

ADDRESS _____

TELEPHONE _____

MOBILE _____

EMAIL _____

I WOULD ALSO LIKE TO BECOME A
MEMBER OF THE DUBLIN LEADER
FORUM COMMITTEE

YES _____

NO _____