

Forging alliances for an inclusive society

A Day in the Life

Personal experiences of disability and mental health difficulty



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Foreword

This booklet offers an insight into the lives of six people with disabilities and mental health difficulties, their families, friends and supporters. There are no heroes in here. The stories reflect the aspirations of people who wish to live lives which are neither extraordinary nor indeed less ordinary, but simply, as one contributor puts it, "to be able to go out into the community and do the normal things that people do."

The lived experiences of the contributors are as diverse as the people themselves and their circumstances. The range of supports required to sustain people across the disability and mental health spectrum are complex, diverse and interlinked. The anecdotal evidence from these stories reveal, that these supports work best when they are individualised, meet the need as it arises and are flexible enough to adapt to changing circumstances typical to all of our lives.

I wish to thank most sincerely Aoibheann Foley, Don Bailey, Kevin Kennedy, Diarmuid Ring, John Murtagh and Ann Dillon, and all of those who participated in this project for sharing so openly with us their personal spaces, their homes and their lives. My thanks also to Fiona Keogh and to Stephen Doyle of Vision Media for their help and assistance.

David Egan

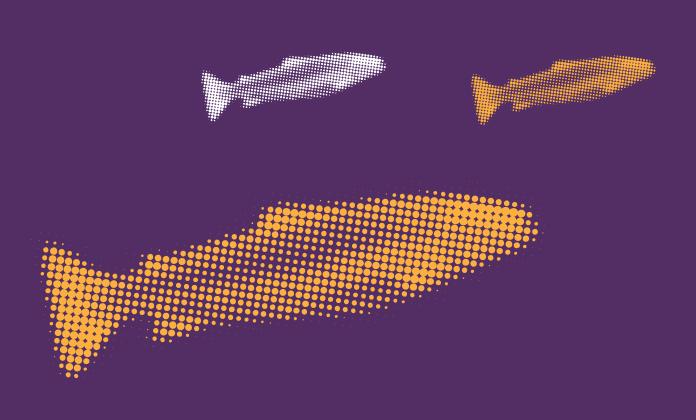
Disability Consultant and Member of Genio

The views expressed in these interviews represent the views and opinions of the individual people who participated in the project.





Don Bailey





Meeting Don Bailey for the first time in his modern apartment there is no indication that this articulate, full-time employee of the Department of Agriculture, Fisheries and Food, spent most of his early life living in institutional care. "I spent seventeen years in St Joseph's in Coole," he says, settling back in his electric wheelchair, "I was twenty-one when I left," he reminisces. "I had no idea how I would fit into society because, coming from a hospital environment where we had only passing interaction with the general community, I had no expectation of what was required of me," he says.

Don's first attempt to integrate into work and a life in Dublin failed due to lack of supports. It was the early 1980's, with little personal assistance available and no accessible transport. "I had no planned supports at work or getting to work. I started in June and by September I knew that I knew nothing. It was a four day existence in a bed and breakfast and a trip home at the weekend to get fed and laundered. It was a peculiar existence at a time when I had no experience of independent living. I had no idea of what even I needed, never mind what anybody else could provide," he says.

He dropped out of work and returned to the family home in Dundalk.

Over the next three years he completed a course in Business Studies at Dundalk Institute of Technology.

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Don's second attempt to join the public service proved more successful. He arrived back at the same Department, the same office and practically the same desk. "Fortunately my colleagues at work saw the problems before I did and provided lifts in and out of work on a daily basis."

Initially he shared a "tiny flat" with a flatmate who also had a disability. Two wheelchair users sharing a small Dublin Corporation flat presented its own challenges. "My flatmate was more able than me and I got fed that way," he says matter of factly.

He also frequented his local pub 'Scruffy Murphys' where, over a period, he got to know 'Scruffy' and the staff. It was 'Scruffy' who, after observing Don struggling in his manual chair, tentatively suggested that an electric wheelchair would give him the independence to get to work on his own. A benefit night was organised and an electric chair, with its offer of freedom, was duly purchased.

Around this time also, after twenty years of coping and struggling, Don became aware through networking with disabled colleagues of emerging Personal Assistant services, offering support with day-to-day activities according to individuals' needs, capabilities, life circumstances and aspirations. He had strong reservations about having a stranger become part of his personal life, even in a professional capacity, and there was little training available to him.

"At that stage I didn't want anyone invading my personal space. That's a journey you can't make until you're ready to make it. A Personal Assistant opens up large opportunities that I knew were available but I didn't know how to take advantage of them until I got some Personal Assistant hours. The older you get, and more disabled, the less energy you have to spend on the mundane, important but mundane things, and the less energy you have for living life. As disabled people we inherit limited expectations, our personal space is defined by our families or by



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institutions, and we have fears about experimenting beyond those limits. I was forced in the end, through incapacity, to use a Personal Assistant. After a very short period it dawned on me how much more of life was available," he says.

In recent years Don has purchased his own adapted van with a wheelchair lift which his Personal Assistants are insured to drive. "Having my own transport allows me to set my own schedule. Personal Assistant hours are not that generous so the more you can do with less time, the better use you can make of your free time and that's desperately important."

In more recent years Don was invited by Dublin City Council to be part of the planning team for his new home, a mixed residential development close to the new Aviva Stadium and Ringsend village.

"We (the residents) built this ourselves from a greenfield site. We were part of a team which included Dublin Corporation Architects and Occupational Therapists. It's now part of a mixed community including disabled people, some elderly folk and young adults and children."

Don's ground floor apartment is a generous open space design with electric doors, adapted bathroom and a guest bedroom which can be used by a personal assistant to sleep over. "Having your own home allows you to do all of the things other people take for granted, to come and go as you please, to live your life," he says.

Don is now a seasoned public servant in the Department of Agriculture, Fisheries and Food. The offices are large open spaces with individual work stations and good access throughout the building. "Society insists we fit the norm and the norm is work. You can't socialise well without being in the norm. The supports I need at work are surprisingly little. I now occupy a semi-managerial role, which takes the physical aspect out of work and allows me to interact with





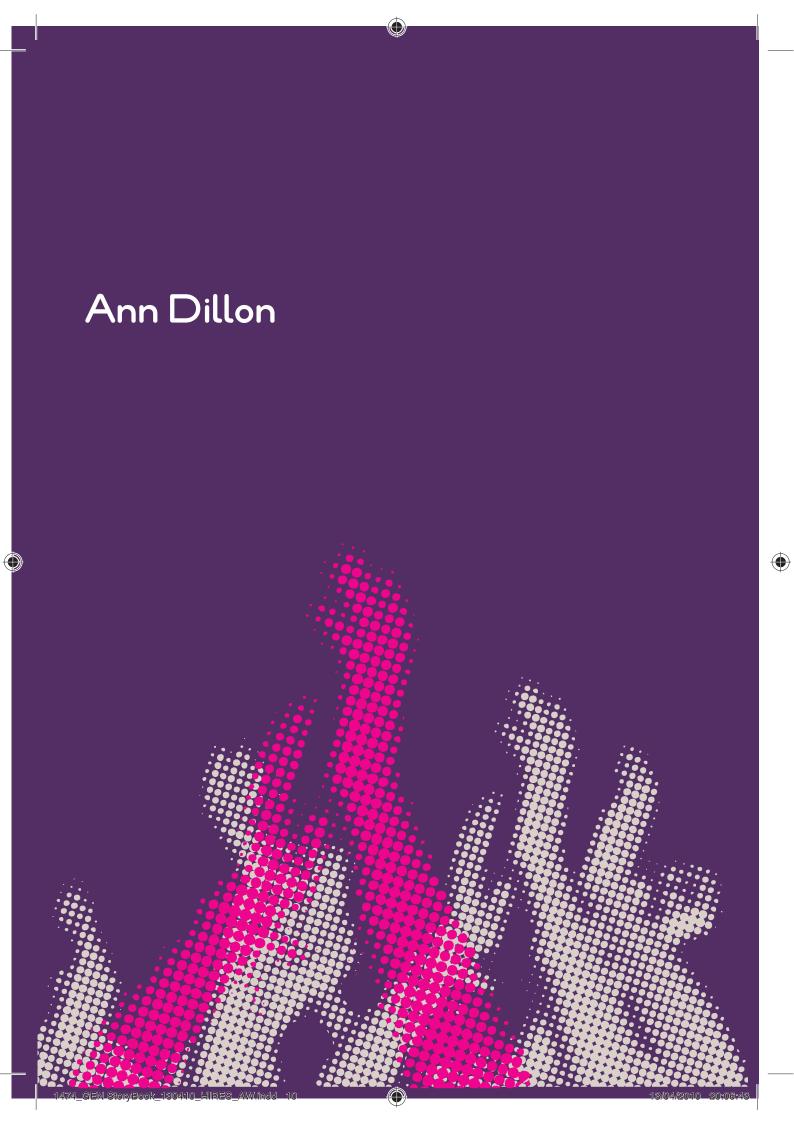
my colleagues much more. Colleagues are very helpful. It's now the norm that Don needs this or needs that, and it's done. "There's no tight management of that informal support but that's there for me because I've grown with it," he says.

Don is active in a progressive and vibrant disability community which is part of the Dublin scene. "I do get involved in disability issues, again because it allowed me a socialisation outlet, initially, but now I do it because I enjoy it. I think once we bring society with us we become part of society, not a subset of society, which is outside society. If we don't achieve that then society is going to fail," he said.

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"Sometimes I get up around eight in the morning. I can get up on my own. People come in here and stay overnight and help me to get washed and dressed. I can cook toast and get my cornflakes myself," says Ann Dillon from her riverside apartment in Birr, County Offaly.

Ann, who was born with Down Syndrome, lived with her parents Mildred and Theo before moving into her own accommodation. "I like to do my own thing, have my own space. There are no rows, no arguments" she says.

Ann is well known in the town where she grew up and where she attended the local primary and secondary schools. "I go to the shops on my own," says Ann. "Everybody knows me. I love buying magazines."

Sarah Davis first became friendly with Ann during their school days. "We were in Primary School together, the whole way up to sixth class. Ann was seven and I was five," says Sarah. When Ann went to Birr Community College Sarah went away to school and later to college but always stayed in touch. Since moving back to Birr Sarah is now both a friend and an advocate for Ann.

"We like to go for walks or swimming," says Sarah, "I also attend meetings with Ann's main service provider as her advocate. Ann and I would meet together beforehand and have a chat. If she wants to bring up something and she forgets to, or doesn't have an opportunity to, I would raise the issue for her," she says.

Another friend is American-born Tara Cunningham, a bubbly young mother from Tullamore and founder of the Release organisation, who works with children with speech impairment.

Tara became great pals with Ann when they first met over ten years ago through Down Syndrome Ireland. "Within four minutes we were, like, talking about Westlife. We've been at every Westlife concert in The Point together since 2001 and we get to go backstage. We can do Google







searches on Westlife and JLS. We follow all the gossip," says Tara. Tara and Ann also like to go shopping, particularly to Dundrum Shopping Centre, "because there are loads of shops."

Ann's first job was in the coffee shop of Doolys Hotel. A few years later she took up a full-time position as an assistant in a garden centre. Ann has not returned to work since having two major strokes in recent years which have reduced her physical capacity but she was determined to live independently again. "Ann, ever since she was a young girl, wanted to live independently," says her mother, Mildred.

"If someone wants to live independently there is a lot of work involved and parents have to be there. Ann does need support. I'm lucky because Ann has great assistance, wonderful friends and she is very independent. We get great help and support from St Anne's (now the Daughters of Charity) staff. St Anne's advised us how to go about getting housing. Offaly County Council pay for Ann's apartment and she has to pay only €26 a week. She has her own bank account, she goes in and takes out money, sometimes too much money, but she takes it out none the less," says Mildred with wry humour.

Eileen, who is employed by the Daughters of Charity, provides assistance for Ann during the week. "I come in four evenings a week to Ann just to make sure she's ok and generally do the jobs Ann is not able to do, like cook dinner, do the ironing; sometimes we go out for a meal, watch TV, that sort of thing. Ann is very capable, she's very good on her own, she'll only do what she wants to do," says Eileen.

Ann also receives support to recruit her own assistance to sleep over and to provide cover at weekends. "The HSE and St Anne's agreed to put some money into Ann's bank account so that she could advertise for young people to stay with her overnight," says Mildred Dillon. "Ann and myself interview the applicants. She's been so lucky with the people she's had. Some girls may want the experience for their CVs or





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The payment also allows the service to be flexible and to address Ann's needs as they arise. "What's nice about it is that if myself and my husband want to go away for a few days we can use that account to ensure Ann has paid assistance during that time. That's a weight off our minds," says Mildred.

Meanwhile Ann continues to enjoy living as an independent person in her home town with a strong appreciation of her place within the family, in her community and amongst her many friends. In contrast there are many people like Ann who live in residential centres away from their communities with paid, professional staff available on a 24/7 basis.

"I go to the day service twice a week, sometimes three times if I feel like it," says Ann. "We go to the pictures. I like action movies and comedies, we go to the swimming pool and then they bring me home again.

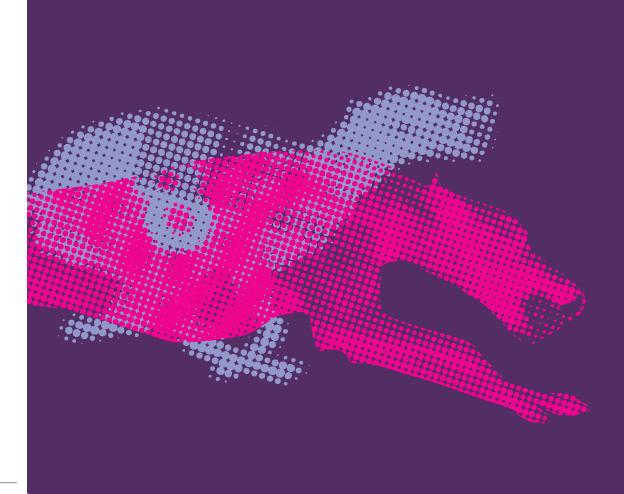
Sometimes I could be late going to bed. I don't mind being on my own. I like living here."

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John Murtagh









Neatly tucked away behind Google's shiny new European headquarters on Dublin's Barrow Street is the home of John Murtagh, a former resident of The Barrett Cheshire Home from 1969 until 2009.

"A few years ago I began thinking about moving out," says John, "I started to plan with Cheshire staff about what I wanted to do with my life. I saw too many people die in the house, I was at too many funerals. I did not want to leave in a box."

John, who was born with Cerebral Palsy and then aged sixty-five, had been planning his move back to the community for over two years. "I was in Barrett for over forty years so I went on trial to see how I'd be able to get on. At first I thought I wouldn't be able to do it but I'm coping well. I found I was able to do things I wasn't able to do in the home. Going around the complex and going to the shops. The people in Spar know me now. They know me from going in and out. I have no fear of going anywhere else 'cos I have to get used to it."

Jane Flynn is an Occupational Therapist and part of a HSE Primary Care Team working with John around assessment for Personal Assistant hours, equipment and technology, and familiarisation with the local environment, including public transport. John uses an electric wheelchair and the built environment can be challenging. Identifying an accessible route to the local shops and to Ringsend village has been a priority. "The idea is that you start by getting used to doing just one route," says Jane, "to get independently to the shops and to Ringsend Tech," where John has attended a number of classes. Independence "just opens up more opportunities and gives confidence," says Jane.

Also working with John during his transition from residential to community living is Suzy Byrne, an Advocate with the Dublin Leader Advocacy Network. "The work that I have been doing is helping to bring people together. John would not have known much about the HSE," says Suzy, "in fact they were paying for his support in residential care."





"My role really was to help him make contact with people once he'd moved out so that he would have other forms of support and other connections outside of his service provider. I did a lot of work with John planning meetings with the HSE, who are funding his package, and with Cheshire, attending meetings with him, making phone calls, making sure all the questions were being asked. It helps him to be able to ask for what he wants. That really is what the whole process is about," says Suzy.

Key to John's independence is his Personal Assistant support. "I do what I can, as much as I can, without any help but sometimes I do need help," says John. "The staff I have here are very good to me and I get on very well with them. We have staff meetings once a month. I was able to advertise and interview my own staff with the help of my Advocate and the person who co-ordinates my service. This was very important to me because I thought I would never be allowed or able to do this. I now have staff working with me that I have chosen and they support me in doing what I want to do. I would like to have more hours of support. My support is provided to me in small shifts each day in order to make sure all my essential needs go smoothly. But it's difficult to plan for things like trips out or meetings," he says.

According to Suzy Byrne, recruiting assistants was one of the major pieces of work with John, to help him interview and select people to work with him. "This was a big change as he would have had no control over his service in the past," says Suzy. "For people who are preparing, and have the opportunity, to move to the community there is a huge issue about knowing what's out there. There's very little time or resources available to help people find out because how can somebody choose a way, or a place, to live if they haven't experienced it?," she says.

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steep learning curve even for someone as intrepid as John Murtagh. He is clearly enjoying the opportunities and challenges that come with independent living. "I never paid a bill in my life before and I'm getting help to manage my money. Sometimes I go to the shops on my own."

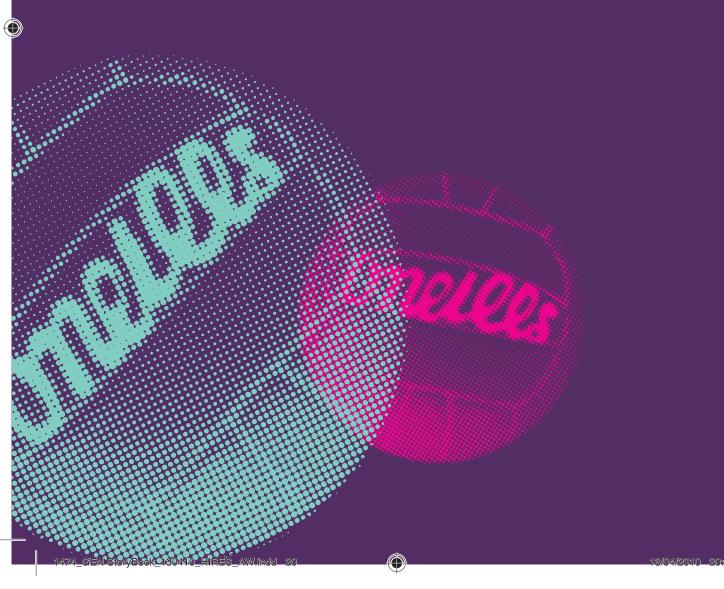
John is active in the Dublin Bus and larnrod Eireann user groups and he is a member of People with Disabilities in Ireland. "Some of my friends live around here and some live in town and they come in to see me," he says. "I've got my sister and my niece; they come into me nearly every week to see how I'm getting on. I have great relationships around here and I go to the dogs [Shelbourne Park] anytime I want to. I've got used to it now and I don't feel alone. I listen to the radio all the time. I've got assistance and if I wanted anyone I've got an emergency button and they'll come to me. Forty years was a long time not to have a full say and it's going to take a long time to get used to it but I wouldn't have it any other way. I think it's great and I think it's the best thing I have ever done in my life."

Integrating into a new community and building social contacts, as a sixty-five year old man with a disability, and speech impairment, is a steep learning curve even for someone as intrepid as John Murtagh.





Kevin Kennedy





Kevin Kennedy is ten years old and lives at home in Mullingar with his parents Martina and John, and his brothers Dillon and Jack. Born with Down Syndrome, Kevin, like most little boys his age, has little understanding of disability and less interest. He lives a busy life filled with school, football, music and all of the hustle and bustle of a regular family home.

"When there are four guys in a house, you learn to fight your corner," says Kevin's dad John. "When his two brothers get ready to go training in the local GAA Club, Kevin is togged and ready to go with them, where he trains with the Under 10's. His coaches are very supportive as are the Club," says John. "It's all part of the weekly routine. For me the whole idea of socialisation is important. Kevin is part of the local community, he does exactly as his brothers do, and his fellow students in school. He's well known in the parish and I like to think that Kevin has brought a little bit to the party as well in terms of his school friends, his teachers and the broader community," he says.

The local National School, which Kevin attends, is a small rural primary school with a strong sense of community and an ethos rooted in social inclusion. "Kevin hit the school running and has been a big feature of the school ever since," says school Principal, Derek Butler. "We had to learn how to meet his needs, we've both evolved a lot, we recognise some of Kevin's needs now and have put supports in place," he says. The school has a total of six children with special needs. Kevin has a Special Needs Assistant (SNA) and gets three and a half hours of resource teaching per week.

"Mainstreaming works," says Derek. "Every child in the class has different learning speeds and different needs. Kevin's SNA is helping him to achieve all that he can be and he's thriving on it."







"Because we are a small rural school, integration probably works a lot better than if Kevin was in a bigger school. All the children here are very aware of Kevin and his needs. He has a few very good friends who play with him during the breaks and it just works very well. I think it has helped all the children in the school and the staff, myself included. Kevin has learned from us and from the other children, but equally important the other children learned from Kevin. We have all learned from Kevin," he says.

Catherine Staunton teaches 28 children in the Third Class where five of her pupils, including Kevin, follow different programmes. "We meet with the parents to develop an Individual Educational Plan," Catherine explains. "We get as much information as possible from other sources, such as parents and speech therapists, which helps us identify strengths and weaknesses. Kevin has good language but we need to encourage him to use full sentences and to express himself more," she says.

Catherine takes it all in her stride and encourages Kevin's extra curricular events during school hours. "For Kevin it is very important to experience as much as possible of everything," she says. "He gets on really well with his peers, he's been here since junior infants, the boys and girls just know him as Kevin, they don't see him as a boy with a disability. He's just one of the gang and that's the way they treat him, which is lovely."

Kevin's Special Needs Assistant supports him throughout the school day with his academic work and also assists in other areas, such as dressing and in the bathroom.

Kevin's main support at home is his mother Martina. "Kevin likes routine," says Martina "He comes down in the dressing gown and, now, he gets his own breakfast. Then we shower, he needs help with all of that obviously and, as long as his clothes are left out for him, he'll dress himself and put on his shoes, then we're off to school," she





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says. Martina works closely with the school who support her "in every possible way." That support includes rostering Kevin to go horse riding one morning a week when Martina picks him up from school. Kevin is also entitled to four hours a week home assistance to help with homework, a service Martina describes "as an absolute God-send. It just takes so much pressure off at that particular point in the day when the other boys are coming in and Kevin takes so much longer to do his homework. It's a much more drawn out event than the other boys," she says.

"I'd like to see that support developed a bit more as he grows older, to use that support to take him out of the house, to bring him to the shop or into town, to maybe buy something for his lunch. As he grows older the real benefit will be in doing something more practical, some life skills, like learning about money or preparing food for himself," says Martina.

Both John and Martina have thought about the future and what it might hold for Kevin. "For us as parents the whole focus would be on a quality of life for Kevin, in terms of social skills, in terms of being independent and going into town, doing all of the things within his limitations that Kevin can do with the proper supports," says John. "We are very fortunate that he's in the local National School, a mainstream school. If we could replicate that in the next phase of his education we would be absolutely thrilled. That is a huge challenge for us, to expand the education supports to give people like Kevin a better quality of life and thereafter to be able to go out into the community and do the normal things that people do," he says.

His views are echoed by Martina. "I would feel he is well capable of living and working independently with supports," says Martina. "I don't want to end up at a situation where at thirty years of age Kevin is sitting at home with us waiting to see what we are doing that day. If





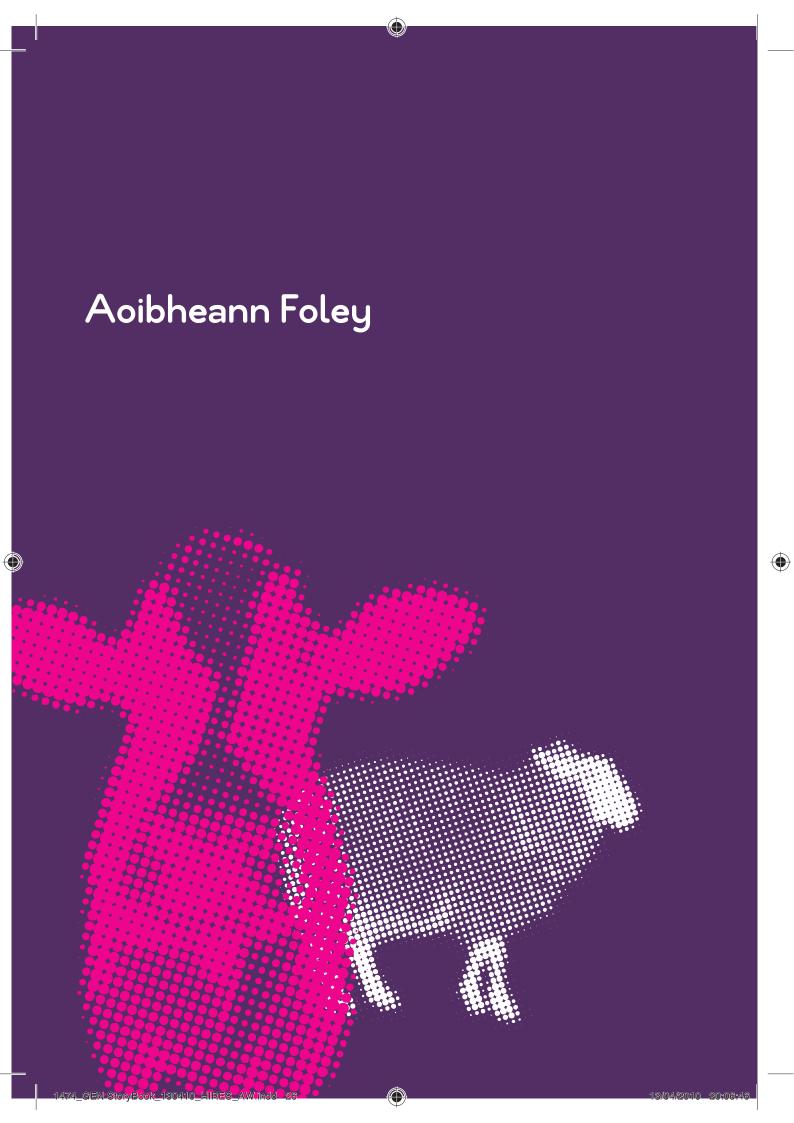


Kevin could live independently, work independently with supports, and have some friends, people of similar ability, then they could do things together and live a good life, an interesting life," she says.

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"She is a joy of a child, she has a huge personality and I'm very, very proud of her," says Emer Foley, whose daughter Aoibheann was born with profound intellectual and physical disabilities. Aoibheann is entirely dependent on others for all of her needs. Now nine years old Aoibheann, who is non-verbal and attends St Mary's Special School in Delvin, requires around the clock attention. The family home remains an uncluttered space in which Aoibheann can move freely on the floor without being a danger to herself.

"Personally I think she's wonderful, she's a beautiful—looking child and she is so loving, and so giving, but she is such hard work; that is unfortunately the bottom line. You have to give every ounce of yourself to her, everything else comes to a standstill," Emer says. "Our family life definitely does revolve around Aoibheann, where she is and how well she is, or how unwell she is. That leaves a very fine balance and you are on thin ice an awful lot of the time. You have to be ready at any given time just to drop all and take her down to the GP or the hospital. You just have to be ready to go, you're on—call all of the time."

Aoibheann's busy day starts early when her assistant arrives to get her up and ready for school. Aoibheann needs to be changed, washed, dressed, and to be fed her breakfast before the school bus arrives at

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9am. She is then gone for the school day, arriving home at 4pm. "Mary, another assistant, is here to meet her off the bus when I'm collecting the other two," says Emer. "Again, she'll give her a drink, she'll feed her, change her, she'll be here for 2 to 3 hours, take her out into the garden to potter around, if she needs a bath she'll give her a bath. Even though it's only a few hours it's a huge benefit to me because it means I can go down town to get the bits and pieces and give my attention to my other girls."

Emer's husband Ollie, together with their two other daughters, Róisín and Clodagh, provide a loving supported and fulfilling life for Aoibheann but it challenges all of them, every day. "I have two other children who are entitled to a normal life," says Emer. "One of the most difficult things is trying to get that normality and trying to get a balance. The other two girls need your attention and they need a life, and Aoibheann's needs are all-consuming."

On Wednesdays Aoibheann doesn't go home from school but travels instead to stay overnight with the Kinkade family on their County Westmeath farm. Nuala Kinkade has known Aoibheann since she was a baby and is part of Aoibheann's 'Share-a-Break' family. "She's been coming here for the past ten years," says Nuala. "We're on a farm so if there's something going on below in the yard Aoibheann would have to come with me. We feed the lambs and give silage to the cows, whatever's going on really, she's part of it. She loves it; she's quite happy down on the farm. My children are in their teens so they're a great help with Aoibheann. She just comes and goes like one of our own and we don't treat her any different. If the girls are going to a football match they'd take Aoibheann along. My eldest son is great for lifting her because she's a dead weight. I take her visiting to my sister. It's like a second home to her here," says Nuala.





"She's actually a little person who, through no fault of her own has all these disabilities and she needs nurturing and minding and to be included, not to be sent away because it's cheaper or because there's nothing else in place"



The Share-a- Break scheme "has been a life saver for us," says Emer, "and in our case it has worked absolutely brilliantly. Aoibheann is absorbed into that family as if she was born with them. There's never a problem. If they're going somewhere they'll pop her into the car and off she'll go."

Share—a—Break, which is run by the Sisters of Charity of Jesus and Mary/ Muiríosa Foundation is a flexible arrangement and Nuala sometimes takes Aoibheann a couple of times a week to allow the Foleys to go out as a family, and for a full week during the summer holidays.

On the days when Aoibheann comes home from school the Foleys take over again when the last of Aoibheann's carers leave at around 6pm.

"Then I'm back on duty or Ollie, her dad, we take it in turns," says Emer. "Again it's very time consuming, very slow, more medication, more feeding, and we try to get Aoibheann into a little routine of sleep. We try to keep things as calm and as quiet as possible which is very difficult with ordinary life going on around you, and we hope against hope that she will wander off asleep in your arms at some point."

Emer and Ollie are both realistic about the future. While they both want Aoibheann to remain living as part of the family, they know there are huge challenges ahead in meeting her support needs. But they are determined that whatever supports are put in place, that they will be on their terms and that Aoibheann will remain at home as part of the family.

The Foleys envisage a small modern house nearby where Aoibheann would have her own room and where she could go for regular breaks.





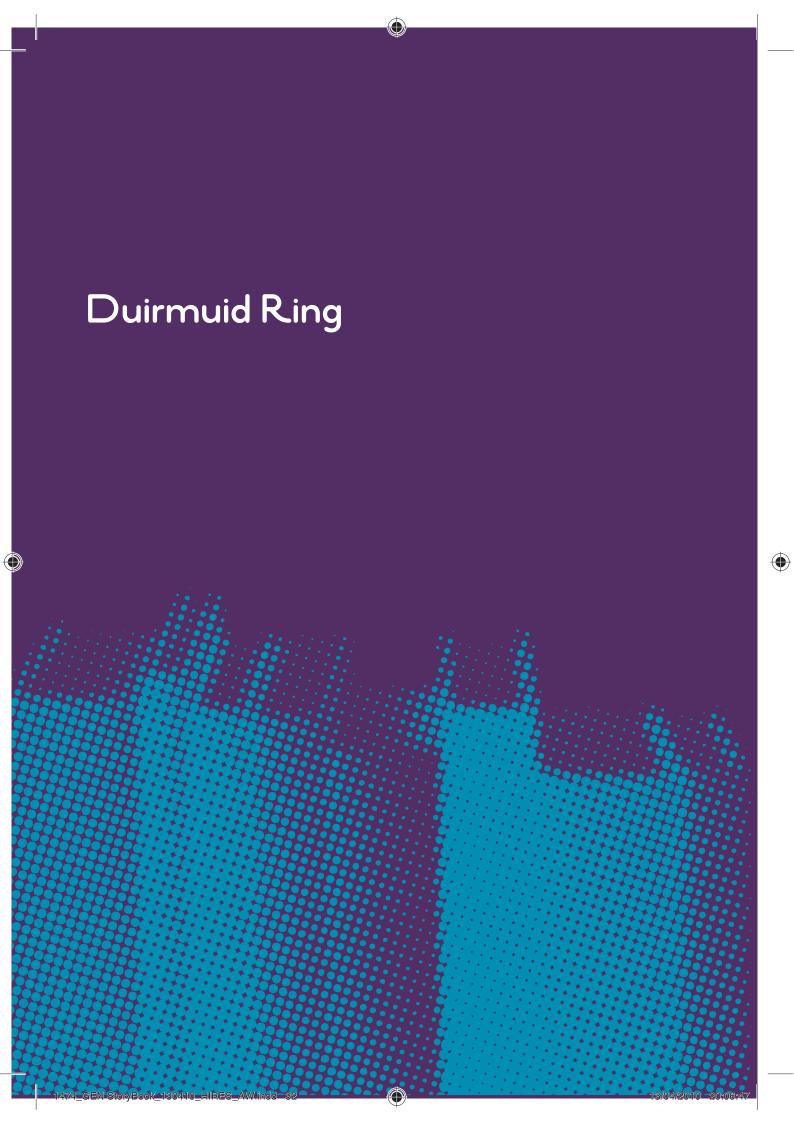


In this way Emer believes that Aoibheann could continue to be supported to live an active and interesting life while the family are also supported to continue supporting Aoibheann. "She would continue to go over to St Mary's for social and sensory integration, use of the pool and all of the other services. She would continue to be brought off on day trips on the Shannon or to the pet farm," says Emer. "All these little things that other little children get from their schools. She would continue to get a few hours assistance at home that would break up her day and keep her interested and stimulated."

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Sitting on a sunny park bench in Dublin's Merrion Square, Diarmuid Ring's conversation is confident and thoughtful as he reflects on a life of hope and hurt. Now aged forty-three, this native son of Cahirciveen experienced a major breakdown of his mental health at the tender age of fifteen.

"I don't put any limitations on my life now," says Diarmuid. "The last ten years of my life have been absolutely amazing in terms of my development. I don't believe people should say 'thus far shall you go and no further'. There are such things as liberation and freedom and they are real things, and I've experienced them," he says.

However, by his own admission, getting to this point in his life has been a long and sometimes painful journey. Diarmuid was fifteen when initially diagnosed with 'chronic anxiety depression' which spiralled out of control until he was nearly thirty years old. During this time he moved between one institution and another within the private and public health systems.

"Initial interventions were unsuccessful," says Diarmuid. "I was very isolated from my family. At that stage I was so young, so depressed and in so much mental health distress. I wasn't improving and I was getting very institutionalised and dependent on the system," he says.

It was Diarmuid's father who decided that he should come home to Cahirciveen where he attended a newly opened day centre. "That was a watershed moment for me," says Diarmuid. "They started me on a Care Plan which I never really had in the private system. With the advice and motivation of the nurse in the centre, and his encouragement and his belief in me as a human being, I began to get better. I initially had a very negative experience in the psychiatric services. I found when a person really did believe in me for the first time in my life, I said, maybe there is a possibility of getting out of this despair. Somebody had confidence in me, somebody outside of the family, who in this case was a professional







nurse, but who was also a nice and decent human being. I didn't come across that for the first ten years of my journey with depression," he says.

Part of the confidence and esteem building measures in the Care Plan included occupation such as rug making, from where Diarmuid graduated to a glass factory and, later, to work in the hospital shop in Tralee. From there he embarked on a three-year training programme in Dublin and then enrolled in University College Cork where he graduated with an honours degree in the social sciences. Subsequently Diarmuid successfully applied for a position as a library assistant in the University, where he works today.

"I think that hope is essential for somebody going through depression," says Diarmuid. "For the first ten years of my engagement with the mental health system hope was not much in use... I accepted that at a young age but when I met progressive people, that hope was instilled back into me. Peers really inspired me because they really believed in hope, believed in the principles of self-determination and hope that is part of the ethos of recovery. I've had ten years of my life taken away from me and even though it's hard, you do come back, you can have a really free and independent life," he says.

Diarmuid is currently Chairman of the Irish Advocacy Network that has an established network of trained peer supporters. "Basically it's about somebody who has come through (mental health difficulties) helping somebody who's going through it," says Diarmuid. "It is that human engagement that no other professional/service-user relationship can possibly have. It is the x-factor relationship because the person knows that their peer has been through this. That is vital because it brings empathy and hope: 'this person has come through and I'm going to get through as well.' No professional can give you that," he says.





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Diarmuid also works as a peer counsellor in University College Cork. "One of the most effective tools I have to sustain myself is as a peer mentor within the University helping other students with mental health difficulties. That is a really vital part of my work in terms of helping other people to go through academia which I went through myself. It's an important part of my work and my independence, and my psychology. Getting up in the morning and being able to say I've got great employment. Work is important and it gives me an independent income, it gives me a psychological and financial freedom that I didn't have before."

"You have to have a purpose and a strategy in life," says Diarmuid.
"You also need to have self-belief but you also have to be realistic. Talk therapy for talk therapy's sake is not effective. You're going to have bad days; you're going to have good days. I'm in psychotherapy for the last year. I now see the benefits of it because I'm at a stage in my life where I'm in control of my own emotions and I'm not as raw and helpless as I was. It's hard but it's beneficial," he says.

In common with people with disabilities, getting appropriate housing is a big issue for people with mental health difficulties. "Service users have problems with relationships," says Diarmuid. "As single people it is very hard to move up the waiting list for Council housing," he says. "People are also allocated houses located in tough housing estates which can exacerbate their problems. "When you think about service users living with the fear and distress of depression," says Diarmuid, "and you double it by putting them in situations where there is more fear and uncertainty. People need a proper choice of where they can live and not just be imposed on an estate which has a lot of problems," he says.

"Having my own house, having my own space, is the most important thing in my life. Not only does it give me freedom, in the sense that I don't have to live with other people or live with strangers, but I also have







the freedom to choose my own schedule. I choose whom I want to bring home, who my relationships are going to be with and who I want and don't want in my house. For me that is a huge God-send, it is liberation."

Despite changing attitudes in Irish society towards mental health there remains a stubborn and enduring negativity associated with people in recovery. "One of the fundamental roots of the problem is that people are defined by psychiatric labels," says Diarmuid. "It then becomes a kind of self perpetuating negativity about human beings. How do we relate to human beings [with mental health difficulties] in this country? Do we relate to their labels, or do we engage with 'people' who are in distress emotionally? This is an ongoing debate between the medical fraternity and people who are in recovery," he says. In the interim "the stigma is very powerful still. People's employment options are completely restricted because of it. It's very problematic."

But on a personal level, for Diarmuid, the road ahead is filled with hope and ambition that is framed by realism and the wisdom gained from a lifetime of experience.

"I'm on this journey now," he says. "I live in hope, I live in fear, I would like to have a more self— affirming relationship in my life but I think this will happen. I'm hopeful but sometimes having too many expectations can put you in trouble. So I am hopeful but I'm also aware that there is more to do. My hurt has lessened. I don't think it has gone; the hurt is part of who I am but at the end of the day, that awful anxiety and tension and depression [are gone]. I'm much freer now and I will continue to address that hurt again and again through the power of good human beings in my life."







About Genio

Our Mission

To accelerate the availability of proven, cost-effective, personalised supports and information, enabling people with disabilities and mental health difficulties at risk of social exclusion to lead full lives.

GENIO works to:

- Identify and promote good examples of cost-effective, personalised supports for people with disabilities and mental health difficulties
- 2 Provide the evidence required to accelerate the availability of these supports
- 3 Support the development of strategic self-advocacy
- 4 Facilitate and capacity-build cross-sector collaboration between key stakeholders (individuals at risk of social exclusion, statutory agencies, NGOs and private/philanthropic organisations)
- 5 Provide practical support in the form of expertise and funding
- 6 Offer independent research and evaluation

GENIO is a non-profit organisation rooted in the belief that by valuing diversity both the individual and society can benefit from the unique contribution of all citizens.



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Forging alliances for an inclusive society

