

NEWS

SPORT

BUSINESS

OPINION

LIFE & STYLE

CULTURE

MORE

Health & Family > Parenting | Fitness | Get Running | Summer of Family | The Health Centre

## ‘I’m tired. I’m scared. I know I have the potential to do something good’

For people with disabilities, living an independent life is close to impossible without a personal assistant – but it’s not easy getting one from the HSE

© Sat, Jan 8, 2022, 06:00



Patrick Freyne



Daniel Airey lost the eight hours a day of help from a personal assistant after he graduated from college. Trying to get a similar service through the HSE has been a battle. Photograph: Laura Hutton



In 2020 I interviewed 24-year-old radio presenter and podcaster Daniel Airey for an article about how young people were coping with Covid. In December he emailed me about an issue he was dealing with.



Daniel has cerebral palsy and is a wheelchair user. After he graduated from college he lost the eight hours a day of help from a personal assistant that he was entitled to while in education. Trying to get a similar service through the HSE has been a battle.

Daniel is very talented. He has a degree in digital media from TU Dublin Tallaght campus and a masters in broadcast production from IADT Dún Laoghaire. He coproduces a podcast, Dan and Darragh Do Ability, with his friend Darragh McNicholas. It has developed into a regular radio slot on Dublin South 93.9 FM.

He has made short films, including a 15-minute documentary called Swim with Richard about the 10K swim his father did to raise money for the hospital where he was born. You can find more of his work on [aireycommunications.ie](http://aireycommunications.ie). He has even appeared on First Dates Ireland. “Yes, I am the guy from First Dates,” he says and laughs.

But without a PA his future feels uncertain. He’s very worried about how he can live an independent life. His parents had always been his main support but the family is having a difficult time. His father is being treated for aggressive prostate cancer.



It is Health Season in The Irish Times. In print and online, we will be offering encouragement and inspiration to help us all improve our physical and mental health in 2022. See [irishtimes.com/health](http://irishtimes.com/health)




“Mum has been my primary care for 24 years,” he says. “She doesn’t get the carer’s allowance. She’s on her own meds for neck problems [and] back problems through years of looking after me to the extent that she has. We’ve got to the stage that if anything happens to them now, I’ve no choice, I go straight into care. And that’s an absolute living nightmare for the family. It’s either a choice of the Government paying something like three grand a week to maintain me in care or I get personal assistance and I can accept job offers and actually contribute to society. Which one is better?”

Daniel was born three months early. “I like to think of that as me being way too eager,” he says. “I had a bleed on my brain and, essentially, the doctors told my parents that I wouldn’t be able to read, write, walk, talk. And it’s a testament to them that I’ve got to where I am right now. I use an electric wheelchair to get around. And even just talking to you about it right now, I think about the amount of work that mum and dad have put into me, and the amount of work that I’ve put in. I just don’t want that to go out the window.”




He inherited a lot of determination from his folks, he says. “When the doctors said what they said, my parents turned round to them and said, ‘No, our son will write his own name’. I don’t know where I was but there was an air of ‘I’ll show you what I can do’. [Years later] I remember sitting at the edge of the pitch and just looking at everybody playing football and thinking, ‘why can’t I do that?’ I remember having a chat with a friend of mine ... It was one of those conversations that I came out of it going, ‘No I’m going to control this, not the other way around’.”

At the moment Daniel receives just 10 hours a week of home care – not PA hours – from the HSE, which falls far short of what he needs to live a full life. “People come in and they get me up in the morning and they come back and they put me to bed at night with showers and things like that.”

 Daniel would love to work in radio or television. “My dream job would be to present.” But he’s in a catch 22 because though he has been applying for jobs he isn’t sure he could take one if it’s offered “because I don’t have a personal assistant ... I’m tired. I’m scared ... I know I have the potential to do something and do something good and leave a mark.”


Ideally a PA would help him get up, wash, have breakfast, get his things ready and take him to work. In the workplace they would help him with the practical details of getting through the day before taking him home for dinner and helping him prepare for the next morning. Personal assistance works best, he says, if there’s a good relationship there.

He worked with the same person for many years in college. Consistency and trust is very important, he says. “You build up a relationship with each other and an understanding of how you do the work. And I think that helps a huge amount ... just being able to talk through things and figure out a solution.”

 Recently he sent a roster to the HSE to give them an idea of what he needed.  The week before we spoke for this article, he had a meeting with them. “They essentially said to me, ‘There’s a lot in this. We don’t know what our budget is for 2022’ [before] taking me on loads of different tangents that didn’t feel like they were helping.” 

“

A personal assistance service can enable myself and lots of other disabled people to have choice and control over our lives. And, unfortunately, that’s not on a statutory footing

 That was a hard day, he says. “I ended up having a full-on mental breakdown on Friday night because it just all came in on top of me ... For anyone else they can get up and they can run and they can box a punching bag, but me I’m stuck in a chair. So that’s bashing into the walls. It’s bashing my fist off an arm rest. It’s a lot of shouting. I’m emotionally, physically, mentally drained from everything. I need answers ... Society has a baseline for people and people with disabilities have to do extra work to get to society’s baseline. They’re constantly catching up ... It’s so stressful. It makes you feel small ... I don’t want to lose who I am. I’m Dan who deals with this disability on my own terms.”



James Cawley, policy officer with the [Independent Living Movement](#), tells me that lots of people find themselves in Daniel’s situation. The [Independent Living Movement](#) would like to see a legal right to a personal assistant for disabled people established in Ireland. “Personal assistance is one way that disabled people can exercise their rights under Article 19 of the UN Convention on the Rights of People with Disabilities,” he says. Article 19 recognises “the equal right of all persons with disabilities to live in the community, with choices equal to others.”

The public personal assistance service is HSE funded but spread across nine different Community Healthcare Organisations (CHO) which makes delivery inconsistent across the country. According to the capacity review launched by the [Department of Health](#) in 2017, 44 per cent of applicants were only getting an average of 42 minutes of personal assistance a day.

Often, says Cawley, people who receive the service are told when to get up or go to bed because the PAs are rostered to go from one house to the next. “That’s not independent living,” says Cawley. “That’s institutionalisation in the home.”

A personal assistance service helps disabled people to work and socialise and live their lives. “A personal assistant is not a carer,” says Cawley.





“It’s distinctly different. I have a right to live independently in the community. I have a personal assistant service. They act as an extension of my limbs. I will direct all of those tasks that I cannot do for myself to [them] ... A personal assistance service can enable myself and lots of other disabled people to have choice and control over our lives. And, unfortunately, that’s not on a statutory footing. There’s no legal right so it could be taken away at any stage despite ratifying the UN CRPD.”




He recalls when he first left college. “All of a sudden I went into the big bad world and it was like [to the State] my impairment disappeared because I had no funding anymore ... I had to go off and source the funding that I had from the HSE again to work. So that was a massive worry for me as a 22-year-old trained teacher going into my first interview without a personal assistant.”

When he was due for that interview the wheelchair ramp on the bus he was travelling in broke, “and I had no personal assistant with me ... The last thing you need when going for a job interview”.

Any disabled person can apply for a personal assistant through their local HSE office, says Cawley. “Then they have to go through a needs assessment, assessed by an occupational therapist. It’s really important that the disabled person is involved in all of those processes. I always request that I get to see what’s written about me because it’s really important that something is not put down on paper that I don’t agree with. Disabled people need to empower themselves to actually question and say, ‘Actually, I can do my own needs assessment, and maybe I can coproduce that with an occupational therapist’.”

Even if someone is deemed suitable for some personal assistance hours, there are often recruitment issues or the CHO who delivers the services doesn’t have sufficient funding. “The service is not ringfenced, it’s bunched in with homecare packages and home care support,” he says.

 “Personal assistants get a tiny fraction of [that budget]. I was talking to a young man in Wexford recently, who wants to work in Dublin, and he’s got the offer of two jobs, but he says, ‘I simply can’t take them because I can’t move my service from Wexford to Dublin’. There’s no portability of service... We need to get a centralised uniform system.”

The lack of proper services here has unacceptable consequences, says Cawley. “If you, as a disabled person, apply for a social house and you are eligible and you get the offer of a house, you can’t take it unless you have the offer of the support package from the HSE and the HSE won’t sign off on the package unless you have the house ... There are thousands of disabled people inappropriately placed in nursing homes under the age of 65, who do not need to be there, because of the lack of housing or the lack of personal assistance.”



Ross Coleman: ‘I’m living in fear that I won’t have the support I need to allow me to live my life.’ Photograph: Laura Hutton



This is a huge worry for the young people I talk to for this article. James Cawley puts me in touch with 24-year-old [Ross Coleman](#) who, like Daniel, is struggling to get the hours he needs. Coleman has a BA from Trinity, an MA from UCD and works as a self-employed Irish translator. He is also a poet, playwright and short story writer.

“I’m a wheelchair user and as a result of that I require assistance with going to the bathroom, with showering, with getting dressed, with getting stuff out of my bag ... When I went to college I had PA support to support me throughout the day for five years. When I left college ... I was thrust into the public system.”

Even when in college, he says, he had no help at weekends or during the summer break. “I was stuck in my house all day. I couldn’t go anywhere and I couldn’t do anything. In most respects it was like being in lockdown.”


“

Because I wanted to use some of my hours on Sundays and because hours on Sundays were more expensive, my hours were reduced to 13 a week...

In 2019, while still in college, he applied for personal assistance hours through the public system. “It was very difficult because I didn’t know who to call and I was constantly being referred to different departments ... When I finally did get a chance to see someone, I was told that such funding for PA hours wasn’t available due to budget constraints.”

He wrote to his TD and he kept stating his case. Eventually he was allocated 15 hours per week but “because I wanted to use some of my hours on Sundays and because hours on Sundays were more expensive, my hours were reduced to 13 a week ... It means, in effect, I can only really have a full life two days a week ... If I wanted to meet one of my friends, I could only really hang out with them at the weekend.”



 Currently he can't use those hours because there's a recruitment issue. "I can't find anyone suitable and who would be around my age and that would suit my personality," he says. "A PA is not a carer. A PA is my arms and my legs ... I had a PA recently and she was one of the best PAs that I'd ever had. Because a) she was around my age. And b) she allowed me do what I wished without any judgement."

Like any person in their twenties, there are things Ross wants to do with his life. He wants to travel. "One of my big ambitions is to teach English in [Japan](#). But on a more basic level, [not having a PA] means that I'm not out in the world meeting people, having experiences and making mistakes ... I live in my family home and I'm dependent on my mum and dad for support ... And I find that that means that I can't be like any other twentysomething because in some regards I feel I'm still their six-year-old child."

Nobody teaches young disabled people about their rights or how to advocate for themselves, says Ross. "I still get extremely depressed because there is no right to a personal assistant service in this country and everything is dependent on funding. So I'm living in fear that I won't have the support I need to allow me to live my life and to achieve what I want to achieve ... There is so much that I can do. I'm a playwright. I'm a poet. I'm a translator. I have two honours degrees. And for me to be put in a home because I can't dress myself or go to the bathroom would be disgusting ... Why am I being punished for something so small and so trivial?"

---

Topics:

[Health Month](#)

[Daniel Airey](#)

[James Cawley](#)

[Ross Coleman](#)

[+](#)