

Case story 2: Ronan, a family member and supporter of his brother John (names, places & identifying features changed)

Ronan is a supporter of his brother John who lives in long stay residential care on the grounds of a psychiatric hospital. John shares a house in the facility with nine others and has been living there for about eight years.

"From day one I felt there were issues to complain about and there are still issues to complain about. Over the years I've complained to staff in person and in writing, and I've encouraged John to speak up and complain himself. This has been interpreted negatively as me 'putting ideas in his head' and 'causing trouble'... One of the recent complaints resulted in an independent investigator being appointed which took about two years from beginning to end to complete."

When John was admitted to the hospital he was originally admitted as a temporary patient under the 1945 Act which Ronan indicated meant that his brother held involuntary status, however after three months had passed this was changed to voluntary status. John was not a *ward of court* and continues to be a resident to this day. Over the years, Ronan has continually found the interpretation of John's status by the hospital management to be problematic. He has consistently queried why his brother was not given the rights and entitlements that he understood a voluntary patient should have. For example, John was not allowed to make any decisions about his whereabouts or finances. In fact Ronan explains that the hospital staff actually removed John's bus pass and mobile phone from him saying it was for "safekeeping." However, in reality Ronan believes this was due to the culture of the hospital. "Patients were more easily managed if they didn't have those outlets." He was not allowed to leave the grounds of the hospital on his own and sometimes not when accompanied either, not even to vote. He was not allowed access to a bank account or financial statements or permitted to manage his own income. In fact, this was actively prevented by the hospital management. As a result, John has to request his own money from staff every time he needs it. Ronan has described this as being a difficult and disempowering process and one that is generally discouraged by staff.

Ronan tried to complain about his brother's financial situation, most notably after the hospital management intervened to stop John's disability payment from being transferred directly to his own bank account. This resulted in Ronan being accused of trying to take John's money when this was not the case.

"We opened a bank account for John and managed to get his cheque sent to his own bank account and then the psychiatrist found out and had it stopped which is pretty weird... They play on the idea that my brother has no capacity and they make out that they're keeping John's money safe for him... I helped John open the bank account, they knew I helped him because he had to use my address for that because if any bank card was sent to the hospital John would never have seen it. They used that against me and insinuated that I was trying to take his money... That must have been what the psychiatrist said to the disability allowance people because the outcome was that his money would go directly to the hospital from then on."

Ronan identifies a culture within the hospital that under-values John's capacity to make decisions:

"There was a never a test of his capacity. That's the culture there. It's assumed that people don't have any capacity. They make it up as they go along. I've had a letter from the psychiatrist saying that John has the capacity to say yes to medications but not the capacity to say no.... that doesn't make any sense."

Ronan encountered many barriers while trying to make complaints to the hospital over the last couple of years. Ronan raised several issues with the management of the hospital during this time. These complaints have ranged from the over-prescribing of medications to challenging John's lack of personal freedom, liberty and invasion of his privacy, along with his right to vote being infringed. He has complained as a family member and also has supported John to make his own complaints.

Ronan remembers an early incident which seemed to set the scene for his future involvement with the hospital in many ways. He explained that his brother liked to vote and had always made a point of voting. The incident concerned an occasion when Ronan was trying to assist his brother to do this:

“John likes to vote and there was an election coming up. He'd been with me a few days beforehand and I remember asking him if he was going to vote and he said he was, he always voted. Naively, when he moved there I thought they would facilitate people to vote. So on the day of the election I rang up to ask if the residents were being brought to the polling station to vote... They responded like I was asking some kind of crazy question and said essentially they weren't going to allow him out, which meant he couldn't vote. I couldn't accept that so I went over to the local Garda station and had the Garda sergeant ring the hospital about it. When the Garda rang them, they said they weren't going to stop John voting as they couldn't stop him from voting if he wanted to vote... They were playing with language because they knew he wasn't allowed outside the grounds of the hospital and John knew that too, none of the residents were allowed. So I drove out to pick John up so he could vote. When I arrived the staff rang the Gardai and complained I was “making a scene and causing trouble”... The staff had hit the fire alarm at one stage because I said I wasn't leaving until I saw my brother and could bring him to vote. Then they rang the Gardai and reported me as making trouble and said on account of my trouble making they weren't releasing John to vote... Months later I heard they didn't ring their local Garda station but rang the Guards near my home instead... They had wanted to intimidate me and make me out to be a “trouble-maker” to my local Gardai! There were several big burly nurses out there who intimidated me and deliberately pushed me out of the house. That's the kind of mentality you're up against.”

Another issue arose more recently when John requested his brother's help to write a letter of complaint about an incident which involved staff removing items from his room when he was out on a trip.

“Another time when he'd been at an event and was away they'd tidied his room and they'd thrown out an awful lot of his stuff. Now, John does keep a lot of bits and bobs but they chucked it all out... As soon as he came back, he knew what had happened and so he went down to the skip and started going through it and found some of his things but there were other items he didn't find. Some of his books were also thrown out... He was very upset about it and he rang me but they denied that he'd found his books in the skip. They denied it which made him look like a lunatic by saying he went looking through the skip for no reason when the things were in his room all along. That was a complete and utter lie. I complained about it and helped John to write a letter as well to complain. The manager did very little, she interviewed the staff and looked at what had been written in the notes and in a letter back to me and to John said the fact of the matter was that the things were not thrown in the skip and that he had gone into the skip of his own accord but had found nothing there as his things were in his room. I rang the manager and asked her why she hadn't interviewed John. I'll never forget the words she used, she said “I know the way it

works here, you don't interview them." So that's the way it works out there, they don't interview the residents, only the staff. They don't see why they should interview residents."

The incident caused John great distress and upset. When John got the letter back from the manager to say the things were in his room all the time, he became very upset: *"He was hurt. He was angry and he was hurt. He said it was lies and they were liars. He called them liars and I know him long enough, I know him very well to know absolutely that what he was saying was the truth."*

Ronan has complained to the hospital manager about several incidents in writing over the years but has only taken the process further formally on one particular occasion because of its potential to impact seriously on his contact with John in the hospital. The incident relates to an allegation made against Ronan when collecting John for a family outing in 2008.

"The major complaint I made was in relation to one summer's day when myself, my kids and my wife were going to the beach and we thought we'd just drop in and see if my brother wanted to come along too. Now John was classed as a voluntary patient, he was never a threat to himself or anyone else. So I decided to call in and see if he wanted to go to the beach as well. I always had a feeling about the hospital, like there were unwritten rules about what you were allowed and not allowed to do... There's an aura about the place. So even though there were no explicit rules that John couldn't go out with us, I felt the staff might be hostile to it... which they were. Anyway, it was a Saturday afternoon, I pulled in and went to John's house and asked him if he wanted to join us and he said he did. The nurse looked at me and said, "well, he has to have his dinner..." and I said "we'll have dinner while we're out." Then she came up with another thing and said "well... he has to have his medication," or something like that. I said he'd be back before his medication time. I felt a real resistance from her and so I asked her if she had a problem with us going out, she said she didn't and so off we went... Monday morning I got a phone call from the psychiatrist. He said that I was reported as being "abusive" that Saturday, and that if I was ever abusive again, I'd be escorted off the grounds by the Gardaí."

Ronan was concerned that the allegation made against him might result in future family contact and outings being curtailed by the hospital. He also felt intimidated by the idea of Gardaí involvement and was concerned about how this might impact on his relationship with his brother in the future. Ronan told the psychiatrist that he hadn't been abusive and that he felt threatened by being told the Gardaí might remove him.

"They can demonise you, so I was extremely careful not to show any emotion, I just denied it and said I was absolutely not angry or abusive and that it didn't happen like that. I said this feels like a threat, like you are threatening me by saying you'll get the Gardaí to remove me in future."

Ronan decided to challenge the allegation through formal channels to establish his innocence and to ensure that the records reflected the actuality of what had happened that day. Ronan was determined that the records reflect the truth so that they could not be used by the hospital as a basis for involving Gardaí or for restricting contact with his brother in future:

"I'm not sure if I knew about the HSE's 'Your Service, Your Say' complaints procedure, but I did know the proper channels to go down, the first port of call being to write a letter of complaint to the manager of the hospital. So I wrote a letter and I said something like I completely deny that I acted abusively. I did not raise my voice and I did not use any bad language. I want you to show me the evidence, to tell me exactly what I've been accused of saying, what words I used and how I used them. I also put down that I felt like I was being

threatened with the threat to have me removed by the Gardaí. I also said in the letter that it's this type of implicit threat that might explain why I didn't see other relatives visiting. At that time I'd been going there for six or seven years and I'd never bumped into another relative in my brother's house and there were nine patients there and I visited regularly. I felt that the hospital gave out an air of "you do what we say, you keep your distance". It's like your loved one is now in their control and you can come but not too often... there's no facility or space to visit with loved ones there."

Ronan waited for a reply and eventually, he received acknowledgement of his complaint and a letter of reply from the hospital manager to say that she would investigate the issue. A year or so later Ronan received a letter with the results of the investigation from the hospital manager.

"The manager had looked at the record book that the staff wrote up and she noted from that, that I had been abusive. She didn't even interview the staff... She backed up everything the psychiatrist had said and found no reason to say that I hadn't been abusive... she also said that the psychiatrist wasn't threatening me but that he was just letting me know the "future consequences of my behaviour"... it was that kind of ambiguous language."

Ronan was appalled by the lack of a proper investigation and so appealed the outcome to the Consumer Affairs Office in the HSE. An investigator was appointed to carry out a full investigation of the complaint and review the preceding investigation. The complaints process and investigation took about two years to complete before a final report was published. Ronan was pleased with the resulting recommendations:

"The investigator recommended that the hospital remove the accusation that I had been abusive and secondly, asked them to remove any reference to me in relation to the Gardaí or threat of Gardaí. I was delighted because they were the two things I wanted. There were other recommendations regarding better communication being needed between the psychiatrist, the staff, myself and my brother, which was good as well."

Ronan was also pleased that the investigator made reference to the lack of a thorough initial investigation by the hospital and received some explanation as to how the original accusation against him had come about:

"Funny enough the investigator picked up on the fact that the manager hadn't even interviewed the staff and that she had only gone through the records, the nurse's notes, to find her objective evidence... it was also interesting to look at the trail of how they arrived at the "abusive" allegation. When the manager went through the nurse's records, it was noted that "Mr O'Brien (meaning me) was disgruntled" with whatever the nurse had said at the time... From that they found a way of slipping into using the word "offensive" because my being "disgruntled" had led to the nurse becoming offended... Because there was offense then, therefore I had obviously been abusive... But it was "disgruntled" that was actually written in the nurse's notes and not "abusive"."

Ronan describes being very content with the recommendations of the investigator but found the process itself had been lengthy and overly protracted which had impacted somewhat negatively on his visits to John at the hospital:

"I was delighted with the recommendations... there were other things I suppose I would have preferred but all in all I think they went about it the best way they possibly could. They interviewed all sides and he was an experienced man which helped... he probably wasn't as intimidated by psychiatrists and the like as someone with less experience would have been. So I think they did everything they possibly could... but because it was so long and drawn out, the threat of removal from the grounds by Gardaí meant that I didn't visit

my brother as much during that period. I didn't want to go near the hospital... I'm glad I went through the investigation but I wouldn't do it again. It's energy sapping. It takes so long and you're stonewalled along the way."

Ronan was very thorough and cautious in documenting everything as he was determined to get results from the complaints process. However, he highlights that the process is cumbersome and draining and requires sustained efforts to see it through.

"I wouldn't go through it again because I've young kids, I'm busy, and like everyone else in the real world we have things to juggle around. It's energy sapping and at the end of the day, you might get a result if you push it hard enough but you have to be very careful. I was very rigorous with everything I did. I was very careful that I didn't ever raise my voice and that I worded everything carefully and took a lot of time writing my letters and so on. If you do that you will get results but as soon as the investigation is over, a few weeks or months later, things will go back to the way they were... I suppose for my own sanity I had to take a step back. I made many complaints over the years and I spent a lot of time and energy at it. There's no way I could sustain it."

Despite the fact that Ronan felt he got the outcome he had wanted from the complaints process on paper, he still feels that little has changed in practice as a result of his efforts.

"To be honest, to this day, I hate going near the place. Even though the report was good, it got me what I wanted and validated me; the atmosphere out there will never change. It's still the same, it's a cultural problem and one report isn't going to change that. So I don't like going out there. It was particularly difficult during the time the investigation was taking place... They got flustered and unsettled by the investigation, with people coming in asking them questions they wouldn't normally be asked. They didn't like that. Though as soon as the investigator was gone and they knew he wasn't coming back, the system just reverted back to the way it was. It's never going to change."

For example, one of the recommendations made by the investigator was the need for improved communication among staff, John and Ronan which would include regular team and family meetings. However, Ronan was disappointed with the hospital's approach to incorporating the recommendations into reality. He felt the resulting meetings that were set up by them were tokenistic, inconsistent in terms of staff attendance and non-inclusive as John was not permitted to attend. Ronan describes the hospital's response after the report, the new meetings and his disappointment at the lack of change:

"It happened in a very cosmetic way only. They invited me to a couple of meetings where I would turn up, and I wasn't allowed to bring anyone else – they didn't say why, there was just no-one else allowed. There'd be six people around the table; the psychiatrist, the nurse, the OT and a couple of other nurses. Then at the next meeting, there'd be all different people, so and so was away on holidays or couldn't come etc. So there was never any consistency or continuity. At the end of the day the psychiatrist has all the power so whatever he said the nurse would just row in behind and then the OT would just row in behind him as well. The other staff have no decision making power there... Another difficulty for me was that my brother wasn't allowed to attend the meetings. They said they didn't want to upset him by having him there and things like that... It's just a bad culture, it's not a place where you can have a conversation and feel like you're being heard. It's a very defensive culture that's just not going to change. They know it's not going to change and so do I. It gets a bit pointless."

Ronan describes feeling quite worn out by the process and having to tackle the hospital management on the treatment of his brother on such a regular basis:

"I've spent a lot of time and energy on this... I just couldn't accept it. You hear about these orphanages and institutions from the 60s and 70s and you just don't think that mentality can operate today but it can and it does. I saw it with my own eyes. The culture... is very subtle, very indirect and very intangible but you know what? It's so real. I've come across so many people that have had identical experiences to me. It's uncanny how similar they are. It's like everyone knows this is what's going on. People are powerless and powerless to even describe it. It's very hard to get a handle on it."

Ronan expressed that he feels quite exhausted by the process of challenging the hospital on their treatment of John over the years. He described having to hold himself back for his own health and wellbeing despite his continued concern over his brother's treatment at the hospital.

"I had to accept that I'm not going to beat this system, I'm not going to change anything. I accepted I had to step back for my own health and sanity. It's tough to know your brother is going to be there the rest of his life and to know there's another way. I know that now, I didn't know it when my brother went out there first but my instincts told me that it was Dickensian. That it was just not acceptable. Since then I've come across other alternatives and I know without a doubt there are other ways of treating people. It's a complete waste... to see him having such a poor quality of life in an institution like that. They just give him all these drugs... it's not helping, it's pointless and counter productive."

Ronan continues to meet his brother but avoids the hospital as much as possible because of the problematic culture he has encountered and done his best to challenge.

"The staff have demonised me because as soon as you open your mouth out there, they tell each other "that fella's a trouble maker" or an "angry" man because it suits them to believe that.. You just can't ask questions there at all and have to accept what they say... I remember picking John up as we were going into town. We were getting the train in and we were getting a bite to eat and he was going back later that night. He wanted some money, some of his money so they gave him ten euro. I said "ten euro!" and they looked at me as though I had two heads because I got him to ask for his own money and that's not done. The staff buy the things for the patients and the patients aren't allowed to have their own money in their own hands and that's the way it is. So if you ask a question like "why's that, it's his money?" suddenly you become a threat to them. It's amazing the looks you get by asking a simple question like that... I don't go near the place now. I do see John though. The only thing that has come out of all that complaining was that John can travel around independently now but that took the best part of five years of campaigning and all sorts of letters of complaint. I do see him now but never out there. I haven't been out there for the last year and a half."

The last complaint that Ronan raised with the hospital was about John's medication as he was "completely unhappy about every aspect of the medication... That was the last issue I raised with them. But again you're fighting a huge battle with all these people with lots of power and no accountability. They know they have that power and they know how weak a position I'm in... so what can you do... you can't do anything."

Ronan and John have struggled a lot through their experiences and did not receive the information or supports that might have helped them manage better with the process. Ronan characterises the experience overall as being traumatising, energy sapping and unsustainable and which has contributed to him withdrawing from challenging the services and treatment of his brother for the time being to maintain his own health and well-being. Ronan describes his experience of how this process has impacted on him in recent years and his attitude to making complaints in the future.

“Over the course of the few years where I did lodge complaints, it was really tough... Emotionally it was really hard. It was characterised by the opposite to support... I felt like I was stone-walled... I needed support but it was up to me to get my own support which I did because it was definitely needed... I feel tired by it... I felt traumatised throughout the complaints process and through the things that led to my complaining from the day that John went out there. It’s been traumatising... There’s so much there and I have so much documentation, I could open it up and talk forever about it but I don’t want to. I want to box it up and let it go because it’s not even the complaints process as there was a bit of empowerment in that process I guess but it’s just the culture, it’s just horrible... I don’t really want to go down that road again. It’s probably a bit defeatist in a way but the complaints process is very impotent against these cultures. Having said that I think if it was a bit better organised it might make a difference. If someone like you or me and a few others were employed to support people to complain, to support them through the complaints process I think that would have the potential to make a huge change. [There should be] people who would be employed and independent and committed and had an idea of what they’d be up against to support people and then you could put that time and energy into it properly.”