

Case Story 1: Ann's Story (names of people, places and identifying features changed)

"Overall, it was long, it was tiring, it was tedious. It was very isolating and it was draining as a parent. If I knew then what I know now, I'd be a much happier woman because I know what's out there now and what we're entitled to."

Ann has been involved with the Irish mental health services for the last ten years as the parent of a young man with a mental health condition. Her son Robert became unwell as a young man and was admitted to an adult inpatient psychiatric facility at the age of 16. He was diagnosed with schizophrenia and has been hospitalised on a number of occasions since that time.

It was a very challenging and difficult experience for the whole family trying to help Robert to access the supports he needed to move forward in his life. In many ways it was made more problematic by the lack of supports and information available to the family during this time, particularly in recent years when a number of incidents created further distress and led Robert's mother Ann to make a series of complaints about his treatment by the local mental health services. For example, Ann describes an earlier incident where manners were considered more important than her son's treatment:

"When Robert was much younger himself, I was very worried and was concerned about some of the medication he was on. The doctor had told me that the medication would correct a brain chemical imbalance... I ended up crying and the doctor asked the nurse to get me a tissue which she did. When she came back she asked me if I had thanked the doctor for the tissue. She was more concerned with my manners than she was about my son's health. I did make a complaint about her... nothing came of it though."

She describes their experience of the services and the complaints process they had to engage with during this time as follows:

"When you're going through it though, you realise you are fighting a system and fighting a culture that doesn't listen to people and you get tired out... That's what has happened to a lot of people, they've got completely tired out by it so they leave it, they don't complain because they think that one voice is not going to make the difference. People get tired... They really do get tired by it. I am a great survivor myself and I have a belief that nobody should be wronged or discriminated against. If I hadn't had that belief and strength I probably wouldn't be here today, instead I'd just be sitting at home resigned to the fact that nothing is ever going to change."

Ann is very dissatisfied with the way the services have dealt with her, as Robert's primary carer, and with the way her son has been treated by the Irish mental health services over the years. In 2008, when Robert was 19 years old he was admitted to another in-patient psychiatric facility following an argument with a family member where physical contact had occurred. Ann was very worried that he was becoming unwell again as the medication didn't seem to be working and Robert appeared more frustrated and stressed than usual which she believes led to the altercation at home. Robert agreed to go to the hospital with his mother but when they arrived they were told they would have to wait in the A&E department for several hours like everyone else. This was particularly difficult as Robert was very agitated due to his being unwell. He was also very restless due to the side effects of one of the medications he was being prescribed which caused him to pace up and down uneasily. Ann insisted that they needed to see somebody from the psychiatric ward urgently: *"There's no respect and no dignity for people going through that system. Nobody should have to go through A&E when they're unwell."*

Eventually, a psychiatrist arrived and Ann explained what had happened at home. Robert agreed to be admitted that night. The next day Ann called to see how her son was getting on but he

wasn't there, he had been discharged but staff had failed to contact her to let her know. She was told that he had gone to a friend's house, but the staff didn't seem sure of where he was. Ann said she was quite upset about it on the phone, *"I was stunned that they didn't know where he was or who he was with. I told them I was holding them personally responsible for his and our safety."* Eventually after several hours, Robert was found but Ann was very unhappy and concerned about the way he had been discharged and the fact that she had not been notified by the hospital despite the fact she was his primary carer at that time.

"This was the third time so I decided to complain about it. I wrote to the Clinical Director, to every local politician, who passed the buck on and eventually I got to see the Clinical Director. We had a meeting, he said they did have discharge procedures. I said, really? I explained the situation of how he had got out and disappeared and told him that in all honesty I was not satisfied. He said he would look into it and make sure the discharge procedures were there. They were in place but he said he would investigate it. That's the last I heard of it. "

Despite lodging a formal complaint, the Clinical Director did not follow up with Ann or Robert formally. There was never an actual resolution to the problem or official outcome as a result of the complaint, and Ann was never informed of whether an investigation followed or the results of any investigation. When Robert moved house to a different area, he then also changed to a different service, as a result Ann did not pursue the matter further. However, the issue remains open and unresolved four years later. Ann has never received a letter in response to her complaint: *"They didn't follow up with me... I also wasn't aware of my rights at that time, unlike now, so I would follow up with them now. The more involved I got with the system, the more I found out. I pass along information to other people as best I can because if people don't know about it or where to go they're really stuck."*

According to the HSE's complaints procedure *Your Service, Your Say* complainants are supposed to receive written acknowledgement of their complaint within seven working days and an update every twenty working days until conclusion or resolution of the complaints process, but this has not been Ann's experience:

"... people are not given this information. You have to go and physically find it yourself and know that it is there to find or approach a solicitor to see if they know. You have to go through a minefield of trying to dig out how and where you go from there. "

Ann was not made aware of the complaints process open to her despite making several written complaints since that time. These further complaints, like that recounted above, were also lacking in any formal resolutions by the services in question. Moreover, Ann was never given any information about the complaints process, nor was she ever advised about her rights in this regard or how to go about it and what to expect. Ann says she only discovered how to complain through, *"pure perseverance... frustration and temper! I looked up the HSE website and found a complaints officer so I thought I'd send her a copy (of the letter of complaint) too and then I sent a copy to every TD so that the Clinical Director was aware that he wasn't the only one... But I was never told after that or in response that I had the choice to take it to the Ombudsman or anywhere."*

Unfortunately there were other incidents that caused Ann to complain once more to the services. She found it very difficult to get emergency support for Robert any time that it was outside office hours: *"There are no mental health services to help you if you get unwell at the weekend because people don't get sick at weekends according to the HSE."* As a result, Ann had to take her unwell and agitated son on a merry-go-round route to gain access to some treatment. They first had to attend an after-hours GP service to be referred to the local hospital. When they arrived at the

psychiatric ward of the local hospital, Robert was not admitted and the family were told they had to return to the original GP for him to authorise the involuntary admission order and sign the Section 9 form. Ann describes the long and drawn out process that evening:

“After the GP, we went straight to the ward, they had a free bed and then the Registrar told me I had to take Robert back out to the GP for him to sign the Section 9 form so that he could be admitted to the hospital... The psychiatrist said they couldn’t do it there. At that stage, the Authorised Officers (AOs can admit involuntary patients) were in effect and trained up but they weren’t using them there. They didn’t want to know. The psychiatrist said she hadn’t heard about them and knew nothing about them. So we had to go back to the after-hours clinic together with his father. They made us take Robert and go through the whole process again although he was obviously very distressed and unwell at the time and ranting and raving. She was new to the team, young and just a Registrar. She didn’t know the system at all. I’m not blaming her but I am blaming the hospital. It was wrong and cruel.”

When they arrived at the GP clinic for the second time there was a different doctor in place which complicated matters and led to further delay for Robert which only added to his distress and anxiety:

“At that stage Robert was extremely agitated and was trying to leave. Eventually the doctor signed the form for us but my son had disappeared by then. We went looking for him... [and] had to call the Guards then. They came out and asked me if he was violent which upset me as no mother should have to be asked such a question. So I had to explain to them that my son wasn’t violent but that he was unwell and wouldn’t go to the hospital with us voluntarily now... They [The Guards] took him back to the psychiatric ward of the local hospital. He was admitted but Robert wouldn’t speak to us then.”

Ann later found out that the after-hours GP could have attended the hospital to sign the form instead which would have made the process far less traumatic for her son and the family but because this information was not provided at the time, Ann took Robert back to the original centre as advised which resulted in the Guards being called. She says that parents are not given adequate information or support and are often excluded from their child’s treatment despite often being the primary carer.

“You have to fight... and it is very draining. You have to have the strength to be able to fight. It took me four years before I started doing anything. Now I don’t care, I’d fight for anybody. I have no problem challenging the injustices that are out there but that’s only in the last six years. So if you’re not a strong person individually you might not be able to cope.”

About a week later, Ann overheard a staff nurse admonishing her son on the ward. She heard the nurse tell Robert that if he were outside the hospital, he would be arrested for anti-social behaviour. Ann tried to talk to the nurse afterwards and asked him to stop labelling her son who was simply unwell and behaving out of character because of it. She requested a meeting with the Consultant to discuss the issue but the nurse repeatedly told her there was no point as she wouldn’t be seen:

“He [the nurse] said I couldn’t see the psychiatrist so I insisted he go and tell the psychiatrist that I needed to speak with him and wanted an appointment. Again he said there was no point, that he wouldn’t see me. This continued for a week, not letting me speak to the psychiatrist... They really exclude us while Robert’s in there and then when

he's out they don't want to know as long as he's with his parents or he has somebody to look after him so that it's not their problem to deal with once he walks out the door."

In the end, Robert managed to arrange a meeting for his mother instead.

"We met with the Consultant who said that he had anti-social behaviour problems in addition to schizophrenia and that it was obvious based on their observations of Robert... I got really angry because it wasn't true... I tried to explain that when Robert is unwell he can behave like he is superior to other people because he is unwell, not because he has some sort of anti-social behaviour disorder..."

Ann made a complaint to the psychiatrist about the nurse blocking her communication attempts and also about removing the diagnosis of anti-social behaviour from her son's records because it was not correct and did not apply.

"I made a complaint about it at the time but it still hasn't been confirmed that it's not in his file... They tried to say he had paranoid schizophrenia with anti-social behaviour problems as well which really wasn't true. My son... can get verbally aggressive sometimes when he's sick... It's down to pure frustration and stress."

Although Ann was quite dissatisfied with the process, she didn't appeal to the Ombudsman at any time because like others in her position she did not know this was available to her and was never given any information or advice from staff on the complaints procedure.

"I didn't know you could bring it to the Ombudsman... if I had known at the time I would have brought it further but I didn't know you could take it beyond the Clinical Director. I thought by taking it to the Director that it would have been resolved. In the first instance, about the discharge procedures and in the second instance, about the anti-social behaviour diagnosis, I felt I'd got my point across. I think the consultant was quite helpful in the latter complaint. He tried to work with me and took it on board that Robert was not anti-social although we didn't get confirmation of the removal of the additional diagnosis. In the two earlier complaints though, they were talking at me and looking down at me and telling me this was the way it was done as psychiatrists generally do."

Ann says she only found out about the complaints process through persistence and determination.

"It was only much later I found out you could go to the Ombudsman.... There's a lot of information that people don't have and don't know about. In my case, I just thought that by going straight to the Clinical Director I would get the problem sorted. I didn't realise that you could go on and appeal it to the Ombudsman. The information wasn't there for me. There's a lack of information for a lot of people. Lack of supports. Lack of everything. Fear is also an aspect as families are worried about the repercussions of a complaint for their loved ones... It's like a secret society past the door... It doesn't intimidate me but it would intimidate a lot of people."

Ann also expressed concern about the lack of information for people using the services about advocacy support:

"For example when my son was in the hospital, there was an advocate working there but Robert didn't know what an advocate was and knew nothing about the service. A lot of people think advocates are someone you complain to and they'll follow the complaints procedure for you but that's not how it works. It's not explained what an advocate is or what they really do. There's no information, all the leaflets about supports and advocacy

have disappeared from the services I've been to regularly. There's no information really on the supports out there for people."

Generally speaking, Ann says she felt the responses to her complaints were not satisfactory and describes the attitudes that emerged as being "very condescending."

"For example, they tell you they have procedures in place and that they'll 'look into it' but they haven't changed. Being honest about it I feel it's very easy to say, 'yes we will look into it and investigate it and thank you for your complaint' and so on, but they don't really deal with it so it doesn't happen again. There's no independent person who can come in and check to see if they're doing things properly when you complain. If there was an independent complaints board or inspector they would be able to go into the hospital at any time and check to see what's happening there. They would be very surprised to see what's going on I think."

Ann expressed her view that many other carers would have a reason to complain but have given up on the system:

"...complaints are very hard to make unless you have the courage and the energy to do it. A lot of people who've gone through the system, tried to complain but got nowhere with it so they just gave up. They accepted it... I'm talking now about people in their 60s and 70s with kids in their 30s and 40s.... they've got so tired of it now... People of their age group have got so tired of fighting and I think they've accepted that the system is not going to change and have just given up. Now there's a newer generation of parents in their 40s and 50s who are just not going to accept it."

Ann continues to express grave concerns about the lack of appropriate accommodation services and other supports for families and their loved ones using the mental health services:

"In order to get Robert treated I had to refuse to take him home so that he would be classified as 'homeless' and therefore eligible for appropriate treatment and accommodation. I was lucky to meet a great social worker who helped Robert into sheltered accommodation which was the first time anyone had actually helped us. It is completely wrong that he had to become homeless in order to get the help he needed."

Ann and Robert are both doing well these days. Robert is happy and living independently. Ann is very proud of him and keeping herself busy with her own work and projects. She concludes,

"Luckily Robert is doing well but if it ever happened again, I'd have no problem nowadays making a complaint and making sure it was investigated and followed up. This is because I have a lot more strength and knowledge now about making a complaint than I did before. I'm more aware of what I'm entitled to and what Robert is entitled to. I think it is very important to make a complaint if it is needed. I know the importance of it now but six years ago I wouldn't have had a clue. It would have been very difficult... parents are struggling. It's taken me ten years to fight my corner and get the information I needed. I have no problem fighting and complaining as I need to but others might not be able for it."