

Good afternoon, my name is Rebecca Seery. I've been working with HIV Ireland for the past ten years in the role of a community support worker and psychotherapist with people living with or affected by HIV. I'm grateful to be here with you this afternoon to talk about my experiences of working with people who are *still* in 2017 experiencing stigma due to their HIV diagnosis.

Previous to my time in HIV Ireland, I worked in the homeless services. A large proportion of the clients I worked with at this time had acquired Hepatitis C. Regularly, clients said 'I only have Hep C, I don't have the virus' referencing HIV. This has always stayed with me, the apparent ease with which a person could speak about one long term chronic illness without any fear; of the reaction they would receive, the service that would be provided or concern of what would be done with this information as opposed to that of a HIV disclosure.

When I began my work with HIV Ireland, this piece around how people saw and viewed HIV became even more salient. As part of my induction to the role, I learned about the evolution of the alliance of organisations that had come together in a time of severe need to provide a service for those who needed care, support and guidance in preparation for what was at this time a terminal illness. In the early days there was no hiding of your illness, your very body was potentially disclosing to everyone your status through your physical appearance.

The fear and the lack of understanding of what HIV and/or AIDS was and/or how it was transmitted resulted from the beginning of people coming to us to talk about their experiences of discrimination. At that time, our role with clients was more one of mediation. We would provide support to people writing a letter of complaint, accompany them to meetings with the person who was alleged to have discriminated against them and aiding them in any follow up. These interventions were with a wide variety of people such as pub managers, shop keepers, taxi drivers, bouncers, and prison officers as well as health care professionals who made judgements based on appearances.

Many came to us telling of their experiences but it was a minority of people who were willing and/or able to go forward with making a complaint as often times they were not physically up to it or they chose not to, deciding to concentrate on other issues they needed to have in place before succumbing to AIDS. Outcomes of complaints sometimes resulted in financial compensation (out of court) but the vast majority ended with apologies.

Our role changed significantly with the advent of new and highly affective anti retro viral medications. The move from preparing people for death to preparing them to live with an illness was the beginning of a whole new experience for our clients and our role as support workers. There was hope in a time which had seemed very bleak. The adjustment for people moved from their bodies disclosing to them having a choice of who, when and how to tell people as they physically began to look and feel well. Unfortunately, the experiences of discrimination and stigma people experienced prior to the medication continued when people chose to disclose their status. The question of whether to disclose or not became almost more stressful than actual disclosure itself as people realised either decision could lead to them not having a home, a job, a new love, or a chance for education or travel.

In many ways little has changed in terms of people's experience of stigma 30 years on. Our work of support and advocacy continues to deal with the very real impact of a HIV diagnosis. Unlike the early days however, we now have the arms of the Work Relations Commission, the Equality and Human Rights Commission, the Ombudsman's Office, and the Garda Ombudsman's office to investigate situations when someone living with HIV is treated differently than someone whose HIV status is negative or unknown.

In 2007, a case where a chiropodist refused to treat a client based on them disclosing that they were living with HIV was brought forward to the Work Relations Commission formerly the Equality Tribunal. A landmark ruling was made in this case, deeming that J. Goulding had experienced discrimination as a result of being refused treatment solely because of his HIV status. This case marked a huge leap forward in terms of the recognition that HIV is a health condition that cannot result in receiving less favourable treatment based on the Employment Equality Act 1998-2011 and The Equal Status Act 2000-2012.

People continue to come to us and tell us that they have been refused treatment or have been treated differently. They come having been left confused, upset, rejected and trying to make sense of what happened. It is not always clear to them or something that they can comprehend that they've been treated differently but they are left with a feeling of something not being right. It can take someone from the outside looking in to help them piece it together as many times they are in complete shock.

The majority of the cases that do come forward are really only in my estimation a tip of the iceberg. Many, who don't make complaints, acknowledge they shouldn't have been treated like this. There is also a sense of not wanting to draw attention to themselves, to ignore it, that maybe it's expected or even ok and you just keep going. Keep going with the weight or niggle that maybe with this diagnosis I too see myself a little less deserving.

Being heard and acknowledged that it wasn't ok to be treated this way can be enough for some. For others an apology and a hope that raising it with the alleged perpetrator will mean it won't happen again is what they need. For others, going forward to the work relations commission and going through mediation and then possibly a formal hearing is important for them as an acknowledgement of what they experienced and also for the alleged perpetrator to be held accountable so that ***this doesn't happen to another person.***

The resounding feeling that comes up for our clients, is ***this should not have happened to*** them and if they can go in any way to prevent it happening to someone else then the sacrifices they are making is worth it. A lot of clients would speak about having felt in a good place with their diagnosis before the incident. Many talked about having not experienced negativity in relation to their diagnosis until the day they were told things such as; you need a specialist service, we wouldn't have the skills to treat you, it's too complex, there could be complications with lots of blood, all staff members would have to know, we have to think of the safety of everyone attending the service/ in the office, they couldn't stay in this accommodation as they'd be sharing a bathroom. These things are being said to clients by employers, dentists, tattooists, disability organisations, employment centres, housing organisations to name but a few.

These experiences can impact on clients mental health as though a dam of emotions have burst and leave them flooded like as if they are back to where they were when they first heard their diagnosis. The sense of shame and rejection I hear my clients talk about as a result of their experiences has resulted in people going into a period of depression, taking time off work, ending relationships, isolating themselves, believing that they are less worthy or deserving, anxiety about seeking alternative services and as a result remaining in pain, feeling really angry, drinking or taking more recreational drugs than usual, suicidal thoughts and going on or increasing an anti-depressant prescription. I cannot emphasis it enough the massive impact these experiences can have on a person's mental health.

Going through the process can be lengthy for people and there is a sense that it's always at the back of their mind so when they have a missed call or email from me they feel a sense of dread. I remember one client saying after successfully being found to have been discriminated against by his dentist that he was looking forward to not hearing from me. As grateful as he was for the support, it was a constant reminder of what had happened and he wanted to move on.

There can be a sense that the emotional impact since the event is not fully assessed in a WRC Hearing. A personal injury claim would take the emotional and psychological impact more into account but with HIV there can be a reluctance to take a case due to the fear of public disclosure and lack of anonymity in a public court. A person who has been successful in a discrimination case but the perpetrator reneges on the agreement must go to the district court to appeal which many clients will not proceed with due to lack of anonymity. Barriers, although not obvious to others feed into stigma.

Medical advances have continued since the advent of the new medication. We have moved from a place of the medication keeping people alive, to keeping them healthy to reducing the fear of transmission that has dominated the sense of self of the person living with HIV, those close to them, and wider society. However, the stigma a person feels internally about being infectious, dangerous and dirty even with the medical developments is still with us today and as much as we would like to believe that those thoughts are not in wider society our clients are being met with them and their insecurities can be reinforced and negatively impact a person's mental health.

Today is a starting point for a public discussion about the impact of a HIV diagnosis on an individual. There needs to be an acknowledgement from the government, of the need for increased mental health resources for people living with HIV across the services that they access. Short term interventions do not reflect or cater for this lifelong complex condition. We need further resources to be able to provide HIV stigma and awareness training in third level and on site settings for healthcare, educational, and community sector workers. Laws are present to protect people with HIV but they do not prevent discrimination taking place. Stigma is insidious and it festers in society and within the mind of the individual, it requires a collective approach to change mindsets. Each of us here today can play a part in our work and personal lives to move this forward through opening, challenging and continuing discussions on stigma and HIV.

Thank you