

Our Life, Our Voice, Our Say

Executive Summary

This report represents the findings and recommendations of the project “Applying a Public Sector Equality and Human Rights Duty Approach to the Human Rights and Equality Issues Identified by Service Users of Opioid Treatment Services”. This project is directed by a steering group, comprising services users and service user representatives, health professionals and members of the Public Sector Duty Team of The Irish Human Rights and Equality Commission (IHREC). It is facilitated by Community Action Network (CAN), a social justice NGO working with drug service users since 2009. The project aims to support the active involvement and leadership of the service users as well as the willing collaboration of representatives of the drug treatment services, in order to address effectively human rights and equality issues identified by the service users themselves.

There are approximately 10,000 service users of opioid treatment in Ireland. Service users come from a diverse range of backgrounds in terms of socio-economic status, gender, age, disability, education level, income and in terms of pathways that lead to problems with addiction. Serious human rights and equality concerns in relation to the lived experience of service users have been expressed in a submission to the HSE commissioned review, documented in “The Introduction of the Opioid Treatment Protocol Report” (Farrell Report, 2010)¹, in the findings of two rounds of peer led research (2012 and 2017), during two dialogue events, (2015 and 2016) and are repeated yet again in this report. The concerns relate to four main aspects of the drugs services, namely

The practice and frequency of **supervised urine sampling**; (Chapter 5)

The **engagement with and participation of service users** in drug treatment service delivery; (Chapter 6)

Availability of information on and access to **treatment choices and care plans**; (Chapter 7)

Availability of information on and access to an effective, transparent and accountable **complaints mechanism**. (Chapter 8)

Service users have named and given evidence of

- Degrading, undignified, invasive, embarrassing, judgmental experiences that often leave them feeling shamed, inadequate, worthless, powerless and angry.
- The impact of language, attitudes and beliefs that underpin their experience of availing of services.
- The lack of privacy and control over the way their day-to-day time is structured, given the demands of attending clinics and pharmacies and how this impacts negatively on their ability to work, conduct family and social life.
- The lack of meaningful, engaged and active participation in care plans, the lack of choice of treatment and sense of possible progression to full health and well-being.
- The lack of an effective complaints system that they know how to use and can believe in.

¹ This is the first external review of the Methadone Treatment Protocol in Ireland, known as the Farrell Report. It sought to examine the regulatory process and oversight of methadone and opiate dependence treatment, focusing on both the 1998 protocol and the processes by which treatment is implemented and delivered. Available at http://www.drugs.ie/resourcesfiles/reports/Opioid_Treatment_Protocol.pdf

The following figures provide an overview of the main findings of the research under the four key issues:

- Urine analysis;
 - 40% of service users expressed that they did not like giving urine samples (supervised or not), 50% described it as degrading and 26% described it as undignified.
 - 95% of women in the survey expressed dissatisfaction with the process, in particular given that the sampling system does not show consideration for female health realities such as periods.
- Meaningful engagement and participation;
 - 26% of respondents reported having a good or very good relationship with their doctor, a slight dis-improvement on the 2012 survey.
 - 84% reported that they have had no participation, and have not been asked their opinion in relation to their treatment.
- Treatment choice
 - 70% of respondents viewed treatment as a barrier to employment, with the times of the clinic, the stigma of being on methadone and the impact of methadone cited as reasons.
 - While 75% of respondents stated that they wanted a care plan, 76% reported that they had not been offered a care plan.
- Complaints mechanism:
 - 59% of respondents reported that they did not know how to make a complaint.

The report notes with dismay that the 2017 user-led survey demonstrates a deterioration in almost all the issues previously identified by service users in the 2012 user-led survey.

In addition to documenting the lived experience of service users and their efforts (including methodologies used) to have their concerns addressed, this report outlines the relevant national and international human rights and equality legal and policy infrastructure. It grounds the issues and evidence in HSE policy and Section 42 of the Irish Human Rights and Equality Commission Act 2014. Known as the Public Sector Equality and Human Rights Duty, Section 42 requires public bodies to take steps to “eliminate discrimination, promote equality and protect the human rights” of both its staff, and the persons to whom it provides services.

The report sets out 28 recommendations which should inform HSE plans, policies and actions to address issues identified in line with its Public Sector Equality and Human Rights Duty. All are based on the lived experience of people availing of drug services and are informed by principles and values which they feel are critical to the provision of drug treatment services such as:

- Dignity and respect;
- Participation and autonomy;
- Equal treatment;
- Proportionality;
- Accountability and transparency;
- Privacy.

If implemented, the recommendations would see the end of the degrading and inhuman practice of supervised urine sampling and the cessation to the use of urine sampling as an evidence base for

clinical decisions. Instead they would ensure the centrality of a positive and supportive relationship between people accessing drug treatment services and people providing them that has respect and dignity at its core. Holistic and integrated treatment would facilitate not only the progressive realisation of the right to health and wellbeing but also to employment, education and participation in family and community life. Active, engaged and meaningful service user participation in care planning that has built in regular review and treatment choice would take account of the changing life cycle and diverse needs of service users. Proactively supporting an open, transparent environment and culture where information is accessible, targeted and relevant would address existing fears in relation to making and effectively dealing with complaints. The drugs services could value accountability and become a learning service that strives for excellence.

Report Recommendations

This report provides in-depth and valuable evidence of the experience of service users of drug treatment services in Ireland. The issues identified by service users in this report should form part of the assessment of equality and human rights issues that the HSE has a statutory duty to undertake in accordance with Section 42 of the *Irish Human Rights and Equality Commission Act 2014*, the Public Sector Equality and Human Rights Duty. The recommendations set out below should inform HSE plans, policies and actions to address issues identified in line with its Public Sector Equality and Human Rights Duty.

Recommendations

Supervised and frequent urine sampling (Chapter 5)

Based on the lived experience of people availing of drug services of urine sampling as degrading and inhuman; and

Highlighting that the HSE commissioned ‘Farrell Report’ and HSE ‘Clinical Guidelines for Opioid Substitution Treatment’ both recognise that urine analysis may be conducted in an inhuman and degrading manner, and with a frequency that is unnecessary;

The project steering committee:

1. Calls for an immediate cessation to the practice of supervised urine sampling by all drug treatment service providers
2. Calls for a cessation to the use of urine sampling as an evidence based approach for clinical decisions in relation to the service users, including as the basis for accessing treatment, withdrawing methadone or allocating “takeaway” doses to service users and contingency management
3. Recommends that the HSE provides training and awareness for medical and administrative staff on more evidence-based approaches to providing adequate levels of treatment and care to service users, including the limitations of urine sampling as a condition for service users accessing treatment
4. Recommends that the HSE provides training and awareness for medical and administrative staff on the diverse experience of people accessing drug services, including specific issues arising from urine sampling for particular groups - for example, women, transgender people, people with disabilities or people who may have suffered abuse
5. Recommends that the HSE provides training and awareness for service providers on the limitations of urine sampling and resulting barriers to accessing important supports when urine sampling is used as a criteria to determine access to services such as, for example, women’s refuges
6. Recommends that the HSE actively promote a culture of dignity, respect and equality of participation for service users in the development and delivery of care plans and treatment to service users

Meaningful engagement and participation for service users (Chapter 6)

Based on the lived experience of people availing of drug services of the key role that a positive and supportive relationship between people accessing drug treatment services and people providing drug treatment services (including doctors and staff in clinics and pharmacies) plays in terms of human dignity and drug treatment; and

Highlighting that the HSE 'Clinical Guidelines for Opioid Substitution Treatment' recognise the importance of dignity when engaging with service users, including building trust and adjusting the nature of interventions to suit individual service users;

Recognising the important role that integrating treatment with participation in employment, education and family and community life can have for recovery and recognising that the HSE commissioned 'Farrell Report' recommends that an integrated services approach should account for family, community and user groups as well as a service model outside of Dublin;

The project steering committee:

7. Calls for the HSE to ensure an end to the culture of blame, stigma and punishment that is reflected in the experiences of service users documented in this report.
8. Calls for the HSE to put a greater emphasis on building a positive relationship and open dialogue between service users and service providers and for deeper and more meaningful service user engagement.
9. Calls for an immediate cessation to the partial or full suspension of medical treatment by service providers or by pharmacies as a reaction to anti-social behaviour. This includes restricting methadone takeaways as a form of punitive action.
10. Recommends the HSE uses the evidence contained in this report as the basis for assessing how current treatment structures impact negatively on the lives of service users, or potential service users.
11. Recommends, based on an assessment as outlined above, a redesign of current treatment and dispensing structures that better facilitate the participation of service users in living a more dignified and fulfilled life.
12. Recommends that that HSE design and promote dispensing and treatment structures that are person-centred and flexible, recognise the diversity of service users and aim to facilitate service users to engage in employment, training, education and carrying out family and caring duties.
13. Recommends that the HSE ensure greater flexibility in how services are delivered and a choice of services to accommodate the diversity of peoples' health needs and circumstances. This includes, for example, meeting gender specific needs; meeting the needs of people with disabilities; taking into account family or work commitments; and taking into account issues arising from the geographical distance between treatment services and where service users are living.
14. Recommends the provision of financial assistance for service users who have to travel to treatment clinics or dispensing pharmacies to avail of services that are not locally available.
15. Calls for the findings of this report to be widely disseminated to both medical and administrative staff in all drug treatment services in Ireland with a view to encouraging a service wide shift to a more client-centred service delivery model.
16. Calls for the HSE to actively support and resource the empowerment of service users with a view to building and developing the leadership of service users to self-advocate and support other service users to do the same.
17. Calls for the HSE to recognise the value of consultation and that service users are diverse and are not represented by one umbrella organisation.
18. Recommends that the HSE put in place a multi-pronged approach to facilitate the participation of service users that draws on a range of engagement approaches. For example, consultation should include a number of opportunities for participation such as engagement with individual services users across different services and geographical locations, focus groups with service

users accessing different services and focus groups with a range of organisations representing or providing supports to service users.

Treatment choice and treatment plans (Chapter 7)

Based on the lived experience of people availing of drug treatment services of lack of information and engagement with their treatment plans;

Highlighting that the HSE commissioned 'Farrell Report' recommends the need to develop a more structured care planning process and care plans subject to regular review and update; and

Highlighting that the HSE 'Clinical Guidelines for Opioid Substitution Treatment' recognise that service users should be fully involved in the development of their care plans, setting appropriate treatment goals and reviewing their progress in treatment;

The project steering committee:

19. Recommends the HSE engage with service users to review the provision of information on treatment choice - including suboxone, subutex, methadone maintenance, methadone detox, methadone tablets, residential and community detox - and ensure it is accessible and usable for all service users in all drug treatment services.
20. Recommends that the HSE ensure that when people start drug treatment, and at regular intervals thereafter, the implications for the different treatment choices available are more thoroughly discussed with them and reviewed regularly as their individual needs and circumstances change, ending the uniform approach to treatment.
21. Calls for the HSE to offer more flexible treatment options at more regular intervals taking into account the changing life circumstances, opportunities and challenges that are present at different stages in a person's life, particularly given the length of time that a person can be in opiate treatment.
22. Recommends that the HSE conduct a review of methadone dispensing practices, taking into account that supervised daily doses runs entirely counter to a holistic approach to treatment with a significant impact on the overall wellbeing of people using drug services and are a barrier to effective participation in employment, education, society, and family life. This review should take into account that most people availing of methadone treatment are stable and should not be required to attend every day for their daily doses. It should also consider, in particular, if consultation rooms could be used when dispensing methadone or if this could be more easily managed if the tablet form of methadone was available, as is the case with many other European countries.
23. Recommends that the HSE ensures that all drug treatment services provide meaningful holistic care plans that are informed by service users' personal goals and are clearly documented in an accessible manner and are subject to regular review and update.
24. Recommends that physical copies of care plans are made available to services users, and not just available on computers.

An effective complaints mechanism (Chapter 8)

Based on the lived experience of people availing of drug services of the lack of information about how to make a complaint and the fears about making a complaint;

Highlighting that the HSE commissioned 'Farrell Report' recognises the need to review the lines of reporting and accountability in all of the services; and

Highlighting that the recommendations on how public hospitals could improve their complaints processes set out in the 2015 Ombudsman Office could inform improvement of complaints processes in drugs services;

The project steering committee:

25. Recommends that the HSE engage with service users to develop and implement a positive action plan to ensure that information on a complaints system is available in an accessible manner.
26. Recommends that the HSE ensure that all drug services create a supportive, open and transparent environment and culture to lessen fear and perceptions that there will be negative consequences / reprisals for making a complaint.
27. Recommends that the HSE ensure that all service users are informed of their right to make a complaint. This may include holding meetings to ensure that service users know how to make a complaint and are introduced to their complaints officer. Care should be taken to avoid conflicts of interest between complaints officers and patient advocates (and review officers) so that there is an independent system of complaints.
28. Recommends that the HSE ensure that service providers publish statistics, case studies and audits of complaints made by service users and use this information to inform their assessment of equality and human rights issues as part of their Public Sector Equality and Human Rights Duty under Section 42 of the *Irish Human Rights and Equality Commission Act 2014*.