

# Lives on Hold

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# Preface

*The Lives on Hold* report details the process and findings of a collaborative peer led research programme facilitated by Community Action Network (CAN) between the following projects:

The Canals Local Drugs and Alcohol Task Force, covering Rialto and Inchicore in Dublin

The Northeast Regional Drugs and Alcohol Task Force, covering Meath, Cavan, Louth and Monaghan

The Southwest Regional Drugs and alcohol Task Force covering Kildare

Uisce, A National Advocacy Service for People who use Drugs in Ireland.

The programme took place during 2023 and the findings were launched in February 2024.

It is accompanied by the Lives *on Hold Monitoring Report* which is an in-depth analysis of the findings as they compare with previous monitoring peer led research conducted by Service Users Rights in Action (SURIA).

# The Findings at a Glance

## ***A DETAILED ANALYSIS OF THE OVERALL FINDINGS AS COMPARED WITH PREVIOUS ROUNDS OF PEER LED RESEARCH CONDUCTED BY SURIA ACCOMPANIES THIS REPORT.***

Key survey findings summarized.

Survey cohort:

229 Service users interviewed across the following areas:

- 140 from Dublin 1,2,8,12,15 and 24
- 85 from the following areas: Lusk, Cavan, Louth, Meath, Kildare, Navan and Monaghan
- 4 no address given.

Profile:

- 66% or two thirds are aged over 35 years.
- 49% or almost half are engaging with Opioid Substitution Therapy (OST) /Methadone Maintenance Treatment (MMT) for up to 10 years
- One fifth over 20 years
- One in 10 for over 26 years
- 83% (of 100 who answered question) not engaging in education or employment.

Frequency of urine sampling:

- 60% (of 99 who answered questions) give urine samples weekly or more often
- 3% give supervised urine samples.

Care Plans:

- 44% do not know what a care plan is
- 42% do not have a care plan.

Offered alternatives:

Of 101 who answered the question

- 52% have been offered counselling ( decrease of 14% since 2020)
- 13 % have been offered rehab /detox.
- 14% have been offered Hepatitis C (decrease of 52% since 2020)
- 59% have never discussed detoxification with their treatment provider and those that have, for the most part raised it themselves.

Meaningful Discussion re Treatment:

Of the 100 who answered the question

- 69% seldom or never have been engaged in meaningful discussion as part of their treatment.

- 31% regularly engage in meaningful discussion (mostly in rural areas)
- 92% were never asked their opinion on their treatment.
- 90% were never given information on their rights as an OST patient.

#### Making a Complaint:

- 38% do not know how to make a complaint.
- 95% have never made a complaint.

## Key Themes

### Standard of Treatment

This round of research reveals that the standard of treatment for people in OST / MMT is still far from adequate. Our findings reflect poor quality of life with few tangible outcomes in terms of better health and re integration into society. There is little or no choice of treatment, infrequent if ever meaningful engagement in treatment plans, almost no participation in how services are designed or delivered. The findings document inhumane / controlling and undignified practices with little or no evidence of attention to a rights-based approach to attaining the right to adequate health.

### Poor Quality of Life

Service users participating in this research recount a life spent endlessly queuing in clinics, pharmacies, providing urine samples and collecting and taking medication under supervision. They have little or no say or choice in their treatment or access to a complaint system they believe in. This results in minimal time or support to engage in employment or education. Over half have been doing this for 10 years, while a staggering one in ten have been living this life for over 26 years.

### Internalized Low Expectations

The qualitative elements of the research tell us of the very low expectation that service users have of improved quality of life. Positive change is named as being able to reduce drug use, stay out of prison, avoid withdrawals, remain "clean" when attending for medication. The dehumanizing language used (clean /dirty), the compliance with a system that controls and punishes, the references to feeling stigmatized, the lack of respect, dignity, unequal power relationships, fear of reprisals if complaints are made, are all features of the current services that urgently need to be addressed.

### Rural/Urban Differences

There is no uniform standard of care for service users with significant differences in how services are provided between rural and urban areas emerging as a key finding of this research.

Rural service users repeatedly alluded to the following, many of which are not enjoyed by their urban counterparts:

- Less urinalysis.

- Rural services users tend to engage with services for shorter time frames.
- They have more choice of treatment, suboxone is prescribed more often in Cavan and Monaghan but not in the HSE clinics in Louth.
- Rural service users express higher levels of satisfaction.
- Many stated that they enjoyed meaningful discussion with service providers.
- Rural service users described having better relationships with their doctors.
- The use of care plans is part of normative treatment practice in rural areas.
- Rural services facilitate better outcomes.
- Rural service users are more likely to be offered detoxification.
- Service users in rural areas are far more inclined to be engaging with the labour market or accessing education.

### Degrading Practices and Language

The entire OST / MMT service continues to be dominated by frequent urinalysis, contrary to international best practice or evidence of it being totally necessary. Treatment continues to depend on the result of a urine test. Our findings suggest that apart from supervised urine sampling, which has now almost completely been eliminated, over half of those surveyed give weekly or more frequent samples. This is a finding that has remained consistent throughout previous rounds of peer research.

Those interviewed tell how this practice impacts their lives. For the most part they feel interrogated, scrutinized and demeaned as the focus of attention is on a test rather than on them as a person seeking a therapeutic relationship. Many describe the absence of any conversation on how they are doing, or support and encouragement to honestly say how they are managing. Instead, it is always about the test results. For many, methadone in itself is not the cause of dehumanization but rather the practices surrounding it.

### Planning for Health / Lives on Hold

Meaningful care plans that emerge from a partnership between client and service provider, that contain agreed goals, choice of treatment options, pathways to progression and reintegration to an adequate quality of life, are reviewed regularly are key features of a rights-based approach to health.

Our findings reveal that almost half of those interviewed neither know of nor have a care plan that has these core elements. This finding does not correspond with the espoused description of services. When one considers the profile of those interviewed and the length of time they have been engaging in treatment, it is inevitable that they go through many phases in their lives - from youth to adulthood, to middle age and in some cases beyond that. There must be multiple points at which they may have been ready for change, when their circumstances altered significantly, when a timely meaningful review of treatment may have been the gateway to a fuller life. Instead, many experience their lives as being on hold.

A detailed analysis of the findings and commentary on same is attached in the SURIA report.

## Recommendations

This research restates the outstanding recommendations first raised in 2017 in the Our Life, Our Voice Our Say report, 2017 and listed in appendix two

In particular we wish to urgently recommend the following:

- OST /MMT services be underpinned by a rights-based approach that promotes dignity, respect, agency, participation, autonomy, non-discrimination, equality and accountability.
- Quality of service provision be uniform and not determined by location or personality of provider.
- Meaningful care planning with an emphasis on active service user participation and choice of treatment replace routine urinalysis as the determinant of treatment.
- An independent, robust, effective complaints mechanism be put in place as a matter of urgency.
- Service users and service providers are made aware of and engage in fulfilling the requirements under Public Sector Human Rights and Equality Duty to take this assessment of issues into account when drawing up plans in relation to drugs services, to address the named concerns and to report on progression a timely and accessible manner.
- Service users be given accessible information on the rights within service provision.

## Where It Began

There are approximately 10,000 people availing of Opioid Treatment Services in Ireland. These service users come from a diverse range of backgrounds including socio economic status, age, gender, disability, education level, income and in terms of pathways that lead to addiction. Serious human rights and equality concerns have been expressed in relation to the lived experience of service users as far back as 2009 when CAN first began working with service users in a coalition, which eventually became known as Service Users Rights in Action (SURIA). This is a coalition of drug service users, service user representatives and community activists. The key areas of concern are:

- The practice of and over reliance on urine testing,
- The lack of an annual review for each person where there is meaningful engagement and choice.
- The lack of information, availability and choice on pathways to health
- The absence of information on and access to an effective, transparent and accountable complaints mechanism within the drugs services

When these issues were first named in 2009, a link to human rights and in particular, the right to health and the right to participation was established. From then onwards, we have framed these issues as rights rather than as needs and have sought to hold Service Providers accountable for the systems, policies, procedures, and attitudes that perpetuate the failure to respect, protect and fulfil the rights of drugs service users. To date, CAN has facilitated and equipped SURIA to conduct four rounds of peer led research, the first in 2012 to establish base line data on the experience of the named issues. The subsequent rounds have been focused on monitoring the progressive realisation of the rights involved.

## A History of Neglect

Over the years of collecting data in these four rounds of peer research, service users have named and given evidence of

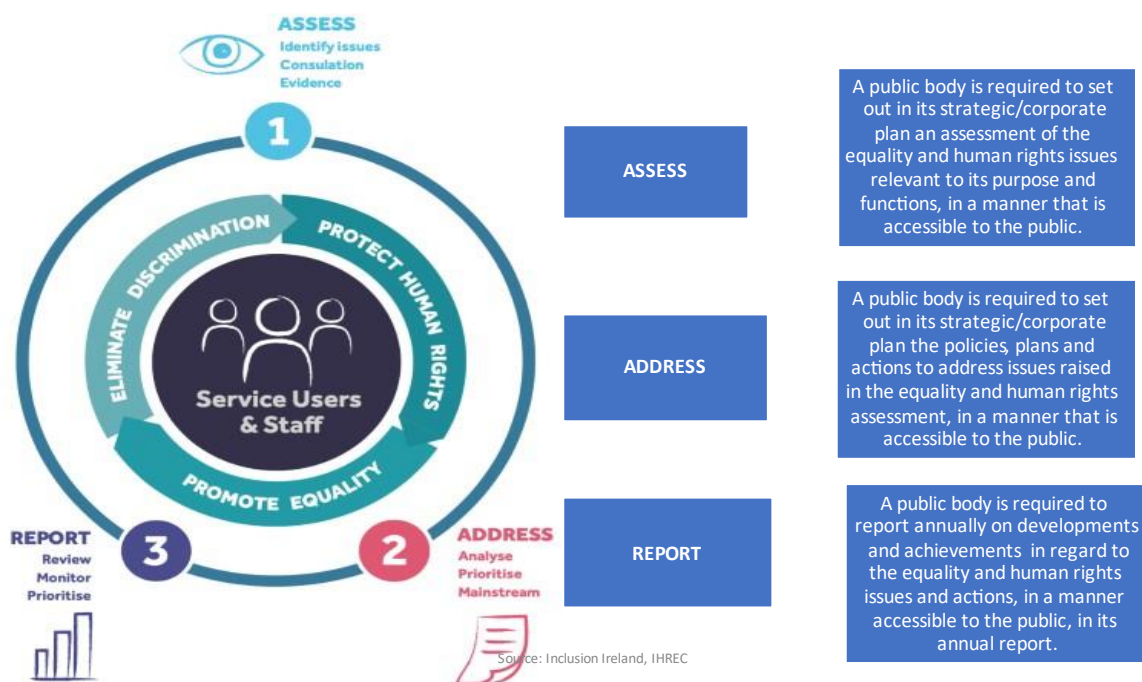
- Degrading, undignified, invasive, embarrassing, judgmental experiences that often leave the person feeling shamed, inadequate, worthless, powerless and angry.
- The impact of language, attitudes and beliefs that underpin their experience of availing the services.
- The lack of privacy and control over 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 wellbeing.
- The lack of an effective complaints system that they know how to use and can believe in.



Detailed information of this experience and the extent of it is available in earlier reports.<sup>1</sup>

In addition to documenting the lived experience of service users and their efforts to have their issues addressed, these two reports outline the relevant national and international human rights and equality, legal and policy infrastructure. (see Appendix 1)

This 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 Human Rights and Equality 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 following chart available on the Irish Human Rights and Equality website outlines the obligations that this Duty places on Public Bodies



This clearly places a duty on the HSE to take on board the evidence and active participation of service users in the drugs services.

To date, this has happened in a tokenistic and meaningless manner.

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[https://www.canaction.ie/wp-content/uploads/2023/03/nothing\\_about\\_us\\_without\\_us\\_2021.pdf](https://www.canaction.ie/wp-content/uploads/2023/03/nothing_about_us_without_us_2021.pdf)

[https://www.canaction.ie/wp-content/uploads/2023/03/our\\_life\\_our\\_voice\\_our\\_say\\_report\\_final.pdf](https://www.canaction.ie/wp-content/uploads/2023/03/our_life_our_voice_our_say_report_final.pdf)

## The Value of Sustained Effort /Positive Outcomes

Since 2012, this campaign has achieved much with no resources other than the dedication and commitment of current and past service users. They have used their lived experience together with their passion and determination to break the silence of inequality and the denial of human rights. In guiding and facilitating SURIA during this time, CAN has witnessed how adopting a human rights-based approach can transform that experience from one of shame and powerlessness to an empowered collective voice of rights holders. The approach also transformed the dominant narrative surrounding drugs service users and how their issues are named, and the language used. Now it was all about rights, equality, dignity, respect, and the failure of the services to meet human rights and equality standards.

CAN and SURIA sought out leverage points and pursued many creative ways to bring about accountability, engagement, and change. Each effort built upon the previous one, gathering further support. The initial letter of support from President Michael D Higgins, gave backing to the early dialogues with a cross section of key stakeholders and human rights bodies. This in turn strengthened our request to be one of the first Public Sector Duty Human Rights and Equality pilot projects<sup>2</sup>. This opened the door for engagement with the HSE, with The Irish Human Rights and Equality Commission (IHREC) as allies. More importantly, it provided a very strong argument for making a request to IHREC to conduct one of the first Equality Reviews in the country<sup>3</sup>. This independent Review was key to the cessation of the degrading practice of supervised urine sampling and the implementation of an Action Plan by the HSE, a major achievement for the campaign.

## The Need for a New Approach

In 2022, the campaign reached a crisis point.

SURIA members had given 10 years plus voluntary effort and were now at a different stage in their own lives. CAN too had facilitated the campaign without resources and was no longer in a position to continue to do so. Despite efforts and support to set up as a limited company and seek funding as an organisation, no resources were forthcoming. This led us to ask a core question i.e..

*Are there champions for this very important work  
to continue?*

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<sup>2</sup> <https://www.ihrec.ie/our-work/public-sector-equality-and-human-rights-duty-faq/implementing-the-duty-pilot-case-studies/>

<sup>3</sup> [https://www.ihrec.ie/app/uploads/2022/08/HSE-Opiod-Action-Plan-Equality-Review-IHREC\\_Final.pdf](https://www.ihrec.ie/app/uploads/2022/08/HSE-Opiod-Action-Plan-Equality-Review-IHREC_Final.pdf)

In exploring this question over many meetings, we began to think about building greater capacity among service users and equally importantly, among those organisations with responsibility for supporting service user participation within services. With this in mind, we targeted Drugs Task Forces to consider engaging with us in a process of bedding down the work of SURIA within their services and areas. Meetings with Drugs Task Forces began at which CAN and SURIA outlined the proposal to design and deliver a new online national programme with SURIA members in a mentoring role and funded by the participating Drugs Task Forces.

## The CAN/ SURIA Programme / Bedding Down the Approach

The purpose of the Programme was to strengthen and develop the capacity of service users and support workers within Drugs Services to generate broad based community ownership for the progressive realisation of the named equality and human rights issues. Participants were invited to attend on a small group basis from within each Drugs Task Force area. Each group consisted of at least two service users and one support worker, working together as a team to apply the programme learning within their own area. The online programme was facilitated by CAN with the support of a member of SURIA. The peer research provided both base line data for each participating area and served as a fifth round of monitoring of the issues named as human rights violations in previous SURIA research. The findings were then analysed and commented upon by another SURIA member.

The anticipated Programme Outcomes for participants included:

- Increased knowledge, expertise, competence, and self confidence in their leadership role within their own area
- Ability to build an effective network of peers with whom they can work collectively for change in the service provision of Drugs Services
- Strengthened voice of service users within and across areas while at the same time build a scaffolding of support around them.
- The capacity to identify, monitor and address identified human rights violations experienced by service users within and across areas.
- Developed skills in carrying out and analysing peer research.
- Enhanced capacity of host organisations to implement and support service user engagement.

The Programme began in January 2023 with participating teams from

The Canals Local Drugs and Alcohol Task Force, covering Rialto and Inchicore in Dublin

The North East Regional Drugs and Alcohol Task Force, covering Meath, Cavan, Louth and Monaghan

The South West Regional Drugs and alcohol Task Force covering Kildare Uisce, A National Advocacy Service for People who use Drugs in Ireland.

Eleven services users and five support workers met on a regular basis online between January and October 2023, with occasional in person support meetings with CAN staff as required. A learning community was formed which facilitated the group to embark on a process of experiential learning. Creative, interactive methodologies made it possible for the group to become familiar with human rights and in particular the Right to Adequate Health. They were supported to see how the theory applied to their lived experience of drugs services. The Human Rights Based approach was outlined and provided a framework for the group to begin to engage with the importance of gathering and monitoring evidence. A member of SURIA shared the experiences of that group in applying this approach over years to the issues named back in 2009. Comparisons of data sets collected during the four rounds of previous research illustrated the power of monitoring and set the scene for the fifth round of peer research to be prepared and conducted within the different geographical areas.

## Forming the Learning Community

Our work is informed by the CAN Model <sup>4</sup>, which rests on the belief that the starting point for any initiative is always with the lived experience of each person who has lived with inequality and/or a denial of rights. We call this Breaking the Silence and doing this in a group context where attention is paid to safety and trust creates a shared understanding of how inequalities are experienced. Patterns and similarities are highlighted, and this moves the experience from the individual to the collective as well as creating a sense of solidarity and identity within the group. It also provides an experience of a more equal way of being in the world, as the process within the group is participative, where every person's contribution is valued.

Doing this online with a mixed group of people with varying degrees of comfort in connecting via the internet was in fact a lot easier than expected. Preparatory meetings with each geographical team helped break the ice and establish the culture of engagement within the local team. Sharing hopes and expectations for how this approach could be applied within the local area first helped pave the way for doing the same with the online wider group.

Initial teething problems of getting connected to the internet and establishing the etiquette of online conversations were quickly overcome. While we recognized that there is no substitute for in-person meetings, we also acknowledged that it would be impossible to cover the geographical spread of the participants any other way. A sense of collective purpose was easily established, allowing the group to engage with the complexities of patterns, themes, similarities and differences emerging across their experiences.

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<sup>4</sup> <https://www.canaction.ie/how-we-work-the-can-model-overview/>

## From Individual Stories to Human Rights

Linking the shared stories and experiences of drugs services to human rights required us to break down the often complex and off-putting language of human rights in ways that made sense. Cartoons, videos and interactive discussion helped to establish the links and enabled people to stay with the challenge of translating the language into something they could easily understand.

Getting through the language barrier, finding the Right to Adequate Health exposed the internalized oppression in relation to language and limiting assumptions about being worthy of an adequate standard of health. Very quickly, the participants realised that they had no expectation of the language of dignity, of the progressive realisation of their right to health. They had no sense of entitlement to pathways and choice in relation to treatment and meaningful engagement with their service providers. Naming shame and stigma and being supported by SURIA and CAN to see this as a failure of the services and not the service user was the beginning of empowerment and the deepening of leadership within the group.

## Applying a Human Rights Based Approach

With the group formed, the issues named from previous SURIA research, the link to human rights established, the next step was to gather the evidence within each area via peer led research.

This was an opportunity to establish area specific base line data in relation to previously identified issues. It also constituted a fifth round of peer research, continuing the monitoring process established by SURIA. It was therefore, important that the questionnaire be similar in focus to previous ones. That said, it was also important that it included questions to monitor the implementation of the HSE Action Plan <sup>5</sup> as presented to IHREC following the Equality Review previously referred to.

Differences between urban and rural contexts were brought into sharp focus when we began to scope the areas to be covered identify the access routes to people to be interviewed. The Dublin based projects anticipated no difficulty in accessing service users to interview, but those working in the NE and in SW foresaw huge problems (outlined later)

## Peer Research Methodology

In a previous SURIA report Nothing About Us Without US, we outline how the peer research we do is part of a methodology known as Participatory Action Research (PAR). Essentially, this is a cyclical research methodology that is beneficial in research with marginalized and disempowered populations. It follows a cycle of Plan, Action, Observe

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<sup>5</sup> [https://www.ihrec.ie/app/uploads/2022/08/HSE-Opioid-Action-Plan-Equality-Review-IHREC\\_Final.pdf](https://www.ihrec.ie/app/uploads/2022/08/HSE-Opioid-Action-Plan-Equality-Review-IHREC_Final.pdf)

and Evaluate and is ideal for monitoring the progressive realisation of rights over time through regular rounds of peer research. As such, it is both a philosophy and a means of helping people to

- Identify their issues and link them to human rights.
- Come up with possible solutions.
- Assess the solutions.
- Create indicators for change.
- Mobilize for action.
- Monitor and evaluate progress over time.

Working directly with service users to identify their human rights and equality issues, to design, pilot, conduct peer to peer interviews, to analyse the findings, set indicators, engage with service providers, and monitor progress over time has facilitated their voice to be heard and validated. In so doing, it recognizes and values the unique knowledge and wisdom of lived experience and the power it has to bring perspective and expertise to the design and delivery of services that are both appropriate and based on respect and rights. On each occasion, we have reflected on the process, extracting key insights and learning which in turn has informed the next round of action and research.

## Gathering evidence

During the course of this online programme, we regularly dedicated time to review and learn from every stage of conducting the research. From the very beginning participants in the learning community were very mindful of the need for self-care when conducting the research. They anticipated a strong likelihood of being triggered and saddened by the responses and indeed this proved to be the case. Where possible, interviews were conducted in pairs and each area put in place a facility to debrief at regular intervals.

That said, once the research began, peer researchers shared how they were able to relate to those they interviewed, to validate their experience, carry new information and awaken expectations that the services could and should be better. Time and time again, those interviewed expressed their appreciation for being heard in a respectful and confidential manner. Being able to offer some token of appreciation for the time given to answer questions, be it in the form of coffee, cigarettes or a small payment all contributed to the quality of the interview.

Peer researchers noted key insights emerging from the gathering of evidence that are worth noting:

**The language** we use, even in the questionnaire that was informed and designed by service users still reflects the language of services and is not easily understood by service users. One example is the term Care Plan. Many peer researchers reported having to explain what this is. Another is the term Goals, be they personal or otherwise.

There were major **differences between urban and rural** settings. These emerged at the outset when the local teams were scoping how to access service users. Urban settings such as any in Dublin make access very easy either through clinics, in hostels, outside pharmacies or on the street.

**In rural areas**, people do not gather in the same way and being exposed and visible when attending any service adds another layer of stigma onto the service user. The exposure and experience involved in attending pharmacies in a rural context was noted on a consistent basis as illustrated by the Team from The North East Regional Drugs and Alcohol Task Force, covering Meath, Cavan, -Louth and Monaghan

*Service users feel they are always kept waiting to be seen, up to an hour. Limited pharmacies giving OST so it can involve public transport or someone helping with transport. To be kept waiting can be very challenging. They feel all other customers are prioritised.*

*Service users do not understand the need for the supervised dose when picking up medication. To have to take medication, wait and have mouth checked is both humiliating and has no purpose as client is leaving with take away meds.*

*Privacy is an issue in some areas, Not brought into a room, medication brought out to main area with water.*

Meeting service users where they access treatment required permission from the service provider. This sometimes proved to be a difficult and complex process. Initially, the rural teams doubted that they could overcome these barriers. This proved to be the case in The South West Regional Drugs and Alcohol Task Force covering Kildare but were surprisingly easy to overcome eventually in The North East Regional Drugs and Alcohol Task Force, covering Meath, Cavan, Louth and Monaghan.

Significant differences were identified in terms of choice and quality of treatment, urinalysis, levels of satisfaction, relationship with doctors and overall progression toward a healthier life, outlined earlier in this report. The findings illustrate that these factors can and do transform the quality of life of service users.

**Homelessness** has a major negative impact on the life and wellbeing of service users. Its absence in rural contexts was noted. Its prevalence in the Dublin area has a noticeable additional negative impact on lived experience. In the words of one peer researcher from Uisce

*" Dublin has become a ghetto for homelessness with people from rural joining urban homeless".*

**Internalized oppression** was evident in many ways during the course of the research. Peer researchers commented on the very low expectation those interviewed had that

they deserved a better service. They do not believe that they can complain, that they should have a meaningful say and choice in relation to their treatment or that change is possible. In one area it was evidenced in the physical state of buildings, the lack of even a modicum of privacy and the fact that neither service providers or service users had any sense that they are inadequate.

*“This conveyed a message of worthlessness of services and people who use them”.*

## Using The Findings

Each area entered the questionnaires into a separate Survey Monkey which produced a statistical report for their cohort of interviewees. Applying the learning from the research was immediate for each team. In the words of one Dublin Team

*“Having a grounding in service user needs and experience has changed the approach to service user engagement options, future relationships with services, new directions for work, new collaborations”.*

All agreed with another who said:

*“This approach can be used for new work and to further collaboration and build service user engagement.”*

Some used it to set up meetings with service providers, to inform submissions to the Citizen's Assembly on Drugs, which was taking place at the same time. Others applied the process to potential new research, either in a different geographical area or with a slightly different and more in depth focus i.e. homelessness and drugs.

The individual reports were combined and given to SURIA and CAN to compile and contrast with previous research.

*The SURIA in depth analysis of the findings as they compare with previous rounds of peer research is attached.*



## APPENDIX ONE: The Link to the Named Human Rights issues in International instruments

The Right to Health is enshrined in a number of key international instruments. The following are particularly relevant to the issues named in this report:

### UN Declaration of Human Rights

All human beings are born free and equal in dignity and rights. Article 1  
Everyone has a right to a standard of living adequate for the health of himself (herself), and of his (her) family, including....medical care and necessary social services. Article 25 (1)

### International Covenant of Economic, Social and Cultural Rights

The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

Article 12 (1)

Article 12.2 (d) refers to the creation of certain conditions - provision of equal and timely access to basic preventative, curative and rehabilitative health services and health education, regular screening programmes, appropriate treatment of preventative diseases, illnesses, injuries, disabilities, preferably at community level.

This is interpreted by [General Comment 14 of the Committee on Economic, Social and Cultural Rights](#) as meaning

Health is a fundamental human right indispensable for the exercise of other human rights. Every human is entitled to the enjoyment of the highest attainable standard of health conducive to living a life in dignity.

The right to health is closely related to the realization of other human rights, as contained in the International Bill of Rights, including the rights to food, housing, work, education, human dignity, life, non-discrimination, equality, the prohibition against torture, privacy, access to information and the freedoms of association, assembly and movement. These and other rights and freedoms address integral components of the right to health.

The Right to Health in all its forms and at all levels contains the following interrelated and essential elements.

#### 1. [Availability](#)

Relates to functioning public health and health care facilities, goods and services, as well as programmes, have to be available in sufficient quantity within the State party

## 2. Accessibility

Health facilities, goods and services have to be accessible to everyone without discrimination, within the jurisdiction of the State party. Accessibility has four overlapping dimensions. Of particular relevance in this case are :

**NON-DISCRIMINATION:** health facilities, goods and services must be accessible to all, especially the most vulnerable or marginalized sections of the population, in law and in fact, without discrimination on any of the prohibited grounds.

**INFORMATION ACCESSIBILITY:** accessibility includes the right to seek, receive and impart information and ideas concerning health issues. However, accessibility of information should not impair the right to have personal health data treated with confidentiality.

**ACCEPTABILITY:** All health facilities, goods and services must be respectful of medical ethics and culturally appropriate ...sensitive to gender and life cycle requirements, as well as being designed to respect confidentiality and improve the health status of those concerned.

**QUALITY :** Health facilities, goods and services must also be scientifically and medically appropriate and of good quality.

## International Convention on Economic, Social and Cultural Rights

Article 2 (1) says

Each State Party to the present Covenant undertakes to take steps, individually and through international assistance and co-operation, especially economic and technical, to the maximum of its available resources, with a view to achieving progressively the full realization of the rights recognized in the present Covenant by all appropriate means, including particularly the adoption of legislative measures.

The right to Health, like all human rights imposes three types or levels of obligation on State parties: the obligations to respect, protect and fulfil.

**Respect:** refrain from interfering directly, or indirectly with the enjoyment of the right to health

**Protect:** To take measures that prevent third parties from interfering with article 12

**Fulfil:** Contains obligations to facilitate, provide and promote.

## The Right to Participate in Decisions

People have The right to participate in formulation, development, implementation and monitoring of all actions that impact on their lives.

This is a cross cutting right that underpins all other rights. The following are some examples of where it can be found:

- UN Declaration of Human Rights
- Article 19 Freedom of opinion and information
- Article 21 Right to Participate in Government and Free Elections and Vote
- Article 26 Right to Education
- Article 27 Right to Participate in Social and Cultural Life of the Community

## International Convention on Economic Social and Cultural Rights

Common Article -1 Right to Self Determination

- 1.1 All peoples have the rights to self-determination. By virtue of that right they freely determine their political status and freely pursue their economic, social and cultural development.

## APPENDIX TWO: The 28 Recommendations of Our Lives, Our Voice, Our Say

### Supervised and frequent urine sampling

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 criterion 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

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

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**

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.