FAMILY ADDICTION SUPPORT NETWORK

HELPING FAMILIES HELP THEMSELVES

Findings from a study on how families are affected by substance misuse in the North East Region of Ireland

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HELPING FAMILIES HELP THEMSELVES

HSE Social Inclusion


Support the Family
Change the Outcome

Contents

List of Acronyms

ADHD	Attention Deficit Hyperactivity Disorder
CDA	Cavan Drug Alcohol Services
CHO	Community Health Organisation
CTL	Central Treatment List
EMCDDA	European Monitoring Centre for Drugs and Drug Addiction
FASN	Family Addiction Support Network
FRC	Family Resource Centre
HSE	Health Service Executive
HRB	Health Research Board
LCDC	Local Community Development Committee
MCDAR	Meath Community Drug Alcohol Response
N&EHA	North and East Housing Association
NACD	National Advisory Committee on Drugs
NDTRS	National Drug Treatment Reporting System
NERDTF	North East Regional Drug Task Force
NFSN	National Family Support Network
SDG	Sustainable Development Goal
SICAP	Social Inclusion and Community Activation Programme
UISCE	Union for Improved Services Communication and Education
UNODC	United Nations Office on Drugs and Crime

Overview

This research study was commissioned by the Family Addiction Support Network (FASN) and funded by the Health Services Executive (HSE) Social Inclusion Division. The study conducted 3 focus groups, interviewed 14 adult family members affected by substance misuse in the North East Region and 11 staff from a range of organisations working with families[1].

The purpose of the study was:

- to identify and understand the ways families affected by substance misuse seek support
- to improve awareness and understanding of how substance misuse affects family members
- to give families a voice and recognition that family members should be seen as part of a whole family unit, not separately
- to guide the provision of services within the FASN organisation and help to change and/or influence the regional and national drug strategies on family support issues.

Families affected by substance misuse can experience a wide range of harms: worry and psychological distress leading to physical and mental ill-health; exposure to threats and violence associated with drug debts and involvement of the drug-using family member in the illicit market; the financial burden of directly and indirectly supporting a drug user; the impact on employment of stress or caring responsibilities; strain on family relationships; harm from domestic violence; and isolation and loss of social life.[2][3][4]

[1] Appendix i
[2] European Monitoring Centre for Drugs and Drug Addiction. (2017). *Health and social responses to drug problems: a European guide*. Luxembourg: Publications Office of the European Union.
[3] Debbie McDonagh, Nuala Connolly & Carmel Devaney (2018): "Bury Don't Discuss": The Help-Seeking Behaviour of Family Members Affected by Substance-use Disorders, Child Care in Practice, DOI: 10.1080/13575279.2018.1448258
[4] The experiences of families seeking support in coping with heroin use / Carmel Duggan National Advisory Committee on Drugs 2007

The families interviewed for this study which is the first from the North East Region had experienced all of these harms and here they share their stories. These stories bring us to places we otherwise wouldn't go and introduce us to people we otherwise might never meet. The centripetal force of story-telling is empathy,[5] the ability to imagine yourself as someone else. Empathy is also the integrating force of community; it is what connects us and brings us together.

Stories allow us to see that change is possible, that the probable can become possible in ways our rational minds would never have believed. But this change needs to be systemic because it is fundamentally about seeing things differently, understanding relationships, seeing patterns and making connections. It is about transformation. Stories help us make those connections, make meaning out of those patterns and move on.

"I would not be worried now that people would respond to me negatively because of the work I have done on myself. I think it would change if the resources were there and it was straightforward for families and they were involved" P17

This study is about the power of story-telling and connecting; it is about the potency of families coming together, sharing and supporting each other. It is a call out for change, change to our perspectives on substance misuse and our approaches to family support, it is a call out to authentically include families in policy and services and value them as experts by experience[6], the lived experience of being affected by substance misuse.

Thank you to the families who participated in the study for sharing their experience, expertise and insights and to the organisations for their perspectives.

In order to protect confidentiality, anonymity and privacy for participants, feedback is numbered 1 to 25 without reference to family or organisation.

[5] Kotlowitz, A. *New York Times* Book Review Podcast, 7 March 2019.
[6] Experts by experience are individuals who share a common experience of a social and health issue, e.g. mental health, substance misuse, homelessness and can provide support for someone who is "new" to the experience or entering recovery

Family Addiction Support Network (FASN)

(Adapted from source: FASN, https://fasn.ie/about-us/)

Background

FASN was established in 1998 by two mothers who were desperately seeking a way to 'fix' their addicted children. They educated themselves about the drugs their children were using and about possible treatments. They sought help in every avenue but found little support. They began sharing their new-found understanding of drug use with others in the community and it became obvious that many people were quietly experiencing the destruction of addiction in their homes whether the user was ready or not to get help.

Recognising the importance of the needs of families, the founders of FASN set up peer support groups in the area. The people involved found great strength in the union of their voices. These groups led to a formal organisation and into a network, which is today known as the Family Addiction Support Network. It is led and run by adult family members (volunteers) who have lived experience of addiction. This peer element is fundamental to FASN as is the training and support provided to facilitators.

Mission

To assist families in the North East to achieve a greater understanding of addiction, empower them to improve their quality of life and fulfil a positive role in the recovery of their loved one, should they choose to take it.

Aims

To provide services to families to improve their quality of life

Peer support groups are the core of the service beyond which services reflect the needs that emerge.

To provide a quality service through best practice

To provide services that are in line with best practice guidelines and national standards

To network with family support groups locally, regionally and nationally

To share what FASN is doing and learn from other services uniting our voice with that of other families so that the needs of families are recognised.

FASN Services

FASN provides a telephone information, support and helpline and five peer facilitated family support groups in Navan, Drogheda, Cavan, Dundalk and Castleblaney, Co Monaghan each week. The family support groups are led by peers who are trained in facilitation and work to best practice guidelines and national standards[7]. FASN facilitators meet monthly with a psychotherapist for professional support and supervision. This peer led model provides healthy modelling by the facilitators of maintaining positive mental health, supporting the building of resilience and hope and through their engagement with professional training and ongoing self-development, the potential for families to be healthy contributors to community and society which in turn reduces the sense of isolation and stigma.

FASN Structure

The FASN team comprises a Coordinator who is trained and is a trainer in the family intervention method of the 5- step approach[8], a Business Manager and a team of peer volunteers who undertake a range of roles including facilitating the family support groups. FASN also utilises an external panel of accredited counsellors to work with Family Members when required. The governance of FASN is overseen by a voluntary board of management.

FASN Funding

FASN receives once off funding from the HSE and ongoing funding from the NERDTF which accounts for a central part of its total budget. The remainder is fundraised by FASN.

Family Support

A Family Support Group is a safe, confidential, non-judgemental place for family members to discuss issues emerging from the problem of substance misuse within the family. From the shared experiences of the group, members may find useful strategies for coping with their particular problem. More importantly, the support group is more than just having a group of friends. It is about respecting each others' right to speak and to let go of the worries and stresses they have as a result of substance misuse in the family. Family Support can be offered on a one-to-one basis or in a group setting.

[7] Quality Standards in Family Support Groups NFSN 2019 which was informed by families affected by substance misuse

[8] There are various interventions aimed at supporting family members attempting to cope with another family member or relative experiencing an addiction issue. One such intervention is the 5-Step Method.

Executive Summary

The National Strategy *Reducing Harm, Supporting Recovery 2017–2025*[9] is the underlying policy that sets the approach and response to substance misuse in Ireland. It has five strategic goals; **1** Promote and protect health and wellbeing, **2** Minimise the harms caused by the use and misuse of substances and promote rehabilitation and recovery, **3** Address the harms of drug markets and reduce access to drugs for harmful use, **4** Support the participation of individuals, families and communities, and, **5** Develop sound and comprehensive evidence-informed policies and actions.

Progress on National Strategy

In February 2019 the National Family Support Network (NFSN)[10] published an update on progress of key actions in the national strategy relevant to family members[11] identifying some progress on all of the key actions. The goals in *Reducing Harm, Supporting Recovery* 2017-2025 also resonated with the participants in this study but, questions were posed on the status of their implementation in the region, e.g. Services including families; a number of participants had the experience of being pushed away by services when their loved one entered treatment rather than included and informed, clearly the needs of families and the needs of the patient are different, but they are not necessarily mutually exclusive. The study understands that there is a pilot programme in the region addressing how issues of confidentiality and privacy can be respected and managed[12] which is proving effective but is limited in its scope. Additionally, participants shared experiences of some services responding to them in a manner which they perceived to be overlaid with judgement and blame rather than responding to a health condition in the same way any patient would be treated in the health services, participants believed that if a health led approach was

> *"We just wanted to know what if anything we could do to help her, what to expect, how best to support and be there for her, we know she is the patient and she needs her space, we just wanted to be involved" P 9*

[9] Reducing Harm, Supporting Recovery A health led approach to drug and alcohol use in Ireland 2017-2025
[10] The National Family Support Network is an autonomous self-help organisation that supports the development of family support groups and networks throughout the island of Ireland
[11] National Family Support Network. *Reducing Harm, Supporting Recovery (2017–2025)*. Updated February 2019.
[12] FASN and Turas have piloted a model of treatment that includes families, it is unclear whether this has been evaluated and its current status.

adopted and addiction was really seen as a health issue it might in fact help reduce the associated feelings of stigma, shame, blame and guilt.

Families valued the family support services provided by FASN and appreciated the training and support for the volunteer facilitators but there was a deep sense of frustration at the overall lack of adequate family support services in the North East Region. There was strong support for a shift in policy to decriminalise drugs for personal use, with participants sharing how the present policy of criminalisation impacts on the whole family. The majority of families in this study had experience of dealing with fear, violence, intimidation, drug dealers and associated debts. Finally, some participants had been in contact with the Drug Related Intimidation Reporting Programme and had found the Gardaí involved in the programme to be supportive and realistic in what they could do.

"I can't believe sometimes the things that have happened, the debts he ran up, the guards coming to the door, they were nice actually, the phone calls threatening us, it is, was a nightmare, I look at myself and think is this really happening, is this me" P18

"I find as a family trying to access any information was just so difficult or knowing what is out there" p3

"I asked GP, they tried but didn't really know, suggested i take something to help me calm down so i went home and started searching" P8

How families seek support

Factual and independent information was what families sought when they became aware of changes in behaviour and/or were concerned about a loved one's addiction. However, the families in this study did not know where to look and/or whom to ask for help. There was also a reluctance to disclose their concerns because of feelings of shame and guilt. Perhaps they would be seen as 'bad' parents and blamed for what was happening. Web based searches were the most common way of finding information, there was no awareness of the national information website www.drugs.ie. Participants who had contacted Family Addiction Support Network (FASN) had no previous knowledge of FASN and were informed of FASN through a third party.

Participants spoke of their first contact with FASN and how much that first encounter meant to them, they were listened to, they felt they could breathe, they had found someone who understood, who had been there, a peer. The other valued and important aspect of that first contact was their call was returned very quickly if they could not immediately speak with FASN.

"I rang "G" and told her a wee bit of the story, she said can I come down to the centre, I didn't know where it was, she gave me directions and I got there, I sat at the table and started crying, I didn't realise how much it was affecting me, physically, mentally and spiritually, but, I thought I was going to get answers to help my son, I didn't think I was sick, that i needed anything, I realised after a while I was as sick as my son" P2

Families also wanted factual information when their loved one entered a treatment service, they wanted to know about the treatment plan, how to support their family member whilst in treatment and, when they were discharged. Unfortunately for many families their experience of services was of being shut out and excluded which compounded feelings of blame, shame, guilt and failure.

"Once your child is over 18 you have no way of accessing information on what is happening, you are sending them into services but very hard to know what is going on, they make no sense sometimes which is understandable but you shouldn't have to rely on them to tell you"P4

How families are affected

Families spoke of the emotional, physical, legal and financial repercussions they experienced, including stress, isolation, anxiety, resentment, anger, depression, bereavement, fear, intimidation, debt and violence. The stigma of addiction along with feelings of shame, blame and guilt were raised both by families and by service providers.

"I made a call to one of the psychiatric services and got a great response, I got the most information from anyone ever, I got talking to the addiction nurse, i could ask 20 questions, nothing was too much trouble about mental health, about services, about GP's, one person who had knowledge of all the different facets" p 11

Inclusion of families in services

There needs to be a recognition that adult family members have two related but distinct needs: first, receiving help and support in their own right; and second, where appropriate, supporting their loved one. It emerged in this study that sometimes one is met but not the other, even though these needs are not mutually exclusive and meeting one complements the other. Including families as service users in their own right was a breakthrough in the National Strategy achieved following widespread discussions and lobbying. Ireland is one of only a handful of countries that has included families in such policies.[13]

Services – gaps and accountability

There were a number of recurring issues mentioned with respect to gaps in services. For example, reference was made to the overall gaps in addiction services in the North East Region the long waiting lists, paucity of community treatment, insufficient counselling services, lack of dual diagnosis and mental health services, insufficient methadone prescribing General Practitioners[14] and very few family support services. Additionally, participants spoke of a perceived lack of professional standards, accountability and transparency by some treatment services towards patients. The Health Information Quality Authority (HIQA) has the national role to set and monitor standards for the quality and safety of health and social care in Ireland. These standards are the National Standards for Safer Better Healthcare[15] and the HSE National Social Inclusion Office is supporting the HSE addiction services to promote and support quality and safety within addiction services in line with these National Standards. It is important that families are aware of and informed of these standards and supported to bring any concerns to the attention of relevant services and overseeing bodies.

"It was not what i expected, it left me feeling uncomfortable, I did not trust what was going on, they spoke to us when we went as if we were children who needed to be told, they had no empathy, but if you say anything they would just tell you to leave so" P15

[13] European Monitoring Centre for Drugs and Drug Addiction (2017), Health and social responses to drug problems a European guide, Publications Office of the European Union, Luxembourg P123-126
[14] Appendix vi
[15] Health Information Quality Standards Authority National Standards for Safer Better Healthcare June 2012

"There is still a taboo around it, people don't talk about it but we can see for ourselves the effects on families, alcohol is different, it is more accepted but with drugs comes secrecy, fear, intimidation, shame, debt, what will they think of me, will they throw me out, will they take my kids" P14

The two-tier health system – i.e. the public and private health care system was mentioned by several families and agencies, with the private system perceived to allow quicker access, service users being treated with respect, better choice of treatment options, explanations provided on treatment, and follow-up services put in place. Sarah Burke has written extensively on the two-tier health system in Ireland[16], it may be that the Sláintecare[17] Plan to transform health and social care will address some of these issues.

Stigma

Stigma, which is linked to institutional, public and private shame, was very present in participants' stories[18] as were feelings of blame and guilt. Participants spoke of how prevalent and entrenched the stigma of addiction appears to be, suggesting that it may be linked to being seen as a 'poor', 'city', 'working class" issue, associated with particular cohorts of the population – e.g. social housing, homeless, young people, those involved in criminal activity – which can lead to the propensity to view those with an addiction as 'other', not like us, different to and separate from the general population. Comparisons were made between the stigma of addiction and that of mental health, with a recognition that the stigma around mental health seems to be diminishing. Mention was made of the 'Green Ribbon' campaign and the public champions for mental health who have spoken out about their own experiences, which has perhaps helped to 'normalise' the issue.

"Addiction is everywhere, we don't want to admit it, I did feel ashamed to begin with but no longer, I love my son, he is a lovely and very good spirit, but he is sick, it is a disease, it is progressive and serious, it has taken me a long time" P10

[16] Burke Sarah Irish Apartheid: Healthcare Inequality in Ireland Dublin New Island 2009
[17] Houses of the Oireachtas Committee on the Future of Healthcare Sláintecare Report May 2017
[18] Lloyd, C. (2013). 'The stigmatization of problem drug users: A narrative literature review', *Drugs: Education, Prevention and Policy*, 20(2), pp. 85–95, doi: 10.3109/09687637.2012.743506.

Participants thought that because drugs were illegal the stigma attached to them was very different, more entrenched and anchored in other cultural and socio-economic norms.

There was no awareness of the Stop the Stigma Campaign, but families were interested and positive about such a campaign.[19]

"We are not criminals, my son is not a criminal, he is sick, he has a disease, it drives him, it was driving me and my family, it still does at times, if he had a broken leg it would be different but is it that different, he needs help not judgement, i am all for this change"P1

Decriminalisation

There was interest in and considerable support for a shift in policy towards decriminalisation and this was linked to a belief that such a change might also help to reduce the stigma surrounding addiction. But, the overriding support for decriminalisation was that participants were very strong in the belief that their loved ones were not criminals; they were sick and should be treated as patients, not criminals. Participants spoke of the repercussions of criminality on their loved one, themselves, their family and the community.

"Usually it is women who phone, want information, help understand what is going on, couples come for first one or maybe two sessions, guys give up usually because they want to fix it, women will stick with it even when they understand it can't be fixed, that's hard because then it is about them" P14

Gender and diversity

Mention must be made of the insights from both families and agencies regarding gender. Gender was described as so obvious as to be not worth mentioning. However, it does warrant mention. The usual scenario described by both families and agencies is that contact is made by a woman, usually the mammy or granny. It is she who makes the call and/or walks into the office or surgery or speaks to the priest. It is she who turns up for the appointment. She may be accompanied by her husband/partner for the first one or two appointments, but it is she who usually sticks with the service. This is a common feature in many health and social care services and one that is slowly being acknowledged. The affects

[19] A CityWide Campaign 2018 – addiction is a health issue not a crime, www.stopthestigma.ie.

of substance misuse on women and men in families, how they respond, and cope are not necessarily the same and services need to understand and take this into account. Moreover, in a region like the North East, with its rural and urban mix and increasing diversity of population in terms of family make up, culture and ethnicity it is crucial that services develop a range of methods to reach out and engage with both women and men – including online platforms and social media channels – to raise awareness of services and support all families and communities in culturally appropriate ways.

Experience of FASN

"I found the group great and "G" well, you could open up to her so easy, I kept coming and so I began to detach myself from my son, it took me an awful long time to realise but that doing his washing, making sure he had everything he needed was in fact just enabling him and building a log for him to go out and start using again, it is just so sad, it's coming to the group that keeps me going, you rear these beautiful souls and it turns out like this" P1

The empathy and sense of community that family participants experience in FASN was palpable in the interviews, with the peer support aspect of FASN consistently highly valued. The quick response participants received from FASN was highlighted but moreover the feeling that they were accepted – there was no judgement; participants were listened to and felt held, they felt looked after. Knowing that G[20] had been through similar experiences was shocking on the one hand but also reassuring; it broke through the sense of isolation, anxiety, fear, shame, blame and guilt. Later, if participants had joined a family support group, this sense of belonging, of being amongst others who were going through or had gone through what they were experiencing was their anchor.

The way the group and facilitator were there for them whilst at the same time gently questioning their reality, opening up other ways of seeing, was at times uncomfortable but ultimately very helpful. Family participants also spoke about the need for more groups, and on the other hand the barriers facing people coming to a group, e.g. distance, not wanting to be seen whilst also recognising that for some, family support groups are not appropriate.

[20] G is the Family Support Coordinator of FASN.

Fundamentally, the message from all participants was that services provided by FASN need to expand alongside wider and more effective ways to reach out to families, to provide support, information, and advice, with peer support in whatever form at the core of that expansion.

Recommendations

Five key recommendations emerged from this study.

1. Reconfigure the FASN structure into a Peer Led hub and spoke federation adding the necessary capacity to scale the present model of peer led family support services. This requires essential and appropriate funding to action.
2. Fund the Evaluation of the pilot *The Community Alcohol Detox* that Turas and FASN have developed for the inclusion of families in services and determine its viability to transition into a model of good practice that is mainstreamed.
3. Progress, resource and promote a regional plan for a gendered health led approach and pilot a regional clinical pathway for dual diagnosis.
4. Fund an appropriate staffing level within FASN to enable them to prioritise the accessing of funding from multiple streams that will be required to support the essential work identified within this body of research.
5. Promote and raise awareness of the Stop the Stigma and Decriminalisation campaigns, create and further develop strategic partnerships between FASN and national structures to not only promote and support these struggles but ensure that the unique issues and needs of families in the North East region are classified and included in policy development and reports.
6. FASN to undertake to raise greater awareness of the services it provides by advertising regionally through a range of medium.

In order to implement these changes, core funding will be required to ensure sustainability of the Family Addiction Support Network.

Introduction

The purpose of this study was to identify and understand the ways families affected by substance misuse seek support, to improve awareness and understanding of how substance misuse affects family members, to give families a voice and recognition that family members should be seen as part of whole family unit, not separately, and to guide the provision of services within the FASN organisation and help change and/or influence the regional and national drug strategies on family support services.

The experiences and voice of families are at the core of this study. Interweaved with their stories is the role and changing status of the Family in Ireland, the part played by community development and activism is highlighted, the need to address stigma, support for the introduction of decriminalisation and a call out made for the "benefits of taking a gendered health led approach to service planning and provision. The uniqueness of the North East Region is the study backdrop, a backdrop that too often is overlooked but must be taken into account if families and communities are to get the support and services, they not only need but have every right to expect[21].

> *"Somebody asked if I knew there was a family support network and gave me the number, I phoned, left a message and within 10 minutes i had a call from a lovely friendly person which was so nice because when you make that call you don't know who you are calling, she was just so calm, i arranged to meet her and my husband came along too" P5*

How families seek support

At the outset it is important to note that some participants spoke about wanting information before they sought any support whilst others had been struggling for some time with a loved one's substance misuse and were desperately seeking support either for their loved one, for themselves, or for both. When participants thought back to that time, those who were looking for information were looking for independent, factual information which they felt was very hard to find. Independent factual information is quite a specific description, and, upon further exploration, it was described as information that was up to date and would not be tainted by judgement, perceived or otherwise; judgement around

[21] Universal Declaration of Human Rights Article 25

substance misuse generally, judgement of those who are substance misusers and/or of families who had a loved one with an addiction. Overall, there was a marked sense of frustration at how hard it was to find information.

"Services need to respond in different ways, it is a big region, the distances, the changing population, we should look at using the web and apps, you see them in other sectors, hospitals remind you of appts by text, counselling is now online, it's a short window to make the connection when someone takes the plunge and asks for help or information" P23

Participants mainly found information through web-based searches. The search themes used were either linked to names of substances and/or changes in the behaviour of their loved one. The results of the searches in some instances flagged the possibility of substance misuse. The other main ways used to seek support were speaking with their General Practitioner, a priest and/or the school.

Seeking Support – How and Where?

None of the families were aware of drugs.ie an informative, interactive and accessible HSE website.

None of the families had been aware of FASN.

None of the families had heard of family support services.

Participants recommended that information, advice and support should be available in a range of different ways, e.g. web based, apps and social media platforms but also in a range of public spaces, e.g. bus and train stations, health centres, post offices, banks, community noticeboards in supermarkets, petrol stations and Garda stations. Participants thought that publicising information in this way would help bring substance misuse out of the shadows. Comparison was made with the increasing discourse on mental health issues, e.g.

celebrities, professional sport players, politicians coming out and speaking and sharing their mental health experiences.

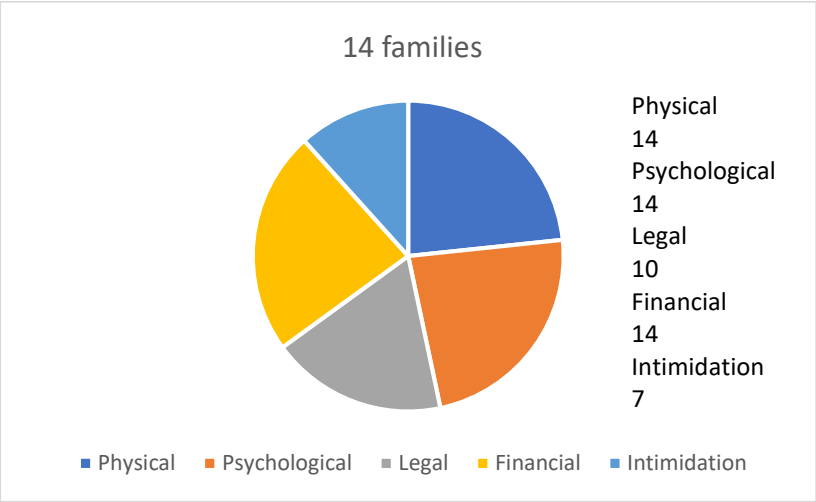
Peer Led +++ **Mainstream information on family support services**

How did substance misuse affect families?

Health Psychological Health Physical Legal Financial Intimidation

14 14 10 14 7

Families spoke of the physical, psychological, legal and financial impact addiction has had on them as well as intimidation and fear. 14 families had experienced physical and psychological affects; 14 families had run into debt as a result of their loved one's addiction. 10 families had to take legal action including barring and protection orders against their loved one and 7 families had experienced intimidation including threatening phone calls, dealers calling to the house, broken windows, pipe and petrol bombs.



Stress	✓
Not Sleeping	✓
Anxiety	✓
Feeling sick	✓
Not eating	✓
Wanting to run away	✓
Resentment	✓
Fear	✓
Anger	✓
Failure	✓
Stigma	✓
Blame	✓
Guilt	✓
Shame	✓
Stuck	✓
Preoccupied	✓
Not going to work	✓
Depression	✓
Denial	✓
Controlling	✓
Frustration	✓

Bring addiction out from under the shadows of stigma, shame and blame, raise awareness around the Stop the Stigma Campaign, be an active player in the lobby for decriminalisation.

Include families in a health led approach and respond to dual diagnosis

Some participants experience of addiction services was that they excluded the family when their loved one entered treatment and/or their approach to the family was perceived as blame and judgement. On the other hand, there were examples provided of services being inclusive and helping all family members. However, what the study found overall was that participants did not know how they could or should be treated but they were at one in wanting to be involved in supporting their loved one in whatever way they could. The difficulty of finding a service who would respond to both mental health and addiction issues was raised by all participants. Participants were well aware that their needs and the needs of their affected loved one were different. They wanted services to include them in very basic ways, e.g. explain the treatment plan, suggest ways the family could help, prepare the family on what they might expect of their loved one before, during and after treatment and provide some advice and information on how to get support for the family themselves

> *"You can't find information on services, that's what you get from another parent, because it is from another parent's experience, I would have loved if the service talked to us, if the medical people spoke to us, if the psychiatric people spoke to us, we are the spoke in the wheel around which it is all going on but we are not included" P10*

Take a gendered approach

The role that women have played in community activism and the development of services in the field of substance misuse is largely ignored in the research but was wholly evident in this study. Participants spoke of the fact that it was usually women who sought information, who sought support, who accompanied their family member to services, who dealt with intimidation. It is mainly women who are using FASN services and it is mainly women who are group facilitators. This is not unique to FASN and it is not to overlook the experiences and needs of men, it is in fact the opposite, to make a case that if a gendered approach is taken then the needs of both women and men are valued and appropriate services developed so that women and men are included and can access services.

Chapter 1 The Family

The family is central to contemporary policy development in Ireland and an analysis by Daly[22] shows that matters of the family can rival other concerns – such as the labour force – in forging a new social policy model in Ireland. The interface between social policy and family has a chequered history in Ireland. Moreover, Orford notes that research on Affected Family Members remains somewhat isolated from the mainstream of social science theory[23] and is fragmentary.

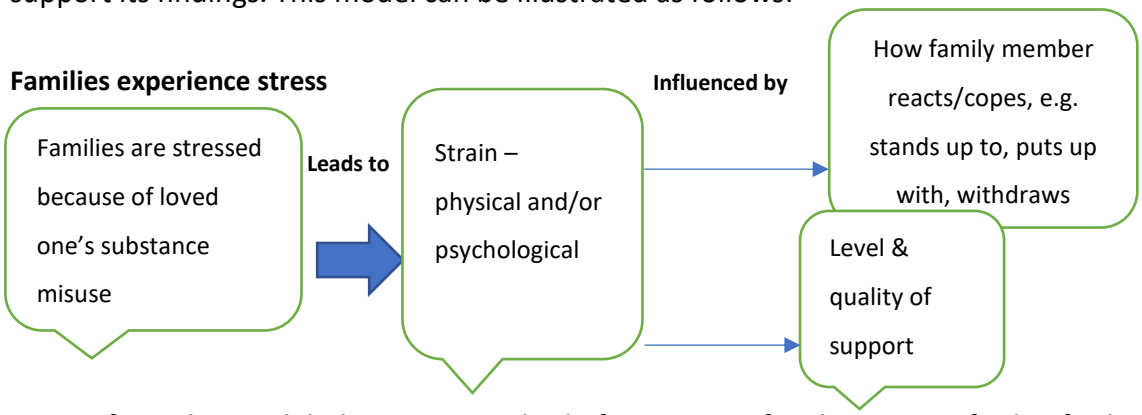
A review of models and approaches to family-based policy and service provision for those at risk of social exclusion suggests three distinct categories[24] – those that seek to strengthen the ability of family members to offer support to the person with the addiction within that family; those that recognise family members as having their own specific and independent needs arising out of their relationship with the addicted person; and finally, those that take a systemic approach focused on shared needs and strengths that cannot be dealt with by concentrating on a member of the family. The review noted that where families are viewed as an untapped resource to respond to the need of a family member, the family is supported to develop assumed strengths, whereas when families are deemed to be failing to fulfil an assumed normative role, services and practitioners try to address this through a professional-led response. An approach that assumes there is an 'ideal' family, or a 'normal' family will inevitably define some families as failing, the family as the 'problem' and the professionals as the experts with the solutions. This pathologises the family.[25] On the other hand, it is important not to assume that the only or most appropriate

> *" I don't know what it is anymore, what is normal, we were just like any other family and then we were in a nightmare, addiction is totally different if you say it to someone, if they have no experience their head is grappling with why and what went on, what did you do or not do, but the other thing is people don't realise how widespread the problem of addiction is now" P17*

[22] Daly, M. and Clavero, C. (n.d.) *Contemporary Family Policy in Ireland and Europe*. School of Sociology and Social Policy, Queen's University Belfast.
[23] Orford, J. (2017). 'How does the common core to the harm experienced by affected family members vary by relationship, social and cultural factors?' *Drugs: Education, Prevention and Policy*, 24(1), pp. 9–16.
[24] Hughes, N. (2010). 'Models and Approaches in Family-Focused Policy and Practice', *Social Policy and Society*, 9, pp. 545–555, doi: 10.1017/S1474746410000266.
[25] Weiss, R. (2018). *Prodependence: Moving Beyond Codependency*. Deerpark, FL: Health Communications, Inc.

solution to family tribulations lies within the family rather than in the interplay between the internal and external environments, which means it is also necessary to address ineffective social policy, poverty, unemployment and other socioeconomic factors and/or gaps in services.[26]

The National Advisory Committee on Drugs (NACD) published research by Dr Carmel Duggan in 2007[27] on how families are affected by heroin use. Though polydrug use and alcohol are more the norm in 2019,[28] this research is as relevant today as it was in 2007. The recognised stages that family members move through have been replicated in many other[29] studies and have been echoed by participants in this study, e.g. *ignorance, confusion, denial, coping alone, desperately seeking help, supported learning and separating the needs of the family and their own needs from that of the drug user*. These stages are not linear, and families move back and forth as they struggle and develop their own way of coping. Orford et al. have consistently challenged models that pathologise families. Indeed, their development of the Stress Strain Coping Support model based on families' own experience as part of AFINet[30] is the antidote to a family-pathologising approach and has a body of research to support its findings. This model can be illustrated as follows:



Arising from this model, the 5-step method of supporting families was crafted: **1** facilitate families telling their story, listening and reassuring; **2** provide relevant information; **3** discuss ways of coping and responding; **4** explore sources of support; and **5** arrange further help if

[26] Orford, J., Natera, G., Davies, J., et al. (1998). 'Social support in coping with alcohol and drug problems at home: findings from Mexican and English families', *Addiction Research*, 6(5), pp. 395–420.
[27] Duggan, C. (2007). *The Experiences of Families Seeking Support as the Result of Heroin Use*. National Advisory Committee on Drugs.
[28] EMCDDA, 2018, Issue 66.
[29] Salter, G. and Clark, D. (n.d.). The Impact of Substance Misuse on the Family: A Grounded Theory Analysis of the Experience of Parents, WIRED and Department of Psychology, University of Wales, Swansea.
[30] AFINet Addicted Families Information Network

needed. A formalised training programme in the 5-step method was developed by Orford[31] and his colleagues, which the NFSN adopted and brought to Ireland. The FASN coordinator is trained and is a trainer in the 5-step method, and this is the model utilised in the family support groups facilitated by FASN.

Before moving on, it is important to note that though attempts were made to contact and reach out to the increasing diversity of the region's population, both directly and through other services, these were not successful. The taboo and stigma around addiction that impacts on all families, may have particular connotations for families who perceive and/or experience social exclusion already. Stigma, shame, blame and guilt are recurring issues discussed throughout this study and can make it very difficult for any family to put their head above the parapet, let alone families who may be already struggling with issues of discrimination and/or who may be mistrusting of public bodies and services, for whatever reason, even when those bodies are clearly part of the community and voluntary sector.

> *"I was in a terrible state, i couldn't string two words together, i first met "G", she just listened and i knew, I just knew from how she was and then how she spoke that she had been through it, then after a few times i came to a group, I didn't say anything the first few times, just listening to what the others were saying i realised I was not on my own, I could breathe, no one was judging me, blaming me, I learned there was a me in the middle of it all that was separate from my son" P3*

The changing nature of the family

The Constitution of Ireland enacted on 1 July 1937 has 50 articles. The family is defined in Article 41: 'The State recognises the Family as the natural primary and fundamental unit group of Society, and as a moral institution possessing inalienable and imprescriptible rights, antecedent and superior to all positive law.'[32] The Constitution has been amended 37 times to date.[33] Recently there has been ground-changing legislation that has helped redefine the changing legal definition of what constitutes a family, e.g. the Children and Family Relationships Act 2015 gives full legal recognition to children born as a result of IVF and to

[31] Orford, J., Copello, A., Velleman, R., and Templeton, L. (2010). 'Family members affected by a close relative's addiction: The stress-strain-coping-support model', *Drugs: Education Prevention and Policy*, 17(s1), pp. 36–43. 10.3109/09687637.2010.514801.
[32]http://www.irishstatutebook.ie/eli/cons/en/html#article41.
[33] Appendix ii.

their parents, who may not be the biological parents. In August 2015 the Constitution was amended as follows: 'Marriage may be contracted in accordance with law by two persons without distinction as to their sex'. A significant factor in the campaign[34] for marriage equality was the sharing of the personal stories of families who are gay and/or have a family member who is gay. This approach was influential in creating a platform for starting conversations and building support; it enabled that sense of empathy and community referred to earlier. Seeing the person behind the label can help to break through discrimination and stigma. Ireland is now looked at in other jurisdictions as a model of how to successfully lobby and campaign in these areas, but it is important to remember how long it has taken to reach this point and the sheer hard work and energy involved.

"All the other stigmas seem to have been broken down, unmarried mothers, gay people, look at mental health and how people are sharing, but addiction is a different story, I still cannot handle anyone talking to me about it, I know they mean well and it would be fine, it's me I'm not fine " P6

Stigma

Building support and starting conversations around the pervasiveness of substance misuse in families and communities throughout the length and breadth of Ireland and what needs to be done has been underway for some time. But perhaps with the launch of the Stop the Stigma Campaign it can take those conversations onto a national platform in the most public way to date. In October 2017 the Press Ombudsman of Ireland issued an advisory notice to all national and regional newspapers following an approach from the Union for Improved Services Communication and Education (UISCE), which had raised concerns at the way language in popular use was stigmatising those who use drugs. In February 2017 Catherine Byrne TD, Minister of State for Health Promotion and National Drugs Strategy, launched a Stop the Stigma Campaign on behalf of CityWide Drug Crisis Campaign. The campaign has parallels with the Marriage Equality Campaign trying as it does to look beyond the label, see the person and hear their story. Feelings of shame and guilt were mentioned frequently by participants in this study and are

[34] Parker, S. (2017). The Path to Marriage Equality in Ireland: A Case Study, https://www.atlanticphilanthropies.org/wp-content/uploads/2018/01/Marriage_Equality_Case_Study.pdf.

well documented in other research on affected families.[35] [36] Many people still believe that addiction is a moral/and or family problem and that people choose to misuse drugs.

The Minister for Health, Simon Harris, has called for a referendum to change the definition of family in the Constitution.[37] The report of public consultation *Families and Family Life in Ireland*[38] carried out by the Department of Social and Family Affairs underlined that there was a need to develop a more inclusive definition of a family to reflect the changing nature of families in Ireland and elsewhere in the world. Such a definition should include grandparents and children, foster parents and children, lone parents and partners as well as same-sex parents and children. The definition of family used in this study adopted the definition suggested in the report of the public consultation and reflects the families who participated.

"Is there a ribbon, that would be something, you could wear it and not have to say anything, how would that be, a silent way of showing support" P6

"What support would have been good, well apart from "G" people who would know more about drugs, people don't talk about it, the shame, in the end I didn't care who knew, people give you advice, throw him out, they don't have a clue, I love my son, my son was sick and he needed help" p12

[35] Orford, J., Velleman, R., Copello, A., Templeton, L., and Ibanga, A. (2010). 'The experiences of affected family members: A summary of two decades of qualitative research', *Drugs: Education, Prevention and Policy*, 17(s1), pp. 44–62.
[36] McDonagh, D., Connolly, N., and Devaney, C. (2018). '"Bury don't discuss": the help-seeking behaviour of family members affected by substance-use disorders', *Child Care in Practice*, https://www.drugsandalcohol.ie/28867/.
[37] O'Halloran, M. (2018). 'Referendum needed to change definition of "family" in Constitution', *The Irish Times*, (17 July), https://www.irishtimes.com/news/politics/oireachtas/referendum-needed-to-change-definition-of-family-in-constitution-1.3568434.
[38] Daly, M. (2004). *Families and Family Life in Ireland: Challenges for the Future*. Dublin: The Stationery Office.

Chapter 2 A Health Led Approach

Globally, a health-led approach to substance misuse is now the norm – part of a shift in policy towards harm reduction. In 2012 the United Nations Office on Drugs and Crime (UNODC) acknowledged the 'growing recognition that treatment and rehabilitation of illicit drug users is more effective than punishment'.[39] Taking a health-led approach to substance misuse is reflected in the Sustainable Development Goals (SDGs) which the UN adopted in 2015.[40] Titled the *2030 Agenda*, the SDGs are multifaceted and influential at an international and national level. For example, Goal 3 calls for countries to 'ensure healthy lives and promote well-being for all at all ages. As one of the 13 related targets, it encourages action by countries to 'strengthen the prevention and treatment of substance abuse, including narcotic drug abuse and harmful use of alcohol'. The Department of Health have linked the SDG's to the 5 aims in the national strategy *Reducing Harm, Supporting Recovery 2017–2025*. Moreover it describes the national strategy as having an overarching vision for 'a healthier and safer Ireland, where public health and safety is protected, and the harms caused to individuals, families and communities by substance misuse are reduced and those affected by substance use are empowered to improve their health and wellbeing and quality of life'.

> *"There are long waiting lists for GP's and treatment, what do people do in the meantime, community detox is available but not enough to meet demand, I have parents phoning me, we work with families with consent of the patient, but inclusion of families is patchy" P19*

Like other European countries, Ireland evaluates its drug policy and strategy through ongoing indicator monitoring and specific research projects, the Health Research Board has responsibility for monitoring and research. The Minister of Health has overall responsibility for the plan along with the Minister of State Catherine Byrne who has responsibility for both health promotion and the substance misuse strategy. The importance of this shift to a

[39] United Nations Office on Drugs and Crime. (2012). *World drug report 2012*, http://www.unodc.org/documents/data-and-analysis/WDR2012/WDR_2012_web_small.pdf (accessed May 2016).
[40] Further information on the 2030 Agenda, goals and targets is available online at: https://www.un.org/sustainable development/.

"My father was a drinker and he had mental health problems, we didn't know anything then, he would go off, it was different then, I think it is changing now, what we thought was ok, the behaviour to my mother, well no, not ok, I suppose it was seen as "normal" it was just accepted, when I look back now it's hard to believe what we put up with but we did and then I realised I had begun to adjust around my son without really noticing until I began coming to the family support group, slowly I came round to seeing what was going on" P7

health-led approach cannot be overstated. Furthermore, that following lengthy discussions and debate alcohol was included so it is a substance misuse strategy was hugely significant. A health led response was endorsed by the Taoiseach at the launch of the strategy when he spoke of substance misuse as a public health issue, '*For the ideal of a Republic of Opportunity to be meaningful, it must apply to all. Treating substance abuse and drug addiction as a public health issue, rather than a criminal justice issue, helps individuals, helps families, and helps communities. It reduces crime because it rebuilds lives. So, it helps all of us.'*[41]

"It's the waiting, waiting, waiting for a bed, trying to keep them safe in the meantime and hoping that this time when they phone there will be a bed and then once they are admitted, the relief, you don't know, you don't realise that you were like a spring until they are in and hopefully they are safe" P10

"People coming to your door, paying off loans, I have grandchildren coming in and out, even though my son does not live here any longer, they still come to the door looking for their money, or they go to my son in law's business, they threaten, the guards are realistic in what they can do, they are kind but realistic, I have had pipe bombs, I told them, I have nothing left" P25

[41] Department of Health Press Release, 17 July 2017, www.health.gov.ie.

Chapter 3 Decriminalisation

Decriminalisation has been introduced in over 25 countries.[42] [43] It was introduced as early as the 1970s in some countries, and there are a range of decriminalisation models that countries have adopted – e.g. a *de jure* model (one defined by law) – whilst others have deprioritised the policing of drug possession through de facto decriminalisation. However, it is also important to understand that – as with any policy implementation – its effectiveness is influenced by a number of factors: 1. thresholds that are realistic and offer guidance; 2. proportionate responses; and 3. an investment in health and social services so that there is a holistic, person-centred response and investment is not confined to those health and social services traditionally linked to substance misuse.

"He is not bad, he was sick, so very sick and so was I, eventually he got help but it took a long time and so did I, I found FASN, he has moved away, we go and visit him and his family but he will not come back here" P13

This study identified a groundswell of interest in and support for decriminalisation. In 2017 a Working Group was established by the Minister for Health Promotion and the National Drugs Strategy to examine alternative approaches to the possession of drugs for personal use. The group, chaired by retired Judge of the Court of Appeal Garret Sheehan, met for the first time in December 2017.[44] A Joint Oireachtas Committee on Justice, Defence and Equality report had recommended a harm-reducing and rehabilitative approach to possession of small amounts of illegal drugs. The Working Group has commissioned research to examine approaches taken in other jurisdictions to the possession of drugs for personal use and has conducted a series of public consultations.

Participants in the study spoke about two main issues with regard to decriminalisation: first, it would send out a strong signal that addiction is a disease – a health issue and should be treated as such[45] – and second, criminalising people who have a disease has wide

[42] International Drug Policy Consortium.
[43] Eastwood, N., Fox, E., Rosmarin, A. (2016). *A Quiet Revolution: Drug Decriminalisation Across the Globe*. Release, March 2016, https://www.release.org.uk/publications/drug-decriminalisation-2016.
[44] Appendix iii, Terms of Reference.
[45] Mayock, P., Butler, S., and Hoey, D. (2018). *'Just Maintaining the Status Quo'? The Experiences of Long-term Participants in Methadone Maintenance Treatment*. Dublin: Dun Laoghaire Rathdown Drug and Alcohol Task Force.

ramifications for them and their families and in the short and long term it is counterproductive. In 2017, there were 12,201 recorded incidents of possession of drugs for personal use, representing over 72% of all drug offences, in a decriminalised system, drugs remain illegal what changes is that those who use drugs are dealt with as needing a health intervention rather than people who deserve to be punished. Viewing addiction as a disease does not in any way imply abdication of responsibility on the part of the addict. As with any other disease, diagnosis requires adherence to a plan for treatment and recovery.

"You can understand it i suppose, unless you experience it yourself you think addiction is someone with a needle in their arm sitting on the pavement in a back lane in Dublin, it's not here in this beautiful county, how wrong we can be" P 11

There are, of course, concerns about introducing such a policy which centre around worries that there will be an increase in drug use throughout all levels of society, but particularly that such a policy shift might send the wrong messages to young people. There are also anxieties that it would result in increased drug-related deaths and an increase in the spread of infectious diseases. However, in its conclusions of its latest research on decriminalisation, Release[46] stresses that 'decriminalisation when implemented effectively does appear to direct more people who use drugs problematically into treatment, it does reduce criminal justice costs, it improves public health outcomes, and shields many drug users from the devastating impact of a criminal conviction.'[47]Portugal, which is frequently held up as a model country that has introduced decriminalisation continually emphasises the substantial investment it made in its health *and* social services including needle exchanges, opioid substitution treatment, treatment and prevention strategies, education, housing and employment opportunities. Their model was one of political leadership and cross government investment, "that will mobilise all elements of Portuguese society: institutions, families and above all the younger generations clearly and unambiguously in a fighting strategy"[48].

[46] Release is the UK national centre of expertise on drugs and drugs law. The organisation, founded in 1967, is an independent and registered charity. See https://www.release.org.uk/about.

[47] Eastwood, N., Fox, E., Rosmarin, A. (2016). *A Quiet Revolution: Drug Decriminalisation Across the Globe*. Release, March 2016, p. 7, https://www.release.org.uk/publications/drug-decriminalisation-2016.

[48] Portugal Drug Strategy 1999

Chapter 4 Taking a Gendered Approach

Gender

Gender refers to the roles, behaviours, activities, attributes and opportunities that any society considers appropriate for boys and girls, men and women, and the relationships between people that can reflect the distribution of power within those relationships. An understanding of gender requires an understanding of the complex social processes through which people are defined and linked and how this evolves over time. These processes operate at all levels – societal, institutional and interpersonal – and across all domains, e.g. cultural, economic and social.[49] [50]

The changing role of women

The role of women in Irish society has changed more dramatically in the 20th century, and in particular over the last 3 decades, than in any other period of Irish history, with the majority of these changes attributed to changes in the economic and labour structures of the country.[51] In 2018 the Department of Public Expenditure and Reform produced a report on the Social Impact Assessment of Female Labour Force Participation,[52] with key findings which included that part-time employment is more frequent for females than males, young Irish women (aged 25–29) are more likely to be employed than their European counterparts, and the gap between male and female participation rates has narrowed as the labour market has improved.

The participation of women in the paid workforce has been linked to a change in the role of women more generally in Ireland. However, the extent of those changes and whether they have gone far enough is open to discussion.[53] Women remain under-represented in the political system, and men continue to dominate higher management in many public and private bodies and in the institutional church structure. Though paternity leave was

[49] Manandhar, M., Hawkes, S., Buse, K., Nosrati, E., Magar, V. *Gender, Health and the 2030 Agenda for Sustainable Development*. World Health Organisation, June 2018.
[50] Schiebinger, L, Klinge, I., Paik, H. Y., Sánchez de Madariaga, I., Schraunder, M., and Stefanick, M. (Eds.) (2011-2018. Gendered Innovations in Science, Health & Medicine, Engineering, and Environment (gendered innovations, stanford.edu)
[51] Sheehan, A., Berkery, E., and Lichrou, M. (2017). 'The changing role of women in the Irish society: an overview of the female consumer', *Irish Journal of Management*, 36(3), pp. 162–171, doi: 10.1515/ijm-2017-0017.
[52] Callaghan, N., Ivory, K., Lavelle, O., DEASP Vote October 2018. Female Labour Force Participation Social Impact Assessment, Department of Public Expenditure and Reform.
[53] O'Connor, P. (2000). 'Ireland: A man's world', *The Economic and Social Review*, 31(1), pp. 81–102.

introduced in 2016, women continue to assume the main responsibility for domestic and childcare activities.[54] Additionally, women played and continue to play a leading role as change agents, not only in the family but as community agitators and activists, which is often overlooked. For example, mothers were vocal and visible on the streets of Dublin in the 1970s, concerned at the rise of heroin use and frustrated at the lack of response by government. It was community and family activism that led to a shift in drug policy in the 1980s and 1990s[55] and the subsequent setting up of the CityWide Drug Crisis Campaign in 1995, within which the seeds of the National Family Support Network grew. (NFSN launched as an independent entity in 2000.) Furthermore, it was two mothers who, in the absence of any family support services, set up FASN in 2011,[56]mirroring the development of the NFSN in Dublin.

> *"It is hard because you don't fit into what people expect, they don't know what to make of you and that's fine, it no longer bothers me, the groups are a lifeline and the monthly meetings "P9*

The changing role of men

As women's role has changed so too the role of men is changing in Irish society which is being reflected in health and social policy, e.g. Ireland is the first country in the world to publish a National Men's Health Policy[57] and has been to the forefront internationally in advancing men's health at a research, policy and advocacy level. Underpinning the approach to men's health policy development and implementation has been an explicit focus on gender-specific strategies related to community engagement, capacity building, partnership and sustainability. Implementation of the Men's Health Policy is embedded in Healthy Ireland[58] action plans[59] for each of the Community Health Organisation (CHO) settings

[54] O'Sullivan, S. (2012). 'All changed, changed utterly'? Gender role attitudes and the feminisation of the Irish labour force', *Women's Studies International Forum*, 35(4), pp. 223–232.
[55] Butler, S. (2007). 'Rabbitte revisited: the first report of the ministerial task force on measures to reduce the demand for drugs – ten years on', *Administration*, 55(3), pp. 124–144.
[56]FASN, www.fasn.ie.
[57] Department of Health. (2016). *National Men's Health Action Plan Healthy Ireland – Men HI-M 2017–2021. Working with men in Ireland to achieve optimum health and wellbeing*, https://www.hse.ie/eng/services/publications/healthyirelandmen.pdf.
[58] Department of Health. (2013). *Healthy Ireland: An Improved Framework for Health & Wellbeing 2013–2025*, https://health.gov.ie/wp-content/uploads/2014/03/HealthyIrelandBrochureWA2.pdf.
[59] CHO 1 (HSE). (2018). *Healthy Ireland Implementation Plan 2018–2023*, https://www.hse.ie/eng/about/who/healthwellbeing/healthy-ireland/community-healthcare-organisations/cho-implementation-plans/cho-area1-hi-implementation-plan-2018-2023.pdf.

within which FASN operate, i.e. CHO 1 and CHO 8. Men's health week which is held every year in June is an example of how the National Men's Health Policy is being implemented. In June 2019 the theme is Men's Health Matters with a call to action of Make the Time Take the Time. Research by the Men's Health Forum in 2004 identified that compared to women, men have limited contact with GP's are reluctant users of primary care services and often present late in the course of illness[60].

How men seek support

As regards dealing with stress, there is some evidence that women and men deal with stress in different ways and that men do not seek psychological help in the same ways as women do.[61] Possible explanations for these differences may be related to the fact that men prefer a practical solution focus rather than emotion-focused interventions. The development of the men's sheds movement which started in Australia and was instigated in Ireland by John Evoy is an example of men coming together and supporting each other. The Irish Men's Shed movement has developed as a way of supporting men to address a range of health issues, e.g. men have a shorter life expectancy then women; eight out of ten people who die by suicide are men[62]; men are more likely to die of preventable causes such as heart attacks and strokes; men are more likely to engage in risk-taking behaviours; and men are more likely to experience addiction. There are now over 400 sheds in Ireland and in 2017 a dedicated male health website was set up by the men's shed movement[63].

> *"To the outside world nothing has changed for him, he has stuck with the coaching, the committees and his other meetings of the things he is interested in, that's how he gets through, none of his friends know they don't talk about personal stuff" P22*

Research carried out by Carragher[64] on Men's Sheds in Ireland in 2013 found that they offer a unique hands-on learning experience and a sense of belonging, whilst also facilitating access to health information, not through the form of leaflets but through informal

[60] Men's Health Forum in Ireland 2004
[61] Liddon, L., Kingerlee, R., Barry, J. (2018). 'Gender differences in preferences for psychological treatment, coping strategies and, triggers to help seeking', *British Journal of Psychology*, 57(1), pp. 42–58.
[62] HSE Connecting for Life Ireland's national strategy to reduce Suicide 2015-2020
[63] Mensshed.ie/malehealth-ie
[64] Carragher, L. (2013). Men's Sheds in Ireland: Learning through community contexts, http://menssheds.ie/2014/03/10/mens-sheds-in-ireland-learning-through-community-contexts/.

conversation, exchanging experiences and sharing concerns. Moreover, Carragher concludes that men sharing in this way, though not unique, is not the norm and can possibly be seen as moving beyond traditional notions of masculinity. Overall, however, whilst the role of men is changing, male gender conditioning continues to be still quite rigid with few examples of positive alternative role models for young men.

A gendered approach

A gendered approach to service planning and provision has been recognised as an important factor in a more equitable and effective take-up of services for some time. However, its inclusion as part of service planning and development still has some way to go. A 2012 National Women's Council and HSE document[65] recommends that health service providers and policymakers 'take into account evidence of sex (biology) and gender (social roles) in the context of the broader social determinants of health'.

> *"My husband and I came to a group, it was not really his thing, he is not a talker in that way, he has his way and I have mine, but we are in this together and that's what matters" P18*

An overview of the research[66] shows that gender, though mentioned, is not adequately interrogated or interwoven. The needs of women with addiction issues are beginning to come onto the agenda, but a gender dimension on families who are affected is often overlooked. This is a missed opportunity, as including such an approach to the development of family support services and community development[67] could have a positive impact on the engagement and inclusion of both women and men in services, and could add to the work being done on relationship, social and cultural factors by Orford et al.[68]

[65] HSE/National Women's Council of Ireland. (2012). *Equal but Different: A framework for integrating gender equality in Health Service Executive Policy, Planning and Service Delivery*.
[66] Doblhammer, G. and Gumà, J. (eds). (2018). *A Demographic Perspective on Gender, Family and Health in Europe*, https://link.springer.com/book/10.1007%2F978-3-319-72356-3.
[67] Community Development in Ireland: Policy & Practice Conference Proceedings 21st October 2015, University College Cork Edited by: ISS21 Local and Community Development Working Group.
[68] Orford, J. (2017). 'How does the common core to the harm experienced by affected family members vary by relationship, social and cultural factors?' *Drugs: Education, Prevention and Policy*, 24(1), pp. 9–16.

Service Provision

"I don't know why more don't come to the group, well yes I do, it's because they are scared someone will see them, I can understand that, I was the same, people think there is no problem with drugs here but once you are aware of it, your eyes are open and I can see the kids strung out as I walk about the town, the groups are good but there are too few, no disrespect to anyone but we need more, and other ways too of getting the message out, of holding out a hand" P 19

"This is now a popular tourist area and lots of great work has been done to make the place attractive to tourists which is great, it brings in employment but there are communities that are not part of the plan, they are not involved or engaged in any of the new initiatives, they are the families that need support but you have to start where they are not where you want them to be" P24

The study points to a need for services to expand and utilise different methods and channels to contact and engage with affected families, and to be mindful, without stereotyping, of the role and different ways in which women and men might wish to connect with services, e.g. not all participants in this study wanted to be part of a group for a range of reasons, including not wanting anyone to see them, the distance they would have to travel, and/or not feeling comfortable in a group. FASN has recruited, trained, supported and retained a group of volunteer peers, women and men who facilitate family support groups. This group meets with a trained psychotherapist on a monthly basis for professional support and supervision. The training of facilitators and the professional support and supervision provided is an important and valued aspect of the model of peer led services that FASN has developed.

Chapter 5 Methodology

The aims of this study were wide ranging:

- to give families a voice and recognition that they should be seen as part of a whole family unit
- to identify and understand the ways families affected by substance misuse seek support
- to improve awareness of how substance misuse affects families
- to guide the provision of services within FASN
- to help to change and/or influence the regional and national strategies on family support.

A qualitative approach was considered most appropriate for several reasons. First, a priority of FASN was that the study would provide a platform for the voice of families to be heard, and a qualitative approach enables a nuanced way for stories to be told, layering in the complexity and contradictions that are part of the lives of participants.[69] Second, since this is the first such study to be undertaken by FASN, a qualitative approach is an effective method to build on and add to the growing body of research on how families seek support and are affected by addiction.[70] [71] [72] [73] Third, this approach lends itself to including families as 'experts with experience' to inform policy and guide the design and delivery of services, which is a relatively new phenomenon in the field of substance misuse, though perhaps slightly more common in other fields of health and social policy, e.g. the mental health [74]

[69] Tolley, E. et al. (2016). *Qualitative Methods in Public Health: A Field Guide for Applied Research*. San Francisco, CA: Jossey-Bass.
[70] Orford, J., Velleman, R., Copello, A., Templeton, L., and Ibanga, A. (2010). 'The experiences of affected family members: a summary of two decades of qualitative research', *Drugs: Education, Prevention and Policy*, 17(s1), pp. 44–62.
[71] Murphy, E. (2014). Exploring the Role of the Traveller Family in Supporting Travellers Experiencing Addiction. Thesis submitted in partial fulfilment of the requirements for the Degree of Masters in Public Health, University College Cork.
[72] Do Governments recognise the needs of affected family members? First indications from an AFINet project by Jim Orford on behalf of AFINet project participants, 1st International Conference, Newcastle upon Tyne, UK, Session 1, Friday 9 November 2018.
[73] Gruber, K.J. and Floyd-Taylor, M. (2006). 'A Family Perspective for Substance Abuse: Implications from the Literature', *Journal of Social Work Practice in the Addictions*, 6(1/2), pp. 1–29, doi: 10.1300/J160v06n01_01.
[74] Commission on the Future of Health and Social Care in England. (2014). *A new settlement for health and social care: Final report*. https://www.kingsfund.org.uk/publications/new-settlement-health-and-social-care.

The eligibility criteria for family members to participate in the study included the following:

- Participants were adults 18+.
- Participants had one or more members of their family dealing with substance misuse.
- Participants had sought help and/or support outside of their family.

Study participants

A purposive and snowball sampling method was used to recruit both family and agency participants. The adult family participants were initially recruited through FASN, but snowballing enabled a wider reach-out to families, which added a valuable dimension to the study.

The agency participants were not all directly involved in the provision of services within the family support and/or substance misuse field. We know from other studies that families affected by addiction seek support in a range of ways, formally and informally.[75] Participant agencies were service providers and/or had responsibility for policy, planning and/or commissioning of services and were operating across the national, regional and/or local landscape. It was important to include a national, regional and local perspective in terms of policy, planning and service delivery. Policy may be set nationally, but how it is implemented regionally and locally is what families experience day to day.

The experiences and insights of agencies, working in allied fields (e.g. Family Resource Centre[76] and/or housing provision) are important to highlight. Though they provide services to families around other issues, the impact of substance misuse on their clients oftentimes becomes a pressing and critical issue, albeit one that is mainly hidden. There was little or no knowledge of family support and/or FASN on the part of these agencies.

Moreover, family participants had not heard of family support and/or FASN prior to being signposted to FASN through a third party. This may be explained first by the fact that FASN

[75] Orford, J., Velleman, R., Copello, A., Templeton, L., and Ibanga, A. (2010). 'The experiences of affected family members: a summary of two decades of qualitative research', *Drugs: Education, Prevention and Policy*, 17(s1), pp. 44–62.

[76] The FRC programme is Ireland's largest family support programme, delivering universal services to families in disadvantaged areas across the country based on a life-cycle approach. The aim of the FRC programme is to combat disadvantage and improve the functioning of the family unit.

is a small voluntary charity with very limited financial resources and is almost totally reliant on peers and volunteers, and second by the fact that the North East is a large region with a population in excess of 400,000.

This study is based on 25 participants: 14 adult family members and 11 agencies. There is some confidence in the generalisability of the concepts and issues that emerged in the study, as they echo and support findings in the growing body of research on how families seek support and are affected by addiction.[77] [78]

Semi-structured in-depth interviews were conducted, and three focus groups were facilitated, two with adult family members and one focus group with a housing agency. With informed consent, interviews and focus groups were digitally recorded and transcribed. There were some instances where participants did not wish to be recorded but were comfortable with notes being taken. The study was carried out in keeping with the Sociological Association of Ireland Ethical Guidelines. All participants were provided with written information on the study, including the system in place for collection, storage and disposal of data and the anonymity, privacy and confidentiality of participants. The face-to-face interviews and focus groups lasted between 40 and 70 minutes. At the outset of both, the purpose of the study was reiterated.

The systems in place for data collection and the storage and disposal of information were also explained, along with the ways the study would ensure the anonymity, privacy and confidentiality of participants. This information was both read and orally communicated. Participants were assured that they could stop, pause or withdraw from the process at any time. Consent forms were read over with all participants prior to them being signed. At the end of the interview and/or focus group, participants were asked for any feedback on the process and contact details were provided to allow them to follow up in any way and /or speak to a counsellor[79] should they wish to do so.

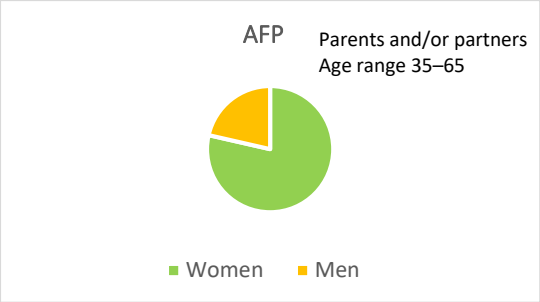
[77] McDonagh, D., Connolly, N., and Devaney, C. (2018). '"Bury Don't Discuss": The Help-Seeking Behaviour of Family Members Affected by Substance-use Disorders', *Child Care in Practice*, doi: 10.1080/13575279.2018.1448258.
[78] European Monitoring Centre for Drugs and Drug Addiction. (2017). *Health and social responses to drug problems: a European guide*. Luxembourg: Publications Office of the European Union.

[79] Appendices ii, iii, iv, v.

Participants

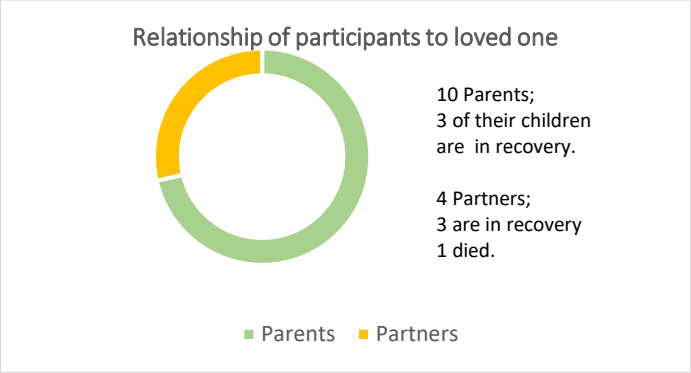
Families

Adult Family Participants (AFP) N = 14, Women 11, men 3 **11** **3**



Ten participants were parents with children aged between 18 and 30, 3 of whom were in recovery. Four participants were partners, three of whom were in recovery while one had died. The substances misused included alcohol, cannabis, heroin, methadone, benzodiazepines and there was also polydrug use. Participants lived in both urban and rural settings in the North East Region.

Relationship of participants to their loved one: N = 14 Parents 10, Partners 4

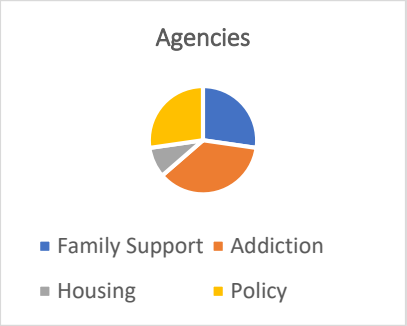


Agency Participants

The agencies who participated were working within and across national, regional and local settings. For example, the HSE, CityWide Drug Crisis Campaign, Ana Liffey Drug Project (ALDP) and National Family Support Network operate nationally; the North East Regional Drug Task Force, Family Addiction Support Network and North and East Housing Association

are regional operations; and the remaining agencies work either county wide or more locally within the North East Region.

Agencies N = 11, 10 NGO Sector, 1 Statutory Sector



Service Providers

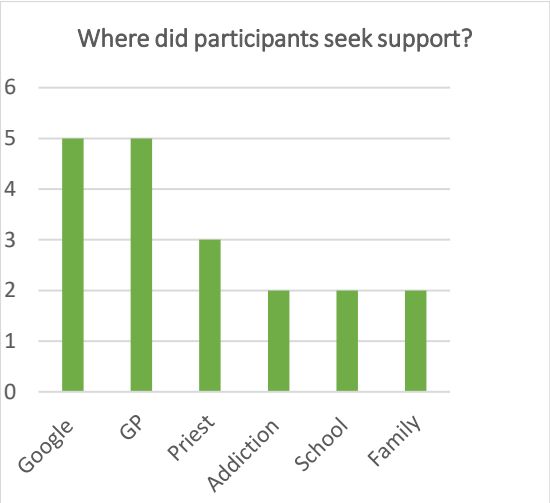
FASN
NFSN
Trim FRC
MCDAR
NERDTF
N&EHA
Turas Counselling
CDA
ALDP
CityWide Drug Crisis Campaign
HSE

The data was collected, collated and analysed using thematic analysis,[80] [81]a process whereby one becomes immersed and familiar with the data and then begins to identify, create, refine and establish meaningful patterns and themes to extract findings.[82]

[80] Maguire, M. and Delahunt, B. (2017). 'Doing a Thematic Analysis: A Practical, Step-by-Step Guide for Learning and Teaching Scholars', *All Ireland Journal of Teaching and Learning in Higher Education* (AISHE-J), 8(3), pp. 33510–33514, http://ojs.aishe.org/index.php/aishe-j/article/viewFile/335/553.
[81] Braun, V., and Clarke, V. (2006). 'Using thematic analysis in psychology', *Qualitative Research in Psychology*, 3(2), pp. 77–101.
[82] Blandford, A., Furniss, D., and Makri, S. (2016). *Qualitative HCI Research: Going Behind the Scenes.* San Rafael, CA: Morgan & Claypool Publishers.

Chapter 6 Findings

Where did participants seek support?



These were the main ways participants sought support; they may have reached out to more than one of these segments concurrently. Participants who used Google spoke about wanting factual, independent information which they found very difficult to source elsewhere.

Seeking support – information

Participants in the study did not know where to seek information and/or support but appear to have stumbled about for both. It was interesting and valuable to probe not only how and where participants sought support but what prompted them to initially seek support, e.g. the level of awareness they had of their loved one's substance misuse, how they became aware of what was happening with their loved one, their psychological and physical state, the physical and psychological state of their loved one, the impact on the rest of the family, and whether they were looking for support for themselves or their loved one. Most participants started out looking for support for their loved one. It is of note that once the threshold of reaching out to seek support was breached, shame, blame, guilt and stigma came sharply into focus.

"I came across FASN by accident, I was looking for something, really I didn't know what, I just wanted it to stop, I wanted to sort it out" p13

Prompts to seek support

Family participants found support in a range of ways that could be described as ad hoc and informal; 10 of the 14 family participants were looking for support for their loved one, and so initially at least their reaching out was not for themselves. This is a recurring theme in the literature.[83] [84] [85]

Five participants described their reaching out as wanting to find 'factual information' and they may have tried a number of ways to find information. It is important also to note that participants may have spoken to a range of people, e.g. GP and a priest, so the ways that participants sought support are not mutually exclusive. In their search of the web, participants entered the signs they had noticed in their loved one and in some cases that search took them to signs of substance misuse. The experience of asking their GP was mixed, helpful and frustrating. In some instances, the GP did not know about different substances and instead offered them a prescription for stress and anxiety.

Before discussing in more detail, the particular pathways participants used, it is perhaps interesting to note the interplay in what was driving the initial reach-out. For example, three participants had a 'general unease' about their loved one and they used the web to look up signs and symptoms, which in turn signposted them to drug use. This was followed for two participants by panic, resulting in them speaking and/or confronting their loved one. A period of denial and minimising then ensued, hoping 'it' would go away. Five participants spoke with their GP, three spoke with a priest, two with the school, which had requested a meeting with the parent due to concerns around the behaviour of their respective children (aged 14 and 15), and two were involved in a family intervention.

[83] McDonagh, D., Connolly, N., and Devaney, C. (2018). '"Bury Don't Discuss": The Help-Seeking Behaviour of Family Members Affected by Substance-use Disorders', *Child Care in Practice*, doi: 10.1080/13575279.2018.1448258.
[84] Devaney, E. (2017). 'The emergence of the affected adult family member in drug policy discourse: A Foucauldian perspective', *Drugs: Education, Prevention and Policy*, 24(4), pp. 359–367, doi: 10.1080/09687637.2017.1340433.
[85] Orford, J., Velleman, R., Copello, A., Templeton, L., and Ibanga, A. (2010). 'The experiences of affected family members: A summary of two decades of qualitative research', *Drugs: Education, Prevention and Policy*, 17(s1), pp. 44–62.

Impact on families

Families spoke about the psychological and physical ways they have been affected, e.g. stress, anxiety, fear, not sleeping, feeling sick, not being able to eat, wanting to run away, anger, resentment, frustration, not being able to think of anything else, blaming themselves, feeling a failure, guilt and shame. Participants were not aware and/or able to acknowledge these feelings at first. It was not until they had found support, e.g. contact with FASN, that they began to understand and allow themselves to see what was going on.

Fear and Intimidation

Families also spoke about being exposed to criminal activity, fear and intimidation; taking out loans; getting into debt; being threatened by drug dealers; not being able to sleep in their own house because of threats and intimidation; having pipe bombs under the car; being threatened with petrol bombs; the threats by their loved one; having to take out protection and barring orders; the impact on siblings, on other members of their family, on their extended family, neighbours, village and local community; and the link to shame, guilt and stigma. However, there was considerable frustration at what was seen as sensationalist media reporting on drug gangs and gangland feuds, notwithstanding that this is a phenomenon, but participants were keen to correct and balance this reporting with their experience of intimidation perpetrated by local drug dealers who may be drug users trying to get the money for their own drugs. Participants in the study were aware of and had experience of using the Drug Related Intimidation Reporting Programme. This programme was seen as very helpful, the confidential nature of the programme was trusted and valued, and the flexibility around venue and time of meetings was appreciated. The limits to the programme and the reality of what could and could not be provided were also understood.

"I couldn't eat or sleep, we couldn't sleep in the house, protecting yourself because of your child, how frightened he was, how scared we were, the threats from them, the debts, paying off, trying to distance yourself physically, mentally, emotionally, I wanted to run away, I did resent him, yes, I love him, but I just wanted it to stop" P18

Mental health

A variety of studies across Europe have estimated that between a third and half of patients being treated for substance abuse have an independent co-occurring psychiatric illness.[86] These findings have been replicated in studies that have focused on cohorts of Irish patients.[87] Psychiatric illnesses found to co-occur with substance abuse problems range from anxiety or depressive disorders to Attention Deficit Hyperactivity Disorder (ADHD), paranoia, schizophrenia and other mood or personality disorders. It is possible that a variety of issues lead to comorbidity as described: drug use may cause users to experience the symptoms of a psychiatric illness; drug use may lead to the triggering of an underlying psychiatric illness; sufferers of psychiatric illnesses may use drugs to alleviate the symptoms of such illnesses; and both problem substance use and psychiatric illnesses may be triggered by common factors such as environmental stressors or genetic predispositions.

"It is still so hard to find a service that will listen and look at the addiction and the mental health issues, he would stay in his room for days on end, he tried to throw himself out of the window, he is trying so hard, we are trying so hard but it just goes on, it began I think when he was 7 or 8 to be honest, looking back, we have been taking him to services since he went into secondary" P 6

The impact of addiction on participants

There is widespread recognition that there are insufficient specialist treatment services for family members, that too few addiction services offer information and/or support for

[86] Schulte, S.J. et al. (2008). 'Treatment approaches for dual diagnosis clients in England', *Drug and Alcohol Review*, 27(6), pp. 650–658; Wynn, R., Landheim, A., and Hoxmark, E. (2013). 'Which factors influence psychiatric diagnosing in substance abuse treatment?' *International Journal of Mental Health Systems*, 7(1), doi: 10.1186/1752-44587-17; Watkins, K.E. et al. (2004). 'Prevalence and Characteristics of Clients with Co-Occurring Disorders in Outpatient Substance Abuse Treatment', *American Journal of Drug and Alcohol Abuse*, 30(4), pp. 749–764.

[87] Dixit, A. and Payne, A. (2011). 'Prevalence of substance misuse comorbidity in an Irish university training hospital', *Irish Journal of Psychological Medicine*, 28(4), pp. 201–204; James, P.D., Smyth, B.P., and Apantaku-Olajide, T. (2013). 'Substance use and psychiatric disorders in Irish adolescents: a cross-sectional study of patients attending substance abuse treatment service', *Mental Health and Substance Abuse*, 6(2), pp. 124–132.

families and that workers in services may have limited training and knowledge to work with family members.[88] [89]

Peer-led national family support and advocacy organisations are available in Ireland and few other countries, e.g. Adfam and Scottish Families Affected by Alcohol and Drugs in the United Kingdom. Bereavement support is often an important component of the work of these organisations, and they may also be involved in campaigning for or promoting naloxone distribution programmes.

"I've learned a lot and I want to give back, I go about my jobs every day, I see what is going on, I see how we close our eyes and hope it will go away, I was like that, I still have bad days, of course I do, days I can't stop thinking, what if this didn't happen or that, it's a spiral once you start thinking like that and it does no good but yes sometimes I can't help it, for a while I find myself going back there" P20

[88] European Monitoring Centre for Drugs and Drug Addiction. (2018). *European Drug Report 2018: Trends and Developments*. Luxembourg: Publications Office of the European Union.
[89] European Monitoring Centre for Drugs and Drug Addiction. (2017). *Health and social responses to drug problems: a European guide*. Luxembourg: Publications Office of the European Union.

Chapter 7 The North East Region

Context

The counties of Cavan, Louth, Meath and Monaghan are a mix of rural and urban landscapes with a unique complexity of political, social and economic factors and a border with Northern Ireland running for 499 km, all of which make for a challenging environment in which to plan and deliver quality and effective health services, moreover, the boundaries between health and local government structures are not coterminous. Two HSE CHOs have responsibility for the delivery of primary and community health services, CHO 1 covers 5 counties: Cavan, Donegal, Leitrim, Monaghan and Sligo with CHO 8 having responsibility for Louth, Meath, Laois, Offaly, Westmeath, Longford and a small part of south-east Cavan.[90]

Local government structures introduced as part of the Local Government Reform Act in 2014 established Local Community Development Committees (LCDCs) to bring a more cohesive and integrated approach to local and community planning and development. The Social Inclusion and Community Activation Programme (SICAP) 2018–2022 provides funding to tackle poverty and social exclusion through local engagement and partnerships between disadvantaged individuals, community organisations and public sector agencies.

Rural disadvantage is a characteristic of the North East Region. Outside of the main commuter areas, public transport and accessibility are significant issues.[91] Some family participants in this study drove over an hour to facilitate and/or attend family support groups. There are acknowledged gaps in the provision of health services, e.g. there are difficulties in recruiting sufficient GPs to serve the population and there are gaps in the overall provision of adequate primary care[92] and substance misuse, mental health, disability and family support services.

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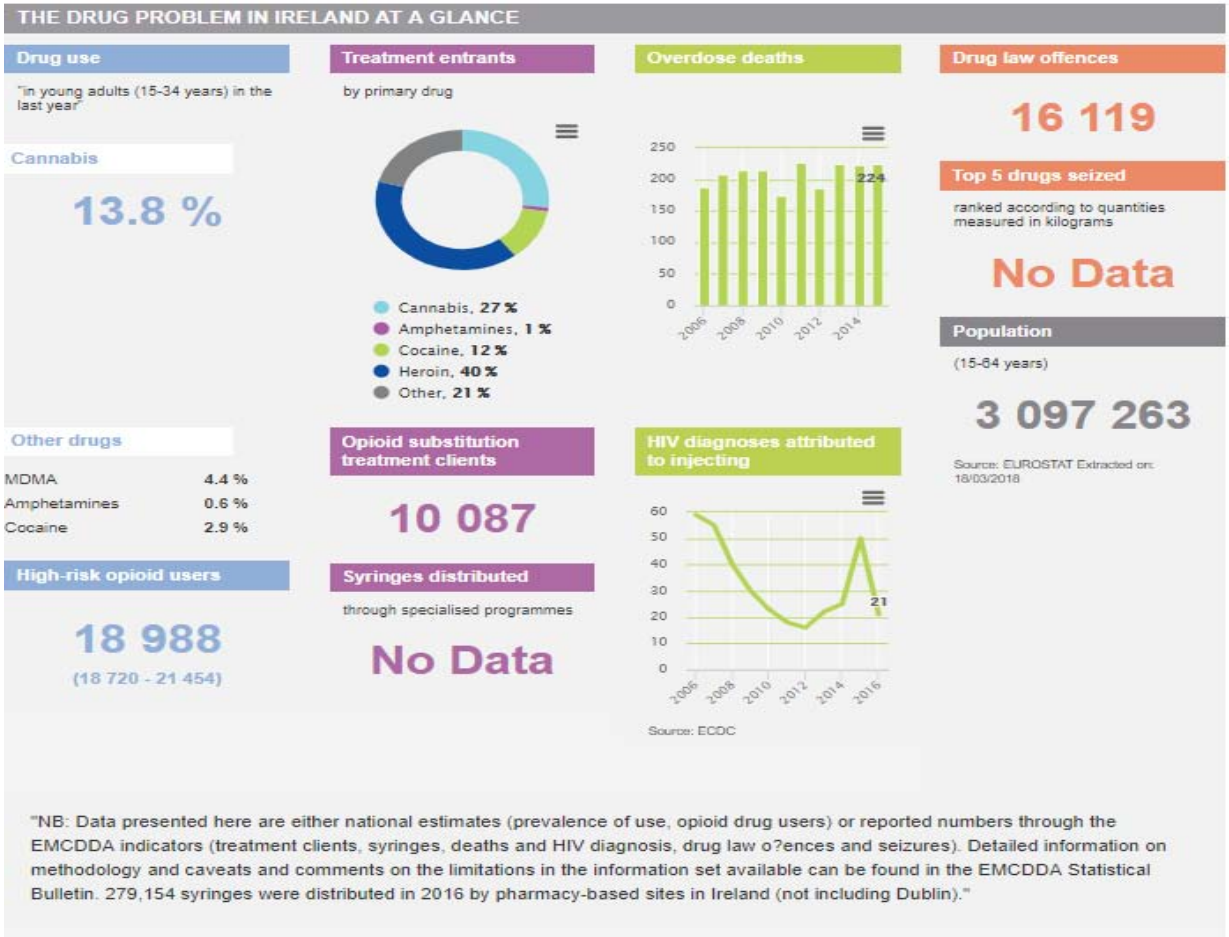
[90] Appendix iii.

[91] Meath County Council. (n.d.). *County Meath Local Economic and Community Plan 2016–2021*, http://www.meath.ie/Community/CommunityDevelopment/LocalCommunityDevelopmentCommittee/LocalEconomicandCommunityPlan/File,63724,en.pdf.

[92] Cavan Monaghan Mental Health Service. (n.d.). *Connection for Life Cavan Monaghan Suicide Prevention Action Plan 2017–2020*, https://www.hse.ie/eng/services/list/4/mental-health-services/connecting-for-life/publications/connecting-for-life-cavan-monaghan.pdf.

Substance misuse Ireland overview

In June 2018, the EMCDDA produced a 30-country report on the trends and developments of drug use in Europe providing a top-level overview of the drug phenomenon covering drug supply, use and public health problems as well as drug policy and responses[93]. The statistical data reported relates to 2016 (or most recent year) and are provided to the EMCDDA by the Health Research Board, (HRB). The HRB is a statutory body with a remit to improve health through research and information and is responsible for promoting, commissioning and conducting medical, epidemiological and health services research in Ireland. The country report for Ireland showed that in the past year use of any illicit drugs has increased over the past decade, with particular increases in ecstasy and cannabis use amongst young people aged 16-34 years. Amongst both adults and young people, cannabis is the most commonly used illicit drug.



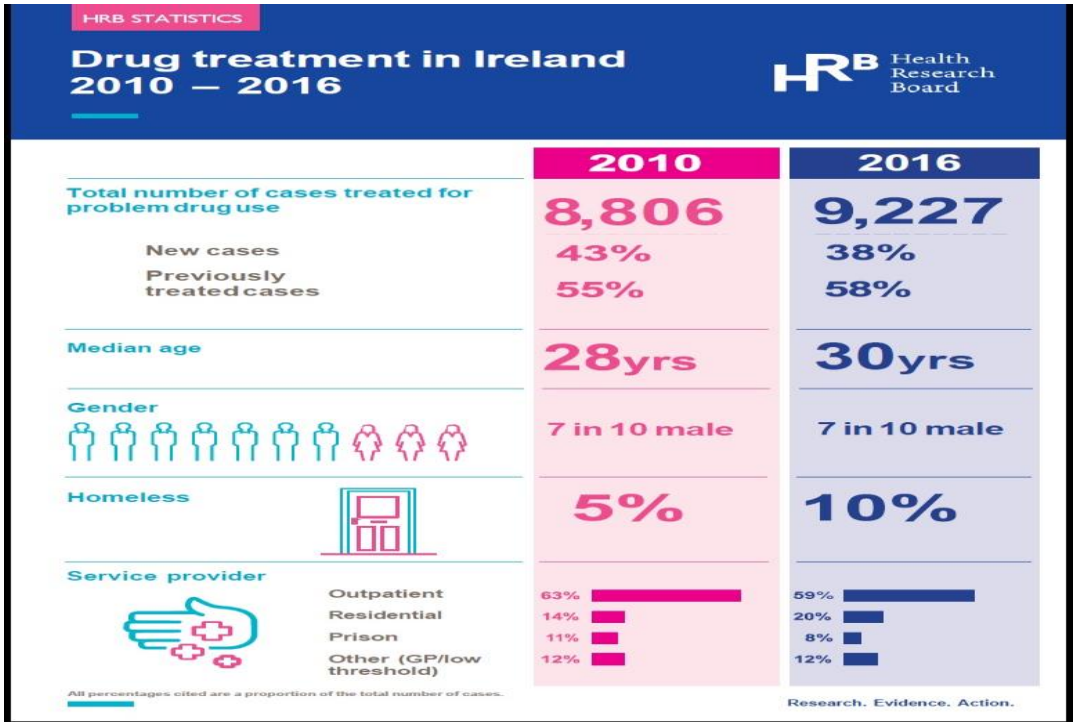
[93] EMCDDA Ireland Drugs Report 2018

Substance misuse Ireland Treatment

The National Drug Treatment Reporting System (NTDRS) is an epidemiological database on treated problem drug and alcohol use in Ireland. Compliance with the NDTRS requires that a form be completed for each new client coming for first treatment and each previously treated client returning to treatment for problem drug or alcohol use in a calendar year.

The NDTRS records the number of cases assessed for treatment for problem alcohol and drug use in Ireland. It includes treatment by statutory and non-statutory services, including residential centres, community-based addiction services, general practices and prison services. For the purpose of the NDTRS, treatment is broadly defined as 'any activity which aims to ameliorate the psychological, medical or social state of individuals who seek help for their substance misuse problems'. Clients who attend needle-exchange services are not included in this reporting system. It is important to note that each case refers to an episode of treatment, not an individual. It also does not include those treated in psychiatric hospitals.

The NTDRS produces reports on a national basis.



National Drug Treatment Reporting System

This study interrogated the 2016 reports from the NDTRS to extract data for the counties of Cavan, Louth, Meath and Monaghan. The following table reports on treatment for both alcohol and polydrug use in 2016, the most recent data available. The table below shows that total treatment numbers for the 4 counties was 1015, those living with family have been highlighted in yellow.

Change my selection criteria.

Year : 2016																			
Gender	Male, Female																		
Ages	Under 18, 18 to 24 years, 25 to 34 years, 35 to 44 years, 45 to 64 years, 65 years or over, Unknown																		
Treatment Statuses	All (combined)																		
Report	Main Problem Drug																		
	All (combined)																		Totals
Living with	Alone		Parents/family		Friends		Partner (alone)		Partner & child(ren)		Alone with child(ren)		Other		Foster care		Not known		
Polysubstance	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	
County																			
Cavan	21	7	37	17	0	~	15	8	23	8	7	0	9	15	0	0	~	~	175
Louth	40	24	75	95	~	~	21	5	30	22	16	10	35	41	~	~	~	~	425
Meath	28	6	76	47	~	5	18	8	40	7	5	~	17	15	0	0	0	0	277
Monaghan	28	6	32	12	~	0	10	0	27	~	~	~	~	~	~	~	0	~	138
Totals	117	43	220	171	6	10	64	21	120	40	32	15	65	73	~	~	5	6	1015

North East Region Demographics

Meath

Meath is a young county; a total of 29 per cent of the population in Meath is under 18 years of age, the highest rate in the country. Disadvantage is an issue across the county and has grown in recent years. There are particular concentrations of disadvantage, e.g. Navan has the highest rate of lone parent families in the county at 23.6 per cent, followed by Kells at 21.1 per cent. Approximately 65 per cent of the Meath Traveller population lives in the Navan Municipal District. Rural disadvantage is a characteristic of the county and outside of the main commuter areas, public transport is an issue.

Substance Misuse Services in Meath

The North East Regional Task Force is located in Navan. Al Anon and Narcotics Anon hold meetings in the county. There are three voluntary organisations providing services and four services provided by the HSE.[94]

Louth

Louth is the smallest of Ireland's 32 counties and is the most densely populated county in Ireland outside of Dublin. The most populated areas in the county are the towns of Drogheda and Dundalk. Louth is the 13th most disadvantaged local authority in the State, with small areas around Drogheda, Dundalk and Ardee categorised as being very disadvantaged. According to the census, in 2016 there were 772 Travellers living in Louth, or 0.6 per cent of the Louth population. In 2016, 89 per cent (113,077) of the population in Louth were Irish citizens and 5.7 per cent of the population were non-Irish nationals. Rural disadvantage is a characteristic of the county, as is poor public transport outside of the main towns.

Substance Misuse Services in Louth

Alcoholics Anonymous and Narcotics Anonymous host meetings in the county. There are five voluntary organisations providing services and two services are provided by the HSE.

[94] www.drugs.ie.

Cavan

Of a total population of 76,176 in Cavan in April 2016, 30.5 per cent (23,258 persons) lived in urban areas, with 69.5 per cent (52,918 persons) living in rural areas. This is the reverse of the national picture, where 62.7 per cent lived in urban areas and 37.3 per cent in rural areas. Cavan town, with 10,914 persons, was the largest town in the county. The majority of people (all ages) in Co. Cavan are single (52 per cent), while 39 per cent are married (including same-sex civil partnership). In terms of ethnicity, the population is 83 per cent White Irish, while 'Other White' people make up 10 per cent of the population. There are 1073 Asian/Asian Irish and 831 Black/Black Irish in Cavan. The census records 477 people from the Traveller community living in Cavan.

Substance Misuse Services in Cavan

Alcoholics Anonymous, Narcotics Anonymous and Al Anon hold meetings in the county. There is one voluntary organisation operating in Cavan and there are two HSE services.

Monaghan

According to Census 2016, the population of Co. Monaghan was 61,386 in April 2016, an increase of 1.5 per cent since the last census in 2011, and 4 per cent of the population is Lithuanian by nationality. A population of 276 Irish Travellers was enumerated in 2016 in Co. Monaghan, an increase of 10.8 per cent since 2011. Less than 30 per cent of the population lives in an urban community; nationally over 60 per cent of the population lives in an urban community.

Substance Misuse Services in Monaghan

Alcoholics Anonymous, Narcotics Anonymous and Al Anon hold meetings in the county. There is one voluntary organisation providing services and two HSE services.[95]

[95] www.drugs.ie.

Conclusion

The interface between changes in social policy and families has a chequered and long history in Ireland. This study is the first to look at this interface within the context of adult family members affected by substance misuse in the North East Region of Ireland.

Driven by the narrative of families, valued as "experts by experience", the findings are underpinned by highlighting the role of women as change agents, not only in the family but as community agitators and activists, who, in the absence of any family support services, set up the Family Addiction Support Network. This emergence of the dynamics of gender is, we believe, an important finding, one that is largely absent in the research literature to date and adds a much-needed dimension to the discourse on the changing nature of family and family support in the field of substance misuse. Other key findings are the potency of family support and more specifically the services provided by FASN notwithstanding the present limitations on FASN. The particular difficulties of trying to navigate through an arc of shock, stigma and shame towards support and recovery in this rural and urban border landscape are interwoven with the very real difficulties of finding and accessing services alongside frustrations at the exclusion of families, the deficit of services and the perceived limited "health" approach to substance misuse. On a wider level, support for a shift in policy towards decriminalisation surfaced. A key backdrop to the study is the National Strategy, Reducing Harm, Supporting Recovery which for the first-time included families as service users in their own right.

The goals in the National Strategy strongly resonated with participants in this study but they would like to see them being implemented more effectively and widely in the North East Region, i.e. that resources are found to expand services, that a health led approach becomes the norm which includes responding to dual diagnosis, that families are included in the recovery of their loved one as appropriate as well as being supported in their own recovery, that a policy of decriminalisation is introduced and that services are supported to work to quality standards which are publicised.

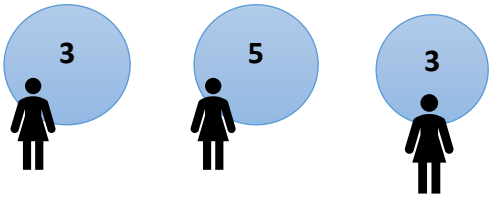
Families want to be involved, their lived experience is invaluable, and they have much to contribute to the development and improvement of services as "experts with experience".

Appendix i

Study Information

Participants

3 Focus Groups – 2 with adult family members; 1 with service provider

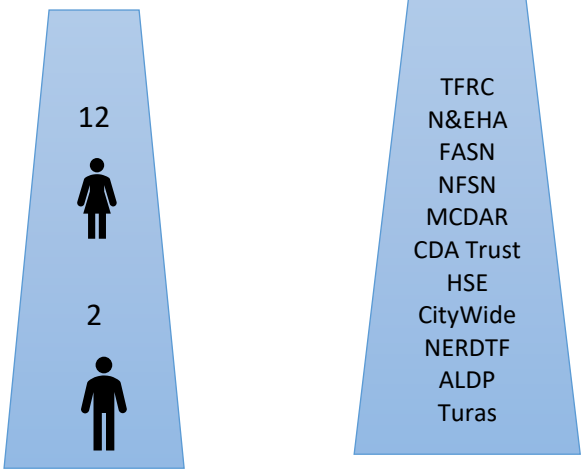


3 women 5 women 3 women

Interviews

25 Participants

14 Adult Family Members 11 Agencies

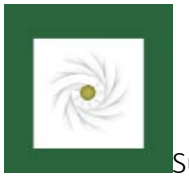


Age group 30–65
Living in North East Region

Some agencies may have both national, regional and local remits, e.g. HSE

TFRC Trim Family Resource Centre
N&EHA North and East Housing Association
FASN Family Addiction Support Network
NFSN National Family Support Network
MCDAR Meath Community Drug Alcohol Response
CDA Trust Cavan Drug Alcohol Service
HSE Health Services Executive
CityWide CityWide Drug Awareness Campaign
NERDTF North East Regional Drug Task Force
ALDP Ana Liffey Drug Project
Turas Community Based Addiction Service

Research Study Information for participants


Súil Eile Consultancy

Family Addiction Support Network

A qualitative research study on the needs of adult family members affected by substance misuse in the North East region (Cavan, Louth, Meath & Monaghan) and their experience of accessing support services.

Súil Eile works to the following principles in conducting this study

- Participants are treated equally and with respect
- Participants safety and wellbeing is safeguarded at all times
- We have a Duty of Care to participants
- We ensure we have informed consent
- Participants' privacy is respected

Compliance with Data Protection Legislation, Data Collection, Storage, Retention and Disposal

Súil Eile will:

Obtain and process personal data fairly
Keep it only for the purposes of the study
Process it only in ways compatible with the purposes for which it was initially volunteered
Keep it safe and secure
Keep it accurate and up to date
Ensure it is adequate, relevant and not excessive
Retain it no longer than is necessary for this study.

Security of Data
Manual data is kept locked and secure.
Computer data is kept secure and password protected; it is backed up and is restricted to one computer and no mobile devices.

Confidentiality
All information provided will be treated confidentially and will not be attributed individually. The only limit to confidentiality is where there is a strong belief that the participant or a third party is in immediate danger of serious harm.

Research Study Conduct of interviews with Participants

At the outset of the interview with the participant/s, information on the study is provided in written format and verbally, the participant is asked if they understand the purpose of the study, information on confidentiality is provided and anonymity for participants is explained.

Confirmation is elicited that participants are contributing voluntarily.

It is explained that the interview will be recorded and that participants may stop/withdraw and/or pause the interview at any time.

A consent form is read over with the participant which they are asked to sign.

The participant is asked if they have any questions.

At the end of the interview, the participant is asked if they have anything else to add, any comments to make, how they found the process and if they have any questions.

Participants are thanked and contact details for Súil Eile are provided for any follow-up.

If English is not the first language of participants, arrangements may be made for a trained interpreter to be present.

Duty of Care

Súil Eile is aware of and attuned to our duty of care for participants. We understand that issues which participants may discuss during the focus group and/or interview could be upsetting; therefore, access to support and/or a counsellor can be arranged.

info.suileile@gmail.com ☎0861025335

Family Addiction Support Network, Lios Dubh, Armagh Road, Dundalk, Co. Louth.

A qualitative research study into the needs of adult family members in the North East Region (Cavan, Louth, Meath & Monaghan) affected by substance misuse and their experience of accessing support services.

Could you help us?

We want to meet with adult family members affected by substance misuse to learn about your needs, hear about your experience of support services and find out how you think services could be improved.

We are arranging confidential interviews & focus groups where adult family members can speak with us in a safe space to share their experiences, views and insights.

All information provided is treated confidentially.

The only limit to confidentiality is where there is a strong belief that the participant or a third party is in immediate danger of serious harm.

This is part of an independent study that has been commissioned by Family Addiction Support Network (FASN) and is being carried out by Súil Eile Consultancy

The results will contribute to the implementation of the National Drugs Strategy 'Reducing Harm, Supporting Recovery 2017-2025' Action 2.1.17 to further strengthen services to support families affected by substance misuse and Action 4.2.44 to promote the participation of service users and their families including those in recovery in the design, planning and development of services and policies.

Follow-up support is available.

Thank you for your participation.

If you would like to participate and/or want further information, please contact Alice on 0861025335 or email info.suileile@gmail.com

How Súil Eile conducts focus groups and/or interviews with Participants

We will begin by providing information on the study in writing and we will also talk through the information with participants. We will ask participants if they understand the purpose of the study and we will provide information on confidentiality and anonymity.

Confirmation is elicited that participants are contributing voluntarily.

It is explained that the focus group and/or interview will be recorded and that participants may stop/withdraw and/or pause the process at any time.

A consent form is read over with the participant which they are asked to sign.

The participant is asked if they have any questions.

At the end of the focus group and/or interview the participant is asked if they have anything else to add, any comments to make, how they found the process and if they have any questions. Participants are thanked and contact details for Súil Eile are provided for any follow-up.

If English is not the first language of participants, arrangements may be made for a trained interpreter to be present.

Duty of Care

Súil Eile is aware of and attuned to the duty of care for participants. We understand that issues which participants may discuss during the focus group and/or interview could be upsetting; therefore, FASN will provide follow-up support to participants if they so wish.

info.suileile@gmail.com ☎0861025335

A qualitative research study into the needs of adult family members in the North East Region (Cavan, Louth, Meath & Monaghan) affected by substance misuse and their experience of accessing support services.

Consent Form for Participants

I ……

have been provided with information on this study,

I understand the information that has been provided to me.

I have been given the opportunity to ask questions about the study.

Confidentiality has been explained to me and I understand that no information contained in the study will be attributed to me personally.

I understand that I can ask for this interview to be stopped at any time, that I can ask for a break at any time and/or I can decide to withdraw from this interview completely.

I am participating in the study on a voluntary basis.

Signed…… Date…….

The only limit to confidentiality is where there is a strong belief that the participant or a third party is in immediate danger of serious harm.

Focus Group/Interview Themes

Can I ask you to think back to when you first became aware that addiction was an issue in your family?

How did you know? (who was the family member?

What was your reaction?

Did you talk to anyone?

How did that go?

What helped at this time?

What were you looking for?

Did you approach any services?

Which services? How did you make contact?

How did you know about them?

When did you approach services? (how long after knowing that addiction was an issue)

What did you expect? What did you need?

FASN/Family Support Services?

How did you hear of FASN and/or FSS? What Family Support Services have you used,

How did you hear about them?

Your first contact with FSS – how was that made, did you phone, call in, email,

Had you heard of family support services before?

Did you have any idea what they might provide?

How was that initial contact for you?

What does support mean to you?

How could services be improved?

How?

How are things for you now?

Is there anything we can help with?

Appendix ii

Department of the Taoiseach
26th February 2019

Constitution of Ireland Amending Acts

	Short Title	Dates of Signature
	First Amendment of the Constitution Act, 1939 [Extended to conflicts in which the State is not a participant the provision for a state of emergency to secure the public safety and preservation of the State in time of war or armed rebellion.]	2 September, 1939
	Second Amendment of the Constitution Act, 1941 [An omnibus proposal, covering a range of disparate Articles, aimed at tidying up the Constitution in the light of experience since its enactment.]	30 May, 1941
	Third Amendment of the Constitution Act, 1972 [Allowed the State to become a member of the European Communities.]	8 June, 1972
	Fourth Amendment of the Constitution Act, 1972 [Reduced the minimum voting age at Dáil and Presidential elections and referendums from 21 years to 18 years.]	5 January, 1973
	Fifth Amendment of the Constitution Act, 1972 [Removed from the Constitution the special position of the Catholic Church and the recognition of other named religious denominations.]	5 January, 1973
	Sixth Amendment of the Constitution (Adoption) Act, 1979 [Ensured that adoption orders made by the Adoption Board could not be declared invalid because they were not made by a court.]	3 August, 1979
	Seventh Amendment of the Constitution (Election of Members of Seanad Éireann by Institutions of Higher Education) Act, 1979 [Provided for the election of members of Seanad Éireann by universities and other institutions of higher education.]	3 August, 1979

	Eighth Amendment of the Constitution Act, 1983 [Acknowledged the right to life of the unborn, with due regard to the equal right to life of the mother.]	7 October, 1983
	Ninth Amendment of the Constitution Act, 1984 [Extended the right to vote at Dáil elections to certain non-Irish nationals.]	2 August, 1984
	Tenth Amendment of the Constitution Act, 1987 [Allowed the State to ratify the Single European Act.]	22 June, 1987
	Eleventh Amendment of the Constitution Act, 1992 [Allowed the State to ratify the Treaty on European Union (Maastricht) and to become a member of that union.]	16 July, 1992
	There is no Twelfth Amendment of the Constitution. On 25 November 1992, three proposals were put to the people, the Twelfth, Thirteenth and Fourteenth Amendments. The people rejected the Twelfth (which dealt with the right to life of the unborn) and approved the Thirteenth and Fourteenth (below).	
	Thirteenth Amendment of the Constitution Act, 1992 [Provided that Article 40.3.3° (the right to life of the unborn) would not limit freedom to travel between Ireland and another state.]	23 December, 1992
	Fourteenth Amendment of the Constitution Act, 1992[Provided that Article 40.3.3°(the right to life of the unborn) would not limit freedom to obtain or make available information relating to services lawfully available in another state.]	23 December, 1992
	Fifteenth Amendment of the Constitution Act, 1995 [Provided for the dissolution of marriage in certain specified circumstances.]	17 June, 1996
	Sixteenth Amendment of the Constitution Act, 1996 [Provided for the refusal to bail by a court to a person charged with a serious offence where it is reasonably considered necessary to prevent the commission of a serious offence by that person.]	12 December, 1996
	Seventeenth Amendment of the Constitution Act, 1997 [Provided that the confidentiality of discussions at meetings of the Government would be respected save only where the High Court, in certain specified circumstances, determined that disclosure should be made.]	14 November, 1997

	Eighteenth Amendment of the Constitution Act, 1998 [Allowed the State to ratify the Treaty of Amsterdam.]	3 June, 1998
	Nineteenth Amendment of the Constitution Act, 1998 [Allowed the State to consent to be bound by the British-Irish Agreement done at Belfast on 10 April 1998 and provided that certain further amendments to the Constitution, notably to Articles 2 and 3, would come into effect when that agreement entered into force.]	3 June, 1998
	Twentieth Amendment of the Constitution Act, 1999 [Provided constitutional recognition of the role of local government and that local elections are held at least every five years.]	23 June, 1999
	Twenty-first Amendment of the Constitution Act, 2001 [Prohibition of death penalty and removal of references to death penalty.]	27 March, 2002
	There is no Twenty-second Amendment of the Constitution. The Twenty-second Amendment of the Constitution Bill, 2001 [relating to the removal of a judge from office and providing for a body to be established by law to investigate or cause to be investigated conduct constituting misbehaviour by a judge or affected by incapacity of a judge] was not passed by the Houses of the Oireachtas.	
	Twenty-third Amendment of the Constitution Act, 2001 [Allowing the State to ratify the Rome Statute of the International Criminal Court.]	27 March, 2002
	There is no Twenty-fourth Amendment of the Constitution. On 7 June, 2001, three proposals were put to the people, the Twenty-first, Twenty-third and the Twenty-fourth Amendments. The people rejected the Twenty-fourth (which dealt with the Treaty of Nice) and approved the Twenty-first and Twenty-third (above).	
	There is no Twenty-fifth Amendment of the Constitution. On 6 March, 2002, a proposal for the Twenty-fifth Amendment of the Constitution was put to the people and was rejected [Protection of Human Life in Pregnancy.]	
	Twenty-sixth Amendment of the Constitution Act, 2002 [Allowed the State to ratify the Treaty of Nice.]	7 November, 2002
	Twenty-seventh Amendment of the Constitution Act, 2004 [Irish citizenship of children of non-national parents.]	24 June, 2004

	Twenty-eighth Amendment of the Constitution Act, 2009 [allowed the State to ratify the Treaty of Lisbon.]	15 October, 2009
	Twenty-Ninth Amendment of the Constitution (Judges' Renumeration) Act 2011 [Amended section 5 of Article 35 of the Constitution.]	17 November, 2011
	Thirtieth Amendment of the Constitution (Treaty on Stability, Co-ordination and Governance in the Economic and Monetary Union) Act 2012 [allowed the State to ratify the Treaty on Stability, Co-ordination and Governance in the Economic and Monetary Union.]	27 June, 2012
	Thirty-first Amendment of the Constitution (Children) Act, 2012 [Provided for an Article expressly relating to children.]	28 April, 2015
	There is no Thirty-second Amendment of the Constitution. On 4 October 2013, a proposal for the Thirty-second Amendment to the Constitution was put to the people and was rejected [Abolition of Seanad Eireann.]	
	Thirty-third Amendment of the Constitution (Court of Appeal) Act 2013 [Provided for the establishment of a Court of Appeal.]	1 November, 2013
	Thirty-fourth Amendment of the Constitution (Marriage Equality) Act, 2015 [Provided that persons may marry without distinction as to their sex.]	29 August, 2015
	There is no Thirty-fifth Amendment of the Constitution. On 22 May 2015, a proposal for the Thirty-fifth amendment to the Constitution was put to the people and was rejected [Age of Eligibility for Election to Office of President.]	
	Thirty-sixth Amendment of the Constitution Act 2018. [Provided for the regulation of termination of pregnancy.]	18 September, 2018
	Thirty-seventh Amendment of the Constitution (Repeal of offence of publication or utterance of blasphemous matter) Act 2018. [Provided for the removal of the word blasphemous from the Constitution.]	27 November, 2018

Appendix iii

Terms of Reference. Working Group to consider alternative approaches to the possession of drugs for personal use

The Department of Health and the Department of Justice and Equality have joint lead responsibility for the establishment of a Working Group in line with Action 3.1.35 of 'Reducing Harm, Supporting Recovery – a health-led response to drug and alcohol use in Ireland 2017–2025'. The terms of reference of the Working Group provide for an examination of:

a) the current legislative regime that applies to simple possession offences in this jurisdiction and the rationale underpinning this approach, and any evidence of its effectiveness;

b) the approaches and experiences in other jurisdictions to dealing with simple possession offences;

c) the advantages and disadvantages, as well as the potential impact and outcomes of any alternative approaches to the current system for the individual, the family and society, as well as for the criminal justice system and the health system;

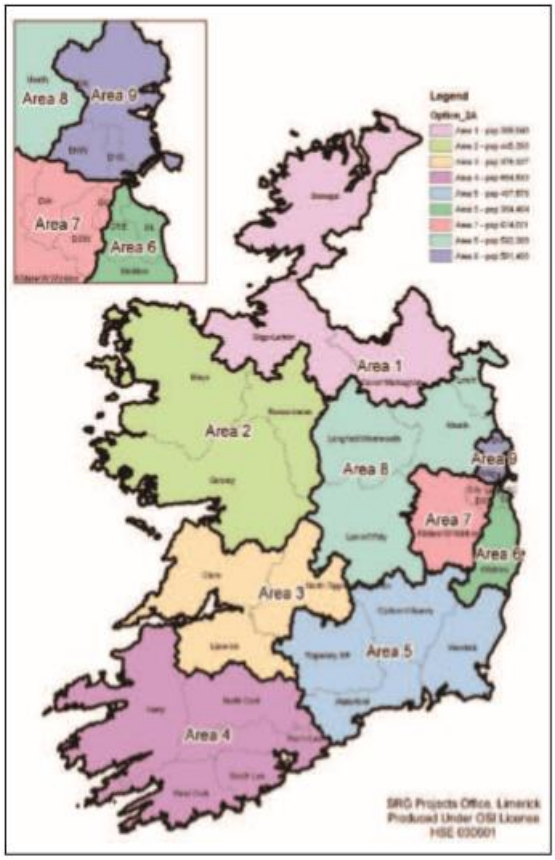
d) the identification of the scope of any legislative changes necessary to introduce alternative options to criminal sanctions for those offences;

e) a cost benefit analysis of alternative approaches to criminal sanctions for simple possession offences; and

f) require the Working Group to make recommendations to the relevant Ministers within 12 months.

Appendix iv

The nine Community Healthcare Organisations are outlined below:



Area 1 - ***Population 389,048***
Donegal LHO, Sligo/Leitrim/West Cavan LHO and Cavan/Monaghan LHO.

Area 2 - ***Population 445,356***
Galway, Roscommon and Mayo LHOs

Area 3 - ***Population 379,327***
Clare LHO, Limerick LHO and North Tipperary/East Limerick LHO

Area 4 - ***Population 664,533***
Kerry LHO, North Cork LHO, North Lee LHO, South Lee LHO and West Cork LHO

Area 5 - ***Population 497,578***
South Tipperary LHO, Carlow/Kilkenny LHO, Waterford LHO and Wexford LHO

Area 6- ***Population 364,464***
Wicklow LHO, Dun Laoghaire LHO and Dublin South East LHO

Area 7 - ***Population 674,071***
Kildare/West Wicklow LHO, Dublin West LHO, Dublin South City LHO and Dublin South West LHO

Area 8 - ***Population 592,388***
Laois/Offaly LHO, Longford/Westmeath LHO, Louth LHO and Meath LHO

Area 9 - ***Population 581,486***
Dublin North LHO, Dublin North Central LHO and Dublin North West LHO

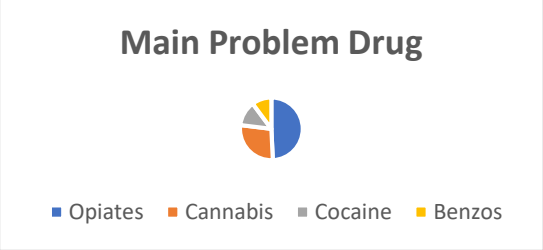
Appendix v

Drug Treatment in Ireland 2010–2016 [96]

The National Drug Treatment Reporting System (NDTRS) records cases of treated problem drug and alcohol use in Ireland. This bulletin reports on cases of treated problem drug use (excluding alcohol) between 2010 and 2016.

Overview

In this seven-year period, 63,187 cases were treated. The proportion of new cases decreased from 42.5% in 2010 to 38.2% in 2016. The majority of cases were treated in outpatient facilities (63.4%) over the period, similar to previous years. The proportion of cases treated in residential facilities increased from 14.0% in 2010 to 20.4% in 2016.



The median age of cases has increased from 28 years in 2010 to 30 years in 2016. The majority of cases, seven in every ten, reported were male. The proportion who were homeless increased from 5.1% in 2010 to 9.6% in 2016. The proportion of Travellers treated increased marginally from 2.8% in 2010 to 3.2% in 2016.

Main problem drug (excluding alcohol):

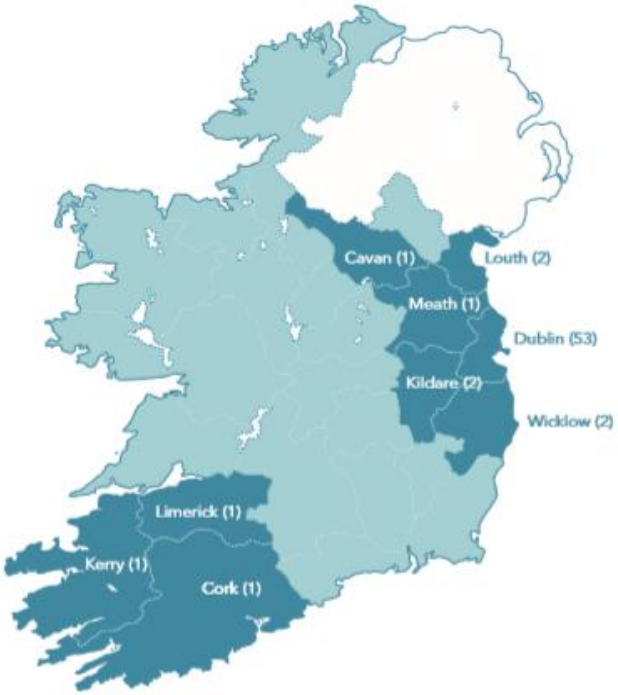
Opiates (mainly heroin) were the most commonly reported drug used. The proportion of cases treated decreased from 58.1% in 2010 to 47.0% in 2016. Cannabis was the second most common drug among those treated. The proportion of cases who reported cannabis increased from 23.0% in 2010 to 26.4% in 2016. Cannabis is the most common drug reported by new cases. Cocaine remains the third most common drug reported. In 2016, 12.3% of cases reported problem cocaine use, the highest proportion since 2010. The proportion of cases who reported benzodiazepines as a main problem drug increased from 4.1% in 2010 to 9.7% in 2016. The proportion treated for Z-drugs increased from 0.1% in 2010 to 1.1% in 2016.

[96] HRB National Drug Treatment Reporting System 2010 to 2016.

Appendix vi

Distribution of Methadone Prescribing General Practitioners in Ireland

Figure 8: Geographical Distribution of Level 2 GPs in Ireland



Source: C. Ó Súilliobháin, Access to Community Based Drug Treatment, presentation delivered to the British Medical Association Northern Ireland and Irish Medical Organisation All-Ireland Conference on Mental Health and Addiction, Dublin, 21 November 2014.

Methadone maintenance treatment in Ireland is provided in addiction clinics, and in primary community care settings by Level 1 and 2 specialist trained general practitioners (GPs). The Irish College of General Practitioners (ICGP) provides training and regulates the Methadone Treatment Programme (MTP).

A Level 1 GP Prescriber can treat stabilised opiate dependent persons in their own practice. Patients may be referred from HSE Drug Treatment Centres, satellite clinics, or Level 2 GPs. Ideally, the client would be attending this GP for all his/her primary care requirements.

A level 2 GP is trained to provide a comprehensive assessment, initiation of treatment where appropriate, stabilisation, maintenance of Opioid Substitution treatment and or detox of an opioid dependent in the primary care setting. Inter-GP referral of opioid dependent persons between Level 1 and Level 2 GPs is encouraged.

Appendix vii

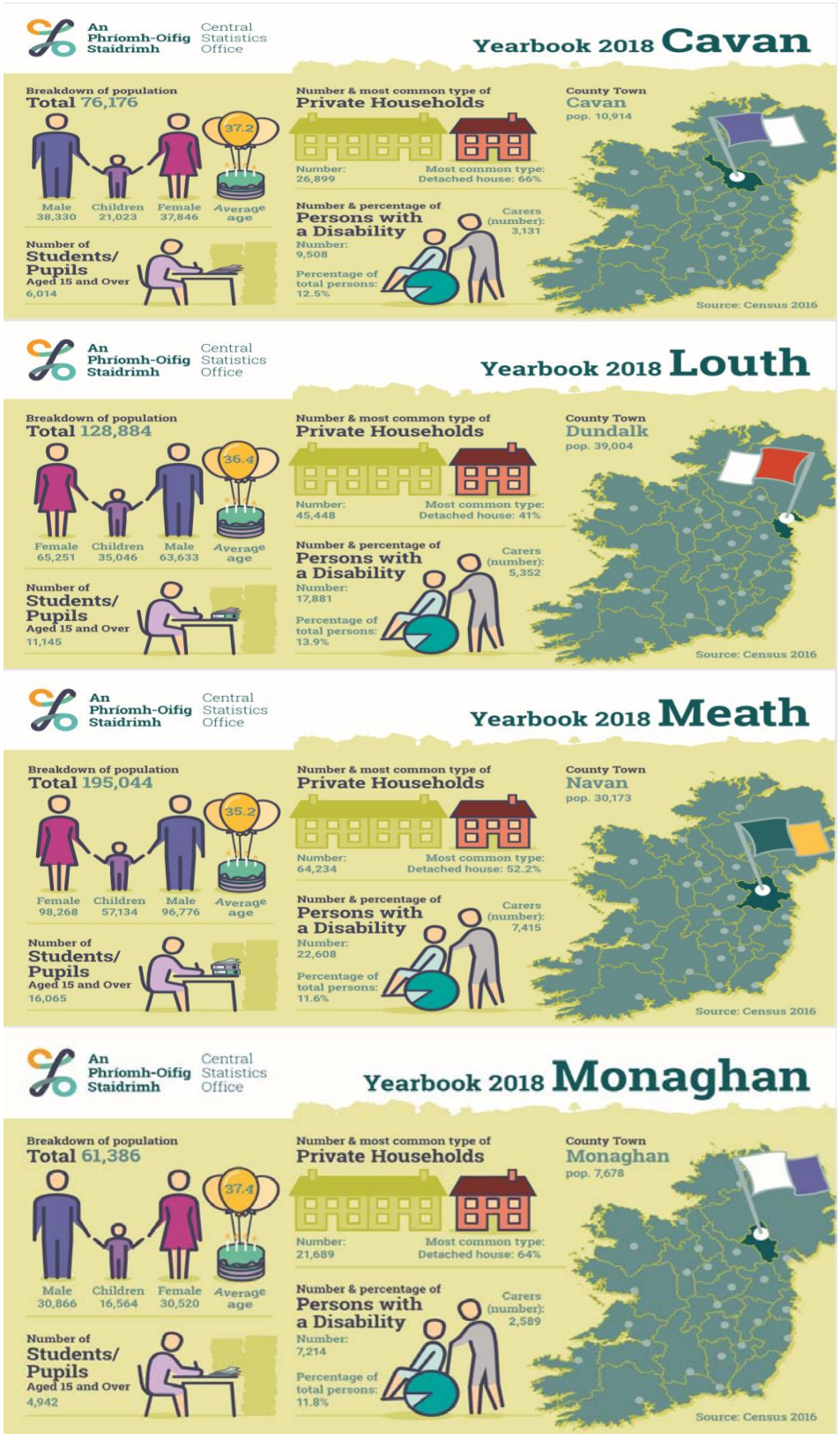
Drugs Task Forces

Local and Regional Drug and Alcohol Task Forces (LDATFs and RDATFs) play a key role in assessing the extent and nature of the drug problem in their areas and coordinating action at local level so that there is a targeted response to the drug problem in local communities. They implement the National Drugs Strategy in the context of the needs of their region or local area through action plans which have identified existing and emerging gaps.

There are 14 Local Drug and Alcohol Task Forces (LDATFs) and 10 Regional Drug Task Forces (RDATFs).

Appendix viii

Census Statistics Office Yearbook 2018 North East Region Counties.



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FASN Memorial Quilt

The memorial quilts are made by family networks who support each other through loss of loved ones from drug use in Ireland.

Family Addiction Support Network
The Hub,
Lios Dubh,
Armagh Road,
Dundalk,
Co. Louth
A91 T668

Office: 042 9355251
Helpline: 087 9046405
Email: info.fasn@gmail.com

Alice O'Flynn
Súil Eile Consultancy

April 2019