

***Holding Pattern: An exploratory study of the lived experiences of those on methadone maintenance in Dublin North East.***

**Dr Marie Claire Van Hout  
Mr Tim Bingham**

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## **Foreward**

The Clients Forum of the Dublin North East Drugs Task Force are delighted to have been able to commission and publish this research report. We believe it accurately reflects the views of clients & service users, with regard to their experience of progressing through treatment, rehabilitation & training locally.

This research report is just one of a number of initiatives being undertaken by the Clients Forum and supported by the Dublin North East Drugs Task Force. It offers a true reflection of peoples experiences in their progression routes and provides a challenge to funders and service providers, to listen & respond appropriately to the needs clients & service users now & in the future.

We would like to extend our gratitude to the Dublin North East Drug Task Force for their support and in particular to Tom O'Brien (Co-ordinator) & Marie Scally (Project Cohesion Officer). We commend the Task Force for their progressive thinking and vision, in not only supporting this research, but in providing ongoing independent facilitation to the forum. We thank them for having the foresight to see the relevance of having the Clients Forum as a sub group of the Task Force, and in so doing, ensuring that the needs of Clients & service users are truly represented and central to the decision making process.

We would also like to thank Dr Marie Claire Van Hout & Tim Bingham (Researchers) for the trojan work involved in gathering & analysing the data to produce this research.

Most importantly, we would like to thank all the clients & service users who gave of their time and energy to contribute their views and experiences. Without you this report could never have been produced. We hope that we have served you well. As Clients & service users ourselves, we hold a deep appreciation for the effort it takes to put yourself on the line and have to tell your story. In this regard you deserve and have our deepest gratitude and respect.

From the outset, we hoped that this research would make interesting reading & reflect accurately the views of Clients & services users locally. We have not been disappointed. Looking

to the future we hope that this research will inform policies locally as well as further afield. At the very least we hope that it will promote a culture of listening to the needs of Clients & service users, in order that services can be maintained or adapted to meet the needs of the people they have been trusted to serve. We look forward to our own continued development as we grow and learn in these exciting & challenging times.

The Clients Forum

Dublin North East Drugs Task Force

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## Executive Summary

### Introduction

According to the European Monitoring Centre for Drugs and Drug Addiction, there are between 1.2 and 1.5 million opiate dependent individuals in the European Union (EMCDDA, 2010) with an estimated 18,136 and 23,576 opiate users resident in Ireland (Kelly *et al.*, 2009). Approximately 11,807 opiate users in Ireland are known to services and are predominantly aged between 25 and 34 years, male, early school leavers, unemployed (Kelly *et al.*, 2009; Carew *et al.*, 2009). In terms of treatment data, records show an increase in both prevalence and incidence rates among 15 to 64 year olds, with 11,538 cases treated in 2007 (Carew *et al.*, 2009). One quarter of treatment cases in 2007 had stabilised prior to treatment entry and were on methadone maintenance (Long and Lyons, 2009). However, the chronic relapsing nature of opiate dependency remains evident with more than half of these cases needing more than one treatment intervention (Carew *et al.*, 2009).

Methadone maintenance treatment is the most common form of treatment for opiate dependency in Ireland and is generally provided by specialised clinics under medical supervision. It has a well established ability to reduce opiate overdose fatalities by stabilising the addicts lifestyle, and reducing poly drug use and harms associated with intravenous use (hepatitis and HIV) (Ball *et al.*, 1988, Gossop *et al.*, 2001; Cox *et al.*, 2007). Research has indicated its effectiveness in reducing drug use and risk activities such as needle sharing, improving health outcomes and reducing mortality, reducing criminal activity, and stimulating social, educational and employment engagement (Ball *et al.*, 1988, Sorensen and Copeland, 2000; Corsi *et al.*, 2002; Esteban *et al.*, 2003; Sheerin *et al.*, 2004; Teesson *et al.*, 2006; Gowing *et al.*, 2006; Mattick *et al.*, 2009). However, despite this evidence base for methadone maintenance treatment benefits, dropout rates remain high, suggestive of relapse back to opiate use and indicative of the '*revolving door*' of treatment re entry patterns (Zanis *et al.*, 1996; Simpson *et al.*, 1997; Bell *et al.*, 2006; Coviello *et al.*, 2011). Methadone is also hampered by community and patient related stigmas (Lloyd, 2010) and is considered problematic in its capacity as social intervention or mechanism of '*social control*' (Lawless, 2006:68) irrespective of its pharmacological capacity to treat opiate dependence (Lilly *et al.*, 2000).

Unemployment remains a problem for individuals on methadone treatment (Zanis *et al.*, 2001; Wong *et al.*, 2004; Svikis *et al.*, 2011). Indeed, research shows that general employment rates for those on methadone maintenance range from 15% to 44% (French *et al.*, 1994; Hubbard *et al.*, 1984; Platt, 1995). Low rates of employment for those on methadone maintenance are reportedly due to poor literacy and employment related skills; lack of prior employment history, lack of access to transport and childcare, poor motivational levels and co-morbidity (Simpson, 1984; Zanis *et al.*, 1994; Platt, 1995; Silverman *et al.*, 1996; Brewington *et al.*, 1998; Wong *et al.*, 2004; Shepard and Reif, 2004; Dunlap *et al.*, 2007). Employment represents a secondary goal for individuals partaking in methadone maintenance treatment (Dole *et al.*, 1968) and is associated with decreased alcohol and drug use, criminality, relapse rates, positive treatment outcomes and positive civic engagement (McLellan, 1983; Kidorf *et al.*, 1994a; Kidorf *et al.*, 1994b; Zanis *et al.*, 1994; Comerford *et al.*, 1999; Gerra *et al.*, 2003; Kemp *et al.*, 2004; Reif *et al.*, 2004; Kidorf *et al.*, 2004). Employment can provide the individual with a sense of social readjustment, reintegration into mainstream society and individual legitimisation (Valiant, 1988; Platt and Mezger, 1985; Platt *et al.*, 1993; Platt, 1995; Comerford *et al.*, 1999; Kerrigan *et al.*, 2000; Gerra *et al.*, 2003; Shepard and Reif, 2004). Research shows that by supporting methadone clients via employment initiatives, a pathway toward self actualisation, increased self esteem, empowerment and financial security is realised (Ruefli and Rogers, 2004).

The research was undertaken on behalf of the Dublin North East Drugs Task Force Client Forum which represents participants on the five Special Community Employment schemes in that area, and who collectively requested local research into the area of methadone maintenance and rehabilitation via Special Community Employment Schemes. The focus of the research was to 'make sense of the lived social world' of methadone maintenance, participation in Special Community Employment schemes and personal understandings of progression situated within individual and group contexts.

### *Methodology*

The researchers utilised a mixed method approach using focus groups with the Client forum representatives of the Special Community Employment schemes, and a series of in- depth interviews with individuals attending the Special Community Employment schemes in the Dublin North East Drug Task Force area. Ethical approval for the study was garnered at Waterford Institute of Technology in May 2011. The research consisted of the following phases;

1. The research team liaised with the Clients Forum and the Treatment and Rehabilitation Sub Group of the Dublin North East Drug Task Force and conferred in order to consider potential sampling and consultation methodologies. This provided the research team with a clear understanding of the reality of local methadone maintenance treatment, vocational training, employment and rehabilitation needs.
2. Desk research assessed the research base on methadone maintenance, vocational training and employment supports within a rehabilitation focus.
3. The research team engaged with the Client Forum (n=11) and the Dublin North East Drug Task Force in order to inform and advise the Special Community Employment schemes about the research process.
4. Two Focus Groups with the Dublin North East Drug Task Force Clients Forum (n=4) were facilitated after the initial introductory meeting with Client Forum. The focus groups were guided by questions pertaining to experiences of methadone maintenance, recovery and rehabilitation, treatment, counselling and vocational supports needed, and experiences of the Special Community Employment schemes. This phase was used to identify the key question schema for individual interviews in each project. Client Forum members were additionally asked to assist as 'gatekeepers' in advising their peers of the upcoming researcher visits and in recruitment of volunteers to partake. The researchers envisaged a certain element of snowballing to optimise on research participation, in order to achieve data saturation among Special Community Employment scheme participants. Four Special Community Employment schemes agreed to partake in the research, with one declining to partake in the research.
5. One-to-one semi structured interviews (n=25) with volunteering participants in the four Special Community Employment schemes were conducted (out of a potential 45 participants). The time spent with these individuals provided detailed knowledge about methadone maintenance and treatment experiences, experiences of the Special Community Employment schemes, needs and experiences surrounding rehabilitation, education and training, and identified avenues for progression.
6. Researcher feedback to the Client Forum in order to discuss interpretation of narratives and create Client Forum dialogue and ownership of the research.

### *Ethics*

Information regarding the research aim, assurances of confidentiality, verbal consent and right to withdraw at any stage were repeated prior to commencement of each focus group and interview, and participants were encouraged to ask for clarification if needed throughout the course of the fieldwork. Participants were advised not to mention any names or identities throughout the research, and were advised that should any information regarding illegal activity be forthcoming, that researchers were duty bound to report to the relevant authorities.

## *Data Analysis*

Thematic and content analysis commenced with several reads of the resultant narratives by both researchers, with periodic briefing sessions between both researchers assisting in the identification of emergent themes and categories of data, within an inter-rater system of corroboration, comparisons and interpretations of the data.

## **Results**

1. The findings, whilst exploratory and context specific to the Dublin North East Task Force area are indicative of methadone maintenance offering participants the opportunity to commence recovery, with additional participation in the local Special Community Employment schemes acting as therapeutic support mechanism.
2. The Special Community Employment schemes whilst experienced in a positive therapeutic manner did little to provide specific vocational training, work placement, and the acquisition of employment related skills, with many participants left with little aftercare on completion of their time on the scheme.
3. Issues relating to lack of visibility of methadone health related material and treatment options, lack of informed decision making around client-doctor dialogues around treatment care pathways, lack of continuity of counselling provision, continued drug and prescribed medication use, whilst on methadone and concerns around long term methadone use are evident.
4. Improved discourse between clients and medical support staff is needed, and most particularly with regard to alternative forms of treatment and the final goal of coming off treatment.
5. Treatment services must endeavour to recognise client desires for being opioid free, and that many clients are afraid of remaining on methadone long term and self detox.
6. Instances of community, family, medical and pharmacy discrimination and prejudice were common and served to stifle treatment progression.
7. The research highlights the need for improved anti discrimination and psychosocial support training for medical, clinic and pharmacy staff working in the addiction field in the Dublin North East Drugs Task Force area.
8. The findings are suggestive of the need for improved interagency cohesiveness in order to create supports at all stages of methadone maintenance, treatment and vocational rehabilitation, and grounded in client centred care planning, provision of individualised vocational and employment training interventions and provision of specific female rehabilitative supports.
9. Greater transparency is needed for Client Forum members in terms of the Dublin North East Drugs Task Force remit, terms of reference, advocacy procedures and capacity to create change.

## **Recommendations for Practice**

### *Clients*

- Development and distribution of an information leaflet in conjunction with the Client Forum, with regard to what services are available as it relates to methadone maintenance and progression pathways;

- Development and distribution of information leaflets in conjunction with the Client Forum, advising pre methadone entrants of health side effects, addiction potential and typical pathways for methadone maintenance;

#### *Stigma*

- Development and implementation of community and family awareness interventions in conjunction with the Client Forum, on methadone maintenance and Special Community Employment schemes in order to reduce community and family related stigma;
- Development and implementation of awareness training for medical, clinic and pharmacy staff in the Dublin North East Drugs Task Force area;

#### *Supports*

- Provide client support for those experiencing difficulties with doctor prescribing and long term methadone maintenance, and set up a system, where key support workers can attend client-doctor meetings to advocate on behalf of methadone maintenance client for treatment progression.
- Develop women specific drop in and additional female specific counselling and childcare assistance in the Dublin North East Drugs Task Force area;
- Develop more drop in and counselling for those on methadone maintenance and considerate of both those partaking and not partaking in Special Community Employment Schemes;
- Develop an aftercare pathway of counselling, treatment, vocational and employment related supports for those on completion of the Special Community Employment schemes;

#### *Special Community Employment scheme*

- Revise Special Community Employment scheme goals in each project, and identify whether the project is dedicated to therapeutic and relapse prevention supports; or dedicated to specific vocational training and employment initiatives;
- Improve each Special Community Employment scheme in relation to the development of timely assessment procedures in order to provide individual care planning, specific vocational training and employment related skills base, provision of work placement or volunteering supports and assistance in curriculum vitae and interviewing skills;
- Ensure Special Community Employment workers adhere to confidentiality protocols;
- Create a network of potential employers or volunteer placements with local employers in order to reduce instances of Special Community Employment stigma.

#### *Client Forum*

- Increase client awareness as to how Client Forums operate and its relationship with the Dublin North East Drugs Task Force;
- Create greater transparency for Client Forum members in terms of the Dublin North East Drugs Task Force remit, terms of reference and capacity to create change;
- Select Client Forum participants to act as forum advocates at Dublin North East Drugs Task Force meetings;
- Allow the Client Forum to select its own participants, which should include those currently using, those on methadone and those in full recovery.

### **Recommendations for Research**

#### *Qualitative*

- Qualitative research on the development of addiction displacement patterns (drug or addiction switching) in the form of prescribed medication abuse or other drugs, whilst on methadone maintenance;

- Qualitative research on client self detoxification experiences in the Dublin North East Drugs Task Force area;
- Qualitative research on women's experiences of methadone maintenance, detoxification and rehabilitation pathways in the Dublin North East Drugs Task Force area;
- Qualitative research on emergent drug trends and potential trajectories of modes of use (IDU/smoking/oral) among the heroin using population in the Dublin North East Drugs Task Force area;
- Qualitative research on the doctors experiences of long term methadone maintenance in the Dublin North East Drugs Task Force area;
- Qualitative research on pharmacy and clinic staff experiences of long term methadone maintenance in the Dublin North East Drugs Task Force area;
- Qualitative research on Special Community Employment staff experiences of long term methadone maintenance in the Dublin North East Drugs Task Force area;
- Qualitative research on the needs and experiences of methadone maintenance clients not attending Special Community Employment schemes in the Dublin North East Drugs Task Force area;

#### *Exploratory*

- Exploratory research on the need for implementation of a local Community Drugs Team in the Dublin North East Drugs Task Force area;
- Exploratory research on the need for development and placement of '*Drop In*' services in the Dublin North East Drugs Task Force area.
- Exploratory research on the need for, development and placement of '*Supported Work Placement*' services operating as adjunct to existing Special Community Employment schemes in the Dublin North East Drugs Task Force area.

## 1. Background to Research

### *Introduction*

According to the European Monitoring Centre for Drugs and Drug Addiction, there are between 1.2 and 1.5 million opiate dependent individuals in the European Union (EMCDDA, 2010) with an estimated 18,136 and 23,576 opiate users resident in Ireland (Kelly *et al.*, 2009). Heroin seizures nationally have increased steadily since 2004 (Long and Lyons, 2009). Opiate use is characteristic of socio economic disadvantage, low educational attainment and restricted economic opportunity (Carew *et al.*, 2009). Approximately 11,807 opiate users in Ireland are known to services and are predominantly aged between 25 and 34 years, male, early school leavers, unemployed (Kelly *et al.*, 2009; Carew *et al.*, 2009). However, opiate prevalence among Irish females has increased since 2001 (Kelly *et al.*, 2009). Figures indicate that the predominant mode of opiate use is inhalation, closely followed by injecting and oral use (Carew *et al.*, 2009). Median ages for first time opiate use are recorded as 19 years, with 20 years for injecting drug use (Carew *et al.*, 2009). Daily use remains most evident in both existing and new cases for treatment, with almost half of new treatment cases using opiates for longer than five years prior to entry (Carew *et al.*, 2009). In terms of treatment data, records show an increase in both prevalence and incidence rates among 15 to 64 year olds, with 11,538 cases treated in 2007, and with most increases evident outside the greater Dublin area (Carew *et al.*, 2009). Small increases were evident in numbers reporting opiates as primary and secondary problematic drug, with increases most notable in the older drug using population (Carew *et al.*, 2009). Additional problematic drugs used were reportedly cannabis, benzodiazepines and cocaine (Kelly *et al.*, 2009). It is notable that one quarter of cases in 2007 had stabilised prior to treatment entry, and were on methadone maintenance (Long and Lyons, 2009). These trends can be explained by an increase in population prevalence of problematic opiate use, alongside increases in service provider data reporting systems, increases in service provision for opiate dependency, greater levels of transfer onto detoxification centres and general practitioner led pathways for recovery (Long and Lyons, 2009). However, the chronic relapsing nature of opiate dependency remains evident with more than half of these cases needing more than one treatment intervention (Carew *et al.*, 2009).

### *Treatment of Opiate Dependence*

Opiate dependence develops following regular use of opioids, and relates to quantity, frequency and route of administration, as well as inherent protective and resiliency factors of individual vulnerability. Repeated use of opiates causes permanent structural and functional brain adaptations, which contribute to compulsive drug seeking behaviours, difficulties in controlling consumption, a withdrawal state upon reduction or cessation and evidence of tolerance, in spite of destructive physical and psychosocial consequences for the user (Raby *et al.*, 2008 World Health Organisation, 2009). Heroin dependence as most common form of opiate dependence is therefore a complex condition often requiring long term treatment modalities which incorporate pharmacological, psycho-social rehabilitation and relapse prevention interventions (World Health Organisation, 2004; Schuckit, 2006). Individuals will present with a myriad of different risk and protective factors, and different psychological, health and social issues. Heroin dependency is noted for the persistence of physiological and psychological abnormalities for long durations post acute withdrawal along with high risk of relapse. It may take six to nine months of abstinence to restore mood, sleep patterns, metabolic rates, temperature, blood pressure and respiratory rates (World Health Organisation, 1993). Successful medical management of heroin dependence involves assessment and clinical observation, treatment of co-morbid medical and mental health conditions and either rapid detoxification (withdrawal over seven-21 days), followed by relapse prevention interventions or the transferral from heroin onto

a substitution opioid, followed by a slow detoxification when the addict is motivated to engage in rehabilitation (Schuckit, 2006). The immediate objectives of treatment are to reduce drug taking, improve the client's functional ability, and reduce the medical and social effects of drug related harm (National Institute on Drug Abuse, 1999). Interventions typically use pharmacological therapy using either agonist maintenance (methadone or buprenorphine), or antagonist treatment using naltrexone (World Health Organisation, 2004; Schuckit, 2006). Substitution maintenance therapy has been found to be safer and more effective than placebo and rapid detoxification in both reducing heroin use and optimising treatment retention levels (Dole and Nsywander, 1965, Ward *et al.*, 1999; Kosten and George, 2002, Kreek *et al.*, 2002; World Health Organisation, 2004, Raby *et al.*, 2008).

#### *Methadone Maintenance Treatment*

Methadone maintenance treatment is most common form of treatment for opiate dependency in Ireland and is generally provided by specialised clinics under medical supervision (Solberg *et al.*, 2002; Amato *et al.*, 2005). It has a well established ability to reduce opiate overdose fatalities by stabilising the addicts lifestyle, and reducing poly drug use and harms associated with intravenous use (hepatitis and HIV) (Ball *et al.*, 1988, Gossop *et al.*, 2001; World Health Organisation, 2004; Cox *et al.*, 2007). Research has indicated its effectiveness in reducing drug use and risk activities such as needle sharing, improving health outcomes and reducing mortality, reducing criminal activity, and stimulating social, educational and employment engagement (Ball *et al.*, 1988, Sorensen and Copeland, 2000; Corsi *et al.*, 2002; Esteban *et al.*, 2003; Sheerin *et al.*, 2004; Teesson *et al.*, 2006; Gowing *et al.*, 2006; Mattick *et al.*, 2009). In addition, methadone maintenance therapy has been proven to be cost effective (Simoens *et al.*, 2006). In principle, methadone maintenance is recommended for any patient who has relapsed after one or more attempts in psychosocial treatment (Raby *et al.*, 2008). It is also recommended for pregnant opiate dependent patients and offers promise in the management of hormonal disruptions in addicted individuals (Schuckit, 2006). It is an important component of community-based approaches insofar that the treatment is offered on an out-patient basis, resulting in significant treatment retention rates and capacity to successfully address health issues, psychological problems, family relationships, housing, employment and financial issues. Methadone maintenance outcomes depend on timely treatment entry, successful detoxification, adequate medication dosage, duration, support and continuity of treatment, levels of engagement in concurrent counselling and presence of cohesive support networks of adjunctive medical, social and community services (McLellan *et al.*, 1993).

Maintenance dosage of methadone aims to avoid any sign of withdrawal, euphoric or sedative effect and prevent the use of illicit opioids, often controlled by urine analysis and patient self report. Methadone concentration reaches a steady state after three to four weeks of daily intake. With chronic dosage (60-100mg per day), methadone stimulates tolerance in the brain opioid system, which prevents intoxication and sedation when consuming heroin. However initial concerns lie in the estimation of the initial starting dose of methadone, which can be life threatening if over estimated, once the daily dosage of heroin is estimated (Schuckit, 2006). This dose level can be maintained for months or years to reduce opioid use, parenteral injections and improve overall health and psychosocial functioning, or reduced to the lowest dose possible (no withdrawal symptoms) over a period of 6 months. Longer treatment duration is correlated with stabilisation and improved psycho-social outcomes, with reduced morbidity, poly drug use and crime involvement (Sees *et al.*, 2000; Cox and Lawless, 2004; Cox *et al.*, 2007; Geraghty *et al.*, 2008; Mattick *et al.*, 2009; Winstock *et al.*, 2011). However, there remains a risk of continued use of non opioid substance use (alcohol, cannabis, benzodiazepines), as methadone does not have a specific pharmacological effect on non-opioid

drug use (Schuckit, 2006; Cox *et al.*, 2007; Kelly *et al.*, 2009). Research has underscored the inherent difficulties relating to long term methadone maintenance alongside methadone diversion onto illicit drug trading (Kreek *et al.*, 2002; World Health Organisation, 2004). In addition, methadone maintenance must co-exist with psycho social modalities (concurrent counselling and contingency management) in order to realize the potential outcomes of treatment (McLellan *et al.*, 1998; Raby *et al.*, 2008; World Health Organisation, 2009). Despite the evidence base for methadone maintenance treatment benefits, dropout rates remain high, are suggestive of relapse back to opiate use and indicative of the 'revolving door' of treatment re entry patterns (Zanis *et al.*, 1996; Simpson *et al.*, 1997a; Simpson *et al.*, 1997b; Bell *et al.*, 2006; Coviello *et al.*, 2011). Methadone is also associated with hampered community and patient acceptance caused by stigma (Strain *et al.*, 1996) and is considered problematic in its capacity as social intervention or mechanism of 'social control' (Lawless, 2006:68) irrespective of its pharmacological capacity to treat opiate dependence (Lilly *et al.*, 2000).

### *Rehabilitation, training and employment*

According to Long *et al.*, (2005) employment rates among treated drug users in Ireland (16-64 years) are much lower than the general population. Unemployment remains a problem or individuals on methadone treatment (Zanis *et al.*, 2001; Wong *et al.*, 2004a; Wong *et al.*, 2004b; Svikis *et al.*, 2011). Indeed, research shows that general employment rates for those on methadone maintenance range from 15% to 44% (French *et al.*, 1994; Hubbard *et al.*, 1984; Platt, 1995). Employment represents a secondary goal for individuals partaking in methadone maintenance treatment (Dole *et al.*, 1968) and is associated with decreased alcohol and drug use, criminality, relapse rates, positive treatment outcomes and positive civic engagement (McLellan, 1983; Kidorf *et al.*, 1994b; Zanis *et al.*, 1994; Siegel *et al.*, 1996; Comerford *et al.*, 1999; Gerra *et al.*, 2003; Kemp *et al.*, 2004; Reif *et al.*, 2004; Kidorf *et al.*, 2004). Methadone maintenance can operate as catalyst for revision of day to day activity, by replacement of prior preoccupation of drug seeking and using behaviours (Koo *et al.*, 2007). Employment can provide the individual with a sense of social readjustment, reintegration into mainstream society and individual legitimisation (Valiant, 1988; Platt and Mezger, 1985; Platt *et al.*, 1993; Platt, 1995; Comerford *et al.*, 1999; Kerrigan *et al.*, 2000; Gerra *et al.*, 2003; Shepard and Reif, 2004). Research shows that by supporting methadone clients via employment initiatives, a pathway toward self actualisation, increased self esteem, empowerment and financial security is realised (Ruefli and Rogers, 2004). De Maeyer *et al.*, (2011) in their research on methadone quality of life have indicated that 'holding an occupation'; 'being independent' and 'having social relationships' all form a framework to enhanced functioning for individuals on methadone.

Dependence on social welfare systems is associated with poorer treatment outcomes and is indicative of the need for tailored strengths based treatment and rehabilitation plans to boost retention and minimise relapse (McLellan *et al.*, 1981; Peters *et al.*, 1993; Platt, 1995; Wolkstein and Spiller, 1998). Kidorf *et al.*, (1998) demonstrated that contingency management (i.e. takeaways, dose alterations) or incentives (Silverman *et al.*, 1996; Silverman *et al.*, 2001; Knealing *et al.*, 2006) incurred positive motivational effects on methadone maintenance clients in securing employment, improving attendance to counselling and reducing supplemental poly drug use (Milby *et al.*, 1978; Stitzer *et al.*, 1992; Kidorf and Stitzer, 1996; Stitzer *et al.*, 1977; Kidorf *et al.*, 1994b; Iguchi *et al.*, 1996). However, research by French *et al.*, in 1992 indicated that whilst a majority of addicts report a strong interest in employment training, their expectations are often unrealistic, with low rates of employment due to poor literacy and employment related skills; lack of prior employment history, lack of access to transport and childcare, poor motivational levels and co-morbidity (Simpson, 1984; Zanis *et al.*, 1994; Platt,

1995; Silverman *et al.*, 1996; Brewington *et al.*, 1998; Wong *et al.*, 2004a; Wong *et al.*, 2004b; Shepard and Reif, 2004; Dunlap *et al.*, 2007). Structural factors confounding this issue include the lack of specific employment training programmes for those on methadone maintenance, unavailability of certain skill specific jobs, employer bias against methadone clientele and weak labour markets (French *et al.*, 1992). Indeed, Platt and Mezger (1985: 117) quote that for addicts who don't have an existing skills base needed for sustainable employment; "*getting a job or keeping a job is a job in itself,*" especially for addicts who have lost or never acquired the skills and discipline necessary for sustained employment. However, according to McIntosh *et al.*, (2008) recovering drug addicts in receipt of employment related assistance were three times more likely to have secured paid employment than those who has not received this specific assistance on job seeking, employment skills and training. In particular, specialist employment interventions focusing on job searching, placement and skills; supported and therapeutic work programmes, and case management protocols have achieved some success (Hall *et al.*, 1981; Dennis *et al.*, 1993; McLellan *et al.*, 1998; Blaney and Craig, 1999; Silverman *et al.*, 2001; Silverman *et al.*, 2002; Kashner *et al.*, 2002; Lidz *et al.*, 2004; Magura *et al.*, 2004; Knealing *et al.*, 2008). In Ireland, vocational rehabilitation efforts are predominantly classified under the headings of education, training and employment initiatives, and involve employment focused training for those in recovery via Special Community Employment schemes in Ireland. Reported outcomes for these schemes in terms of rehabilitation, vocational training and employment outcomes are mixed (Indecon Report, 2002; Kempe and Neale, 2005; Lawless, 2006) and have highlighted the need for the current provision of Special Community Employment schemes to be supplemented by Motivated Stepped Case [MSC]; Bridge to Workplaces (2008) and the Customized Employment Supports [CES] model (Magura *et al.*, 2004; Keane, 2007).

The National Drugs Strategy 2009-2016 has highlighted the need for greater service user involvement and the development of local service user forums. The research was undertaken on behalf of the Dublin North East Drugs Task Force Client Forum which represents participants on the five Special Community Employment schemes in that area, and who collectively requested local research into the area of methadone maintenance and rehabilitation via Special Community Employment Schemes. The focus of the research was to '*make sense of the lived social world*' of methadone maintenance, participation in Special Community Employment schemes and personal understandings of progression situated within individual and group contexts.



The Dublin North East Drugs Task Force area

*The next chapter shall present the methodology employed.*

## 2. Methodology

### *Research Aim*

Qualitative research based on 'bottom up' subjective experiences of individuals remains most appropriate and particularly within the addiction field (Neale *et al.*, 2005). The research aimed to situate client experiences of methadone maintenance along a continuum of recovery, with particular attention devoted to stabilisation experiences, vocational training needs and identified avenues for progression. The researchers utilised a mixed method approach using focus groups with the Client forum representatives of the Special Community Employment schemes, and a series of in- depth interviews with individuals attending the Special Community Employment schemes in the Dublin North East Drug Task Force area. Ethical approval for the study was garnered at Waterford Institute of Technology in May 2011.

### *Research Design*

The research consisted of the following sequential phases;

1. The research team liaised with the Clients Forum and the Treatment and Rehabilitation Sub Group of the Dublin North East Drug Task Force and conferred in order to consider potential sampling and consultation methodologies. This provided the research team with a clear understanding of the reality of local methadone maintenance treatment, vocational training, employment and rehabilitation needs.
2. Desk research assessed the research base on methadone maintenance, vocational training and employment supports within a rehabilitation focus.
3. The research team engaged with the Client Forum (n=11) and the Dublin North East Drug Task Force in order to inform and advise the Special Community Employment schemes about the research process.
4. Two Focus Groups with the Dublin North East Drug Task Force Clients Forum (n=4) were facilitated after the initial introductory meeting with Client Forum. The focus groups were guided by questions pertaining to experiences of methadone maintenance, recovery and rehabilitation, treatment, counselling and vocational supports needed, and experiences of the Special Community Employment schemes. This phase was used to identify the key question schema for individual interviews in each project. Client Forum members were additionally asked to assist as 'gatekeepers' in advising their peers of the upcoming researcher visits and in recruitment of volunteers to partake. The researchers envisaged a certain element of snowballing to optimise on research participation, in order to achieve data saturation among Special Community Employment scheme participants. Four Special Community Employment schemes agreed to partake in the research, with one declining to partake in the research.
5. One-to-one semi structured interviews (n=25) with volunteering participants in the four Special Community Employment schemes were conducted (out of a potential 45 participants). The time spent with these individuals provided detailed knowledge about methadone maintenance and treatment experiences, experiences of the Special Community Employment schemes, needs and experiences surrounding rehabilitation, education and training, and identified avenues for progression.
6. Researcher feedback to the Client Forum in order to discuss interpretation of narratives and create Client Forum dialogue and ownership of the research.

### *Administration of the Research*

The Dublin North East Drug Task Force Client Forum focus groups were undertaken at a community centre in the area and were approximately 60 minutes in duration. In-depth interviews were conducted in classrooms at each participating Special Community Employment scheme and ranged from 30 to 45 minutes. Information regarding the research aim,

assurances of confidentiality, verbal consent and right to withdraw at any stage were repeated prior to commencement of each focus group and interview, and participants were encouraged to ask for clarification if needed throughout the course of the fieldwork. Participants were advised not to mention any names or identities throughout the research, and were advised that should any information regarding illegal activity be forthcoming, that researchers were duty bound to report to the relevant authorities.

#### *Data Analysis*

All focus groups and interviews were fully transcribed and supplemented by researcher held field notes and memos. Thematic and content data analysis commenced with several reads of the resultant narratives by both researchers, with periodic briefing sessions between both researchers assisting in the identification of emergent themes and categories of data, within an inter-rater system of corroboration, comparisons and interpretations of the data. The resultant data analysis was then presented to the Dublin North East Drug Task Force Client forum in the form of an executive summary of research findings and utilised in order to assist in the interpretation of findings and potential explanations for data outliers.

*The next chapter shall present the Dublin North East Drug Task Force [DNEDTF] Client forum results.*

### 3. Results: Focus Groups with the Client Forum

The researchers developed a template of potential questions in order to stimulate and facilitate initial Client forum discussions, with assistance from both the Treatment and Rehabilitation Sub Group of the Dublin North East Drug Task Force and the Dublin North East Drug Task Force tender brief (see *Potential Guiding Questions* below). The questions were approved by the Dublin North East Drug Task Force Client Forum in a meeting with their facilitator, and Client Forum representatives were advised of the date of the first focus group. Two focus groups (one males/one female in each, n=4) were conducted on separate occasions, due to the low recruitment rate at the first focus group. Additional attempts to boost Client forum participation in their research were made with facilitator assistance. Please note that participants did not wish to disclose exact ages, and indicated a range to the researcher.

#### *Potential Guiding Questions*

##### Experience of Methadone

1. What is it like taking methadone
2. Is the access to methadone services easy, and are there enough general practitioners [GP's] in the Dublin North East Drug Task Force area to prescribe and cater for users in all areas?
3. Are clients on Methadone Treatment stigmatised in their communities?

##### Recovery and recovery supports

1. What does recovery mean to you?
2. Has Methadone helped or hindered your recovery?
3. Have you ever tried to detoxify in the past and how often?
4. Do you think that you are being encouraged enough in your recovery?

##### Experience of Special Community Employment

1. What is your experience on the Special Community Employment scheme
2. Do the Special Community Employment schemes develop personal and employment skills and reach a pathway to return to work [i.e. Special Community Employment schemes and Individual Learner Plans]?
3. Is participation in the Special Community Employment Schemes seen as positive or negative in any way?
4. Education and training
5. What are the education and training needs of those on methadone?
6. What are the education and training needs of those in recovery?
7. How can education and training pathways be improved?

##### Progression

1. Is rehabilitation viewed as being on methadone or being drug free?
2. Is there a clear pathway for the user from engagement, through detoxification, treatment and on to aftercare?
3. Is there a coordinated and integrated service response with the development of formal care plans and aftercare in the Dublin North East Drug Task Force area?

##### Client Forum

1. Are you satisfied that the Client Forum is working well?
2. How often do you meet?
3. What supports do you want from the Clients Forum?

## *Themes*

The focus group narratives shall be presented in the following key themes; 'Access and Alternatives to Methadone'; 'Stigma and Prejudice'; 'Understandings of Recovery'; 'Special Community Employment Schemes' and 'Client Forum'.

### *Access and Alternatives to Methadone*

Participants commented on the treatment seeking restrictions in terms of detoxification, access and entry to methadone maintenance treatment. Information on and alternatives to methadone treatment were generally not discussed.

*"Any detox programme you are going into you have to go to \*\*\*\*\* Street to be assessed." Male aged 40-45 years*

*"There are enough doctors, it is too easy....they didn't offer me any other treatment except for methadone." Male aged 40-45 years*

*"I wasn't made aware of the long term effects of methadone, I was just put on methadone and that was it, I wasn't told that I had to detox. No one steers you in the right direction, when you are detoxing you're not up to looking for help you need to be taken by the hand ....I have tried a few times [to detox], but I wasn't given any help , if I was given help I wouldn't be where I am today..." Female aged 40-55 years*

One female participant described having to provide three positive urines for heroin in order to qualify for entry;

*"You have to give 3 dirty urines; it was hard for me because I had to score to give 3 dirty urines before I was put on methadone." Female aged 35-40 years*

Two participants observed the clinic settings to represent places where 'other' drug use was commonplace, and act as triggers for relapse;

*"I was with a clinic, but I learnt more about drugs that I didn't know about." Female aged 40-55 years*

*"I am trying to leave the clinic because I have the conversation that happens at the clinics, have you got any tablets, where do you get your gear..." Male aged 40-45 years*

A dependence on general practitioner [GP] relationships was observed by the group, which impacted on levels of methadone related knowledge, attempts to reduce dosage, support systems and seeking detoxification. General practitioners attitudes to drug use were observed to stifle attempts to reduce and come off methadone;

*"It's a curse because it's harder to come off than heroin. We don't get much support, the ball is in your court, the doctor has called me a 'lifer' that's way it's a curse. I want to come down on it but the doctor has told me I have to stop smoking hash." Male aged 40-45 years*

*"I was in my late 20's early 30's when I started on drugs...I hate it , its degrading, its taken over my whole life, I was with a family GP but I felt he was looking down his nose at me. The GP I have now is lovely ...he treats me with respect, I go in once a week to the doctor." Female aged 40 to 55 years*

### *Stigma and Prejudice*

Instances of prejudice and discrimination were frequently described by both male and female participants, and grounded in lack of individual control, stereotyping of the general public, medical and pharmacy staff, and concerns for lack of confidentiality;

*"If you're late for the clinic they may not have your script, you would have to ring , some people may not have any credit and can not ring in....Having to walk into the clinic, and then the chemist, some people are on 'dailys' and have to walk into*

*their chemist everyday and drink it in front of everyone. In the chemist there should be a partition... "Male aged 40 to 45 years*

*"it's not acceptable, anyone that does accept it, has had a experience of drugs somewhere down the line, those who don't accept us we are just junkies in their eyes....just with the chemist, they always watch you when you're in there. You have to go in by yourself, you're waiting around... there are times I have been waiting for 30 minutes, they put everyone before you...you're pushed aside until the coast is clear .when you're in the chemist you're ducking and diving watching to see anyone you know. There is a stigma there; people do look down your noses... " Female aged 40 to 55 years*

Female participants in particular described the inherent clash between mothering roles and that of methadone dependency, with subsequent loss of control and self esteem;

*"It's a lot harder for women, we are rearing children... It sticks with you then it gets passed down to your children, it will never leave you. " Female aged 40 to 55 years*

*"It's a godsend because I am not on heroin, my child doesn't know I am on methadone and I don't want them to find out either, I want to come off it... it's like a ball and chain and you need it, its horrible being on it 2 years ...70 mls I am coming down....My confidence was gone, its like a shame on the family." Female aged 35-40 years*

#### *Understandings of Recovery*

All participants agreed that rehabilitation meant being drug free [and not on methadone] with several observing how methadone stimulated the beginning of the recovery process.

*"It's [methadone] helped me...get me away from Heroin and other drugs, it has my relationship back with my girlfriend. Prison saved me, it's where I got clean....The amount of money I have spent on drugs I could have bought 2 or 3 houses...It's [recovery] the best high you can get ..When I graduated the hairs on my neck stood up when I got that certificate, I got mentally strong" Male aged 40-45 years*

*"Getting my life back, and to be just normal, happy a life without methadone....It's [methadone] helped definitely, it's got me off the heroin, I just want to get off it, I am too old." Female aged 35-40 years*

Issues pertaining to lack of control and autonomy in achieving recovery for the methadone dependent were frequently observed, and related to lack of control over dosages, lack of control over general day to day freedom;

*"It's a nightmare being on methadone...you're like a car engine you can't go anywhere, unless you have it inside you, you can't have a shower unless it's inside you because you are shivering.....Was 23 / 24 when I started....degrading, horrible, you can't leave the country..." Male aged 40-45 years*

*"In a way its helped but another way its hindered, I am still on the same amount as I was on when I started." Male aged 40-45 years*

*"My recovery started when I was on methadone and I stabilised but it also became a habit when I was topping up on methadone ...It's totally down to the individual....Everything my life, feeling well again, even though I am on a small amount of methadone I don't feel normal.....I fit in the best that I can, I just don't feel complete. I am grateful for the methadone that stabilised me, that got me away from all the hard drugs.... I want to do what normal people do, I want to go to college, I just don't feel complete while I am on it. When you drop your methadone you do become stronger and with a bit more normality, you get*

*stronger mentally...Going into 'detox' next week and hope to go to college, I need to keep busy because if I stay idle I could start using again..." Female aged 40-55 years*

### *Special Community Employment Scheme*

Several participants observed additional stigma, stereotyping and prejudicial experiences when partaking in the Special Community Employment Schemes, with these employment schemes observed to be stereotypical of active users, difficulties in being selected for entry and issues grounded in mistrust ;

*"A lot of people class the scheme as full of drug addicts... when you get clean you start building back up the trust with the family and everyone else. People know I am away from drugs I present myself better but because I am on a CE scheme and I walk out with others who are still using, they think I am still using." Male aged 40-45 years*

*"Helped by my family yeah, the scheme no , they say it's your choice, it's like a competition in there ( to please the co-ordinator) , I have seen a lot of changes....I am doing it ,it's up to me, I can see me walking out the gate with a skill, it's sad to see people walk out the gate and have nothing to do...."I would like to see these projects moving forward and getting people work, we should have a chance to get back into employment." Female aged 35-40 years*

*"I have seen people (workers) on projects before that wouldn't be suitable for the project so you would find it hard to confide in them.... I wouldn't be here today if it wasn't for the scheme...We can still link into the project when we leave if we need to chat." Female aged 40-55 years*

*"No There are hurdles in the way, its like running the grand national , there is no aftercare in the scheme , its too hard to get into these places, there are people who want help." Male aged 40-45 years*

### *Client Forum*

The participants observed that the Client Forum was operating well, but needed additional supports, greater levels of involvement from all relevant parties and consistent external facilitation.

*"Attendance at the meetings have been good , we all get on....We meet once a month but I don't think it's enough, we should meet twice a month, some people forget ...No one from the DTF has called out to any of the schemes. We need to advertise the forum in different places." Male aged 40-45 years*

*"Facilitators chop and change we tell one feller everything and then a new feller comes in asking the same questions." Male aged 40-45 years*

Several participants observed that each Special Community Employment Scheme project operated different guidelines for the selection of clients, and varied degrees of support for the Client Forum.

*"We need to give more people the option of joining. The management pick the people from the schemes if your stable ...some people are doing it off their own steam." Female aged 40-55 years*

*"We have to make our own way from the project, I have to come on the train, never get refunded, the key workers will never give us a lift." Male aged 40-45 years*

*"Yes its going forward and making changes...If we don't come here (to the forum) we get a red card, its like a red card for having a dirty urine....Female aged 35-40 years*

There seemed to be a lack of knowledge of the work, role and the structure of the Drugs Task Force.

*"Feed back to the DTF - They are hearing it back off the facilitator, we don't see anything being changed." Male aged 40-45 years*

*"They (DTF) are hearing but what are they doing...."We (client forum) are speaking up for the people, to give them a voice, everyone is losing interest because they feel nothing is being done....We should meet more often, some people that I know pulled out because they felt it wasn't going anywhere and just lost interest...The facilitators change a lot." Female, aged 40-55 years*

Following these initial discussions, the researcher discussed with the groups a definitive listing of proposed interview questions for administration in each Special Community Employment Scheme (see *Final Interview Questions* below).

### *Final Interview Questions*

Experience of Methadone

1. What's it like taking methadone?
2. Is the access to methadone services easy, and are there enough General Practitioners in the Dublin North East Drug Task Force area to prescribe and cater for users in all areas?
3. Are clients on Methadone Treatment stigmatised in their communities?
4. Are you satisfied about the length of time that you are on methadone?
5. Do you think you were given enough information about the long term effects of methadone before you start taking it?
6. What do you think about giving supervised urinalysis? What has your experience been?

Recovery and recovery supports

1. What does recovery mean to you?
2. Has Methadone helped or hindered your recovery?
3. Have you ever tried to detox in the past and how often?
4. Do you think that you are being encouraged enough in your recovery?

Experience of Special CE

1. What is your experience on the Special Community Employment scheme?
2. Do Special Community Employment schemes develop personal and employment skills and reach a pathway to return to work [i.e. Special Community Employment schemes and Individual Learner Plans]?
3. Is participation in Special Community Employment Schemes seen as negative or positive in any way?

Education and training

1. Are the education and training needs of those on methadone different from the education and training needs of those in recovery? If so why do you think this is so and what are the differences?
2. How can education and training pathways be improved?

Progression

1. Is rehabilitation viewed as being on methadone or being drug free?
2. Is there a clear pathway for the user from engagement, through detoxification, treatment and on to aftercare? If so, how difficult or easy is it to progress?
3. Do you think that local services are connected enough to each other? If not, how does this affect you and how could it be changed?

Client Forum

1. Are you satisfied that the Client Forum is working ok?
2. What supports do you need from the Client Forum?

*The next chapter shall present the Special Community Employment scheme interview results.*

#### 4. Results: Interviews with Special Community Employment Scheme participants

The interview narratives shall be divided into two parts, namely 'Experiences of Methadone' and 'Experiences of Recovery, Progression and Special Community Employment Schemes.' 11 females and 15 males partook in the interviews, with an age range of 28 to 49 years. Please note that some participants did not wish to disclose exact ages, and indicated a range to the researcher.

##### Part 1: Experiences of Methadone

###### *Methadone Access*

Access to methadone appeared to be relatively easy in terms of reasonable waiting lists, entry requirements of three 'dirty urines' and progression to weekly 'takeaways' after 16 weeks clean urines;

*"It's a lot easier, if you want the help, do a bit of running around, give a few dirty urines, there is help out there." Male aged 29 to 33 years*

*"I believe now in some clinics you can get in on a day or two." Male aged 39 years*

*"Yeah I have never had a problem." Male aged 34 years*

*"I go to the clinic, but if you're clean for 16 weeks you get weekly takeaways, I have done all that... I am on weekly take aways." Male aged 36 years*

Several female participants described having to use heroin in order to provide the required three 'dirty' urines;

*"It took me a few months to get onto a clinic so I had to smoke before I got onto one" Female aged 46 years*

*"When I went on I had to wait and I was using, and then I went onto my doctor... I had to wait...I had to give dirty urines before they would put me onto the programme that's a while ago." Female aged 28 years*

Some participants observing a 'conflict' where some private general practitioners did not request supervised urine testing;

*"I don't mind it should be one for all everyone should be doing it...not just half of the clinic. I am on a private doctor and I don't have to give supervised urine, a good few of us are on private doctors and a few private doctors won't give out that information". Male aged 37 years*

Some participants recognised the need for the supervision of urines;

*"I don't mind that, it's something you need to do to get clean." Male aged 33 years*

*"Sometimes it can be embarrassing....I suppose the supervised urines are there for you and so the doctor knows where he stands, obviously people are going to give dirty urines, I don't really have a problem with it." Female aged 28 years*

*"I don't mind that, I just give my urine." Female aged 49 years*

The majority of participants and especially female participants observed that giving urine samples under supervision felt degrading and embarrassing;

*"I understand the need for them but surely there has to be a more private way of giving them." Male aged 33 years*

*"It's not nice having to do it in front of someone....there are mirrors all around the toilet, I just want my life back I am sick of it ...I just want my life back. " Male aged 37 years*

*"Of course you have to give urines, its very degrading, I am at the clinic for too long and when I am giving urines, I ask myself what am I doing here, someone watching me going to the toilet." Female aged 34 years*

*"I suppose it's an evil necessity, it can be very degrading." Female aged 46 years*

*"Mortified, it's embarrassing I feel all my dignity has gone, to have someone standing there while you go to the bathroom, you have nothing left." Female aged 48 years*

*"I hate them its so degrading when you give your samples when people are watching you, it's a different world compared to when you're not taking methadone." Female aged 28 years*

Several participants observed the need for more clinics and doctors to prescribe methadone, due to greater numbers of prison discharges requesting methadone continuation, greater numbers of heroin addicts in the area seeking methadone when withdrawing, and anecdotal reporting of street methadone sales. It was reported that some participants had to go into the city to access services with bus journeys frequently difficult to negotiate with presence of drug dealers;

*"There aren't enough doctors in the area, on a Friday there are about 80 - 90 people between two doctors." Male No 12*

*"There should be more GP's prescribing." Female No 2*

*"I don't think there are enough GP's prescribing, I am moving from a clinic to a chemist, only this week they have found a GP to take me on...It seems to be very hard to get one outside of the clinics." Female No 8*

*"Not really no, my local GP isn't taking any more people on methadone, the clinic is going to get black and black, you see there is a lot of people getting out of prison now... they are staying on the methadone in prison and carry over, I think there should be another clinic in the area with more counsellors." Male No 2*

*"That place (the clinic) is a nightmare, people tried to break into again, it's the people that aren't on the clinic, guys that aren't on the clinic that don't get medication." Male No 4*

*"There are a good few clinics but there are waiting lists, there are more people who are on it that won't admit to being on it, there are a lot of people who are on methadone that aren't on heroin, they buy it on the street." Male No 9*

#### *Methadone related Knowledge, Information and Informed Choices*

Levels of information supporting initial and ongoing choices around methadone maintenance treatment and detoxification appeared scant, and grounded in dispensing controls and lack of contact with doctors and clinic staff. Basic consumer health, drug and side effect information was not provided with some participants questioning their informed consent for undertaking long term methadone maintenance treatment with little support or suggestions to taper or reduce, and less information provided with regard to final detoxification and treatment;

*"Most of the information I have learnt in clinics has not been off doctors its been off clients that's where you find the information...there is a lack of information, its only if you go looking for something then you're told about it other than that its just in and out, its like a revolving door you go in give your urine, you get your dose and then go unless the doctor wants to see you." Male aged 29-33 years*

*"No, I was never encouraged to detox, I was never told anything about treatment... I had to find it all out myself I am in treatment for the past 4 months and I am still only finding out about places..." Male aged 33 years*

*"No definitely not, you go into a doctors or a clinic and say you're doing heroin, they would write you a script, they are getting paid for it, so they just put you on it and forget about you, its not a detox.... You're on methadone end of story, just leave you on it." Female aged 46 years*

*"No , no information at all, not a bit of information, I was just put on it, I was never sat down and told what's happening , I was never told anything, this is methadone, come in every day." Male aged 41 years*

Other participants did not realise that methadone was a form of treatment for heroin dependency, with informal heroin using networks creating the 'street illusion' that methadone could act as a temporary stop gap when heroin could not be sourced;

*"No I didn't get any, I was told there you go this will get you through the sickness, the government are keeping us stable, for their purpose to keep us out of prison." Male aged 37 years*

*"No when I first started taking it, I hadn't a clue that it was a way of not being sick in the morning, until you did score." Female aged 28 years*

*"No, all I knew if you hadn't got money for heroin the methadone would help." Female aged 28 years*

*"I started buying on the street first, what I believed it was this magical cure that it stops you taking Heroin and then you just come down. I have come detoxed off heroin a couple of days sickness and it was over, but it was coming off methadone that started me using....The methadone was worse." Male aged 39 years*

Several participants described methadone related symptomatology, which in most cases were not explained or advised of by prescribing staff, and with understanding of methadone maintenance additionally compromised by the addictive state of the individual prior to commencement;

*"I think I was given enough information, I don't think I took it in properly its now I realise that methadone gets into your bones, its now I am having trouble with joint pains, but I believe it can be down to hepatitis which I have....I was given enough information I just didn't absorb it properly." Female aged 46 years*

*"No , I think there is a poster around but it doesn't tell you what methadone does to your body, I started having problems with my teeth, they are all rotted away and I clean my teeth everyday, I know its over the methadone. You go to the clinic... give your name... get the methadone through a little slot, there is a jug of water on the side if you want it, never said anything about rinsing my mouth out with water.." Male aged 33 years*

*"I suffer bad with my stomach, when I am taking methadone after I get all the pains." Male aged 37 years*

*"It brittles your bones and rots your teeth and then it's like another dependence I am being reduced at the moment. Have been on methadone for 11 years I never wanted to go on a methadone programme." Female aged 49 years*

Both male and female participants described the physical side effect of methadone dose consumption;

*"I am sick of it I would give up methadone today if I could, without going through the withdrawals...They are asking people like me to drink an equivalent to a cough bottle every morning. I am on 80 mls, that can't be healthy... I am feeling sick all the time I have no appetite." Male aged 33 years*

*"Drinking 50mls of methadone... I was feeling drowsy... I was feeling stoned it's just not because of detox... I am cutting down on my methadone I just don't want wake up every morning and take 50mls..." Male aged 29-33 years*

*"When you're on methadone your brain is a bit asleep." Male aged 28 years*

*"It's just waking up in the mornings feeling sick and when you're sick you have to take the methadone..." Female aged 34 years*

*"You get sick of going to the doctors and then go the chemist especially with my young feller and asking why I am going to this chemist (10 years) You're thinking, get up take my foy [methadone] [methadone] get some energy, you have no energy." Female No 7*

Several participants remarked that an attempt to come off methadone was more difficult than from heroin;

*"No absolutely not, we were told it was non addictive, that it wasn't addictive....they were just giving it out to people, the doctors were just writing scripts for money. Even clinics don't explain to people the side effects, no one gives you a leaflet.... when you take your fist sip of methadone you're on it literally forever until you decide to come off it and that when you do come off it you're going to go through hell....I was injecting for a long number of years, I stopped injecting because I couldn't get a vein, I was also using a lot of crack cocaine. I used the Heroin to come down off the crack and used to inject first thing in the morning to wake up. But now I use methadone which is just as addictive even worse I know friends of mine who find it very hard to come down even 2mls a week..." Male aged 40 years*

*"No I was told nothing about it , I was told it would help my withdrawals off heroin I think I was 17 when I first started taking methadone, I think they saw me as a candidate for coming off the heroin and then the methadone, but once I got onto the methadone I didn't want to come down even after being on it a couple of months because of the withdrawals you fear from it.. Its one of the biggest regrets of my life is going onto methadone; it's harder to come off than heroin..." Male aged 33 years*

*"I tried for over 2 years to stay at home and I came off it [methadone] for 4 months but I felt just as sick as the first day I stopped taking the heroin, Male aged 29-33 years*

Many participants described this situation as a 'government holding pattern', and sought information elsewhere via other methadone using client networks;

*"The government are keeping us stable, for their purpose to keep us out of prison." Male aged 37 years*

*"The government tried to put a plaster over something that was a bleeding wound and its after getting infected and the shit is going to hit the fan very soon..." Male aged 33 years*

*"I have no choice I feel like the government owns you when you're on the stuff, "Female aged 49 years*

### *Methadone and Control*

The majority of participants described the effect of methadone as long term control mechanism. Mixed observations were made with regard to lack of personal control and self efficacy to reduce their methadone dose or self detoxify. Relapses appeared part of the methadone pathway toward recovery;

*"I believe originally it was put out there for harm reduction, and now it's just to keep people quiet. I have been on the opposite side of a doctors biro and the power they have over you...I have been on drugs for most of my life from a early age looking back on it now it was a free drug...If you look out there now there are a lot of clinical addicts, they don't have to go out and rob, they don't have to go out and do anything, they sit back get their methadone , get their tablets... they are government junkies, these are young people growing up they don't see any wrong because it being given to them." Male aged 39 years*

*"When I was on it I didn't like it, I didn't like the thought of being stoned and not being able to function, so the idea for me was to get off it, so I tried to get off it, I kept failing, I kept going back and using gear and that, the workers here tried to show me where I was going wrong, I wasn't seeing it then...I eventually did and got off it, I set myself a target of six months and just got off it after being on it for 10 years. I started realising I was getting older, I didn't want to be 45 / 50 and still on it, I had to get off it." Male aged 41 years*

Several participants described the daily restrictions of methadone consumption in terms of personal freedoms and said;

*"It was a ball and a chain I had to take methadone everyday, I couldn't plan too much I couldn't commit too much. I was always conscious I had to take methadone...I had to go to a doctor I had to go to a chemist, so it was a big part of my life it was a necessary evil..." Male aged 28 years*

*"Horrible, I am lucky I get a weekly take away, I am on a private doctor, that's part isn't too bad but having to take it, your restricted, I tried a good few times but relapsed, been on it for 7 years." Female aged 46 years*

*"It's like a ball and chain you can't go anywhere, it holds you back. It does keep you off drugs. I wish I didn't have to take it..... It's like holding you to ransom. You have to be at the chemist everyday." Female aged 48 years*

*"Its horrible, getting up in the morning time, taking it, if you go away you're worried about your methadone, I am trying to get off it this year." Male aged 37 years*

Some participants observed a fear to cut down completely and appeared satisfied to remain on low dosage methadone. However, other participants described intense frustration with long term methadone dependency and indicated earnest intentions to detoxify, in order to take control and return to a normal life;

*"The doctor told me I was on it for life, I am on 80mls now and trying to cut down 1ml or 2mls a week, there is help. Some people like the methadone and want to get off it. I have been on it for 12 years...I have to get back to a normal life." Male aged 37 years*

*"Compared to heroin when I first tried getting onto methadone in 2002, I planned to stay on it for a short time because I7 or 18 years of addiction behind me, I never planned to stay on the methadone for this long. My experience was I would get onto methadone, the doctor would get me stable, and then we would work down from that, it hasn't worked out that way, I started in 2002 and I have been at the clinic ever since.. They started me on 30mls and then went up 10mls increments at one stage I was on 90mls I was on that for a couple of years, I have cut down and now on 50mls. I wanted to do a detox this year." Male aged 29-33 years*

*"It's a nightmare , basically it's a nightmare, I am one of the first people to be on a clinic in this area me and another guy, there used to be two pre fabs, you went in and gave a urine in one, came out and got your medication in the second one, that's going back 22 years ago and I am still the same...I got nowhere in life."  
Male aged 37 years*

Most participants expressed concern at the length of time for their methadone maintenance treatment with a majority of participants observing that they were never advised that this therapy was intentionally long term and had subservient relationships with their doctors;

*"No it should have been shorter, when I went on methadone I was told it was only for 6 months, that was ok...as I could get myself on it and then somehow come off it but then it was going on into years and years, I was never seeing no way out, not that I was even thinking of a way out because I was getting it all the time, it was handy enough to get, you just keep going back for it." Male aged 41 years*

*"I don't think I should be let go on the length of time I have , obviously its up to me , if there had been some kind of push from the doctor...I would probably be off it, I am kind of person who takes what's given to me." Male aged 34 years*

*"Oh god no, once I started the methadone clinic I said I would do it for 6 months turns into 2 years and 2 years turns into 3 then 4 (on it for 6 years) I hope to be in treatment in a few weeks... At the end of the day it's our own choice, you can't blame the doctors or anybody else for me being on methadone for so long, it's my choice, it's my fault. I have been off methadone for 2 years and I will do it again, I didn't have the tools for staying clean..." Female aged 34 years*

*"No I think I have been on it for too long, actually the last 3 years has stable, its the longest I have ever been on it, the doctors don't encourage you to cut down, you're the one that has to run to them and say that you want to cut down ...otherwise they wont cut you down which I think they should even 2mls every 2 weeks or something but not to keep you on it for life." Female aged 48 years*

*"No I wish I was off it but through my own fault I am on it longer." Female aged 28 years*

*"No I should have been encouraged to come off it years ago I have been on the clinic since I was 16, they told me it would be a three month detox, now I didn't because I have got strung out over the years." Female aged 28 years*

*"I am as much to blame for not speaking up for myself but I have only learned that in the tools that I have learnt down on the CE scheme. I feel when you become a addict especially a long term addict its like your life stops, I feel like that same 15 year old that had the first smoke, I don't feel like 32 years old." Male aged 46 years*

Many participants described a lack of doctor client dialogue, in terms of reaching a mutually agreed timeframe for reduction;

*"I was planning to go into a detox in a few months, I went to my key worker and talked it out, because I am clean and on take always, I have been on take always for about 7 years. I went to my doctor and explained to him that I got myself down to 50mls I spoke to the doctor , I hadn't seen the doctor in 2 years I would only see the doctor if I had a dirty urine. I was smoking cannabis and my doctor said I want some clean urines and then I will let you come down on the foy [methadone] [methadone]. I felt the doctor was not listening to me. So I decided that I was going to carry on my own and now I am on 20mls of methadone and now I hope to go into treatment very soon.....The thing is with the doctors*

*once your stable they don't care, they don't want you to go down they don't pressurise you and as you see in my case clean for so many years and the doctor won't let me go down because of cannabis. I tried explaining having to wake up in the morning and drink methadone...Now I want the so called normal life...I am alright on 20mls, my brain is starting to work a little bit better, things are working out I am starting to feel normal again. Taking 20mls is nothing to me... I have to say the clinic and the staff have been great. I think when the doctors get you stable for a certain amount of time, you should be called in every few months and asked if you would like to come down off your foy [methadone], if that was the case for me I would have been off it. I know it's meant to come from me, but it could be discussed with the doctor." Male aged 29-33 years*

*"I would like to see doctors cut people down,...it seems they want to keep you on it when I cut down by five mls to 80 I was doing grand on it and he kept saying 'do you want me to put you back up' he shouldn't be saying that he should be saying you're doing well, cut down a little bit more." Female aged 48 years*

In contrast, several female observations appeared more accepting on the general practitioners part;

*"My doctor is so caring, he doesn't judge you, your not a no-hoper, you can do it, he encourages you, even if you're after relapsing, he will say get back up there and don't give up." Female aged 34 years*

*"Once the doctor knew I wanted to go in for treatment (detox), he was very supportive I don't think my doctor is as bad as some of them, some doctors will give, give, give... I couldn't even get tablets off him." Female aged 28 years*

*"My new doctor is much better she got me to cut down and took me off all the tablets, she sees her patients as individuals. Since she has come along I feel I have been noticed. I don't know if she hadn't had come along and given me the encouragement I don't know if I would have had the strength to do it myself." Female aged 28 years*

### *Stigma*

Experiences of prejudice and discrimination attached to methadone maintenance were frequently discussed and related to feelings of public labelling as 'junks' due to prior drug addiction;

*"People on methadone some people would view them as being drug users, that's down to a percentage of people that abuse the system that reflects on the lives of people trying to get their lives together. I think there are 2 different categories of people who are on methadone, there are people on methadone living a life and there are people on methadone trying to live a better life." Male aged 28 years*

*"Its hard to get on in the world... you are branded a junkie." Female aged 49 years*

*"People drive by and say look at him... he is on foy [methadone], people look at me and say he is a scumbag." Male aged 37 years*

*"Not so much being on methadone but stigmatised because they have been on drugs, when people hear you on methadone they hear your off crack they hear your off heroin fair play you're doing well, a lot of them wouldn't understand it 'you're a junkie scumbag' you robbed my house, you took this from my son, you sold this to my son / daughter, that stigma never goes ..There are a lot of people who still look at me as junkie scum, but I am not, maybe when I was in active*

*addiction, that wasn't the real me, I am only getting to know who I am now and I have regrets." Male aged 40 years*

*"What people say to your face would be different to what they would say at home....If you're a heroin addict in this estate you're seen as a scumbag. When people know you're on methadone you're more accepted, everyone wants to feel more accepted. Whether you're an addict or a recovering addict or you have never took drugs you want to walk into the community and hold your head up high and say hello to your neighbours without expecting dirty looks back." Male aged 29-33 years*

Feelings of stigmatisation occurred most frequently within clinic and pharmacy settings when purchasing and consuming methadone on the premises;

*"Its real downgrading because you have people there watching you drinking it, the whole going into the clinics and everything, you feel really below people, you have people driving past going to work and people at the bus stop and everyone knows what you're going in for, there is no privacy in it, everyone knows your whole business. Most times before I go into the clinic I would be watching who was at the bus stop or driving past." Female aged 28 years*

*"Yeah, people look down on you, going in and out of the clinics for the methadone... people don't want to associate with you, they don't really look at you as a person, your downgraded if you're on methadone, you're a junkie...you're no good you're this that and the other." Male aged 41 years*

*"Yeah very much so, every morning I have to go into my local chemist and I have to drink my methadone in front of all the other customers...its very embarrassing, because as soon as they see you taking that cup they say ahh he's a junkie, these are neighbours that would have thought I was somebody respectable until they see me getting my methadone in the chemist." Male aged 33 years*

*"Foy [methadone] isn't really a stigma around here but I have been in the chemist when the neighbour comes in, I go like a tomato, because its embarrassing, they have started to put up little alcoves, there is methadone written on it, so if you seen coming in people know exactly." Male aged 42 years*

*"Some people would see you coming out of the clinic and then straight away they know what you're on methadone, straight away they are addicts." Male aged 34 years*

*"Yeah, when I am at the chemist I ask the girls not to give it to me in front of people I know, they will think obviously she is on drugs or a junkie, I know they have their reasons but we not all bad..." Female aged 28 years*

Pharmacy staff were also observed to engage in biased behaviour;

*"One of the chemists around the area, he wont let you go in if there is someone in the chemist, he tries to hide handing out the methadone, it's like he doesn't want to hand it out but he wants the money for handing it you." Male No 5*

*"When people are on methadone come in he stands there with his arms folded watching them, its like do you think they are going to rob you or something, it's like being labelled. One of my neighbours was in there the other day and he shook his head at me, he won't give it to me if there is anyone in the shop." Female No 5*

Several female participants reported attempting to hide methadone use from neighbours, with some accessing pharmacies outside of their local area;

*"I was actually going to a chemist who was away from my area for 1.5 yrs every single day including Sundays, there is a chemist around the corner from me, but I*

*have known him for years and years, so I wouldn't go to him because I didn't want him to find out." Female aged 48 years*

*"You find your neighbours look at you differently when they find out you're on a methadone clinic, some may talk to you some may blank you altogether. " Female aged 46 years*

*"If you're known to be on methadone, you're judged, you're a scumbag, you are classed as a junkie, I am the only one on my estate as far as I know that takes methadone, to them I have been off it for years and I wouldn't let them know I was still on it, its kind of a shame thing, there is a label with it." Female aged 46 years*

*"I remember bringing my young feller around to school; I remember standing in the school yard everyone was looking at me at me when I brought him into school. It made me feel belittled, useless and want to use more because the way I was perceived." Female aged 28 years*

However, one female participant observed community level support for treatment seeking;

*"When I went in for treatment the people who I thought was looking down on me were coming over to me saying you look great , fair play to yer, people that would have walked by me in the street. I felt great, it was great to hear it, it did boost my confidence. So what people were saying to me that you're a better person now you're clean than you were 6 months ago when I was using. I was still the same person only I had a problem." Female aged 28 years*

Varied levels of stigma attached to families experiencing heroin addiction were reported;

*"A lot of mothers are stigmatised, I know my mother does because some of her sons ended up on heroin. When it came to her youngest son getting help she was heart broken, she was wondering what the people in the community think..." Male aged 29-33 years*

Several female participants described attempts to hide methadone use from their families and children;

*"I think there is a stigma attached to clinics...where as with a doctor it's not so noticeable, if you don't want your family to know and you go to the doctor its not questionable whereas if you say you're going to the clinic, what clinic,...what's it for. "I think I have been on it too long, I have been on methadone for 11 years; both my sons know my mother went to her grave not knowing...my brother and sister they don't know. In my 20's I never viewed I would end up an addict. I have to say that I blame where I live on that, but everyone makes their own choices. "I would have like more support from my family, but they don't know." Female aged 46 years*

*"There are lot of girls in the clinic, it doesn't seem right for a girl to be taking methadone especially a mother, I have 3 children, it doesn't feel right to be on methadone. I go away to see my mother and my doctor gives me 3 weeks supply I have to hide it from her. ..My mother doesn't know I am on it... My children know I am on it, I tried to hide it for a while, they don't like it, they don't like it at all, my daughter in an argument will call us junkies... my husband is on methadone too..I hate that word junkie." Female aged 48 years*

*"I can't even look at people because I have been on drugs, my mam never even took a valium, never touched hash, my mam nearly died when she found out I was on drugs." Female aged 49 years*

Some participants described the effect of addiction and methadone maintenance on personal, peer and family relationships;

*"Now that I am off it my old friends are all around me more so and my family, I am looked at differently, when people knew I wanted to come off it friends supported me while I was on it they didn't want to know me and now its helping me to know I had people there all along I just had to make a decision either drugs or my friends....my friends saw methadone as a drug, they say its the same thing, its only a substitute." Male aged 41 years*

*"I have had girlfriends that are on foy [methadone]; I got rid of them because I didn't want to be with a partner that was on foy [methadone]." Male aged 37 years*

*"Even my sister we don't get on, I got clean a few years ago and it was like our relationship was totally different, she was acknowledging me but now because I am back on the methadone we wouldn't really get on." Female aged 46 years*

*"Unless you have it in your family people can be quite small minded as they don't understand. It's in a lot more families now so I don't think they are as quick to judge." Female aged 28 years*

Other female participants described the 'double standard' of public acceptance of male methadone treatment as opposed to that of females, which was observed to be grounded in socially defined roles for females as mothers and caregivers;

*"It's more acceptable for men to be on it, if myself and my partner was on methadone and we wanted a child, it would be alright for him to be on methadone but I am on methadone I am the one bringing the child into the world, who has to go through withdrawals, I would be the one carrying a methadone baby." Female aged 28 years*

*"Yes because the woman normally have the kids but that's a simple fact of law, its good that women on methadone are able to keep their children, having said that it is much better if your not on anything, some women are able to cope very well and give their children a very good life, and its a shame that they are all stigmatised, there are a lot of good mums around on methadone." Female aged 43 years*

*"You could see people looking at you because you're pregnant and still on drugs, you are looked at differently..." Female aged 28 years*

Some female participants observed the connotations of heroin addiction and sex work;

*"Where I come from I know some girls that have been prostitutes for drugs, its like it when you're on methadone men think you're a prostitute, you're easy, like every woman is a prostitute for drugs, which is not the case , everyone's rock bottom is different.." Female aged 34 years*

#### *Drug using Pathways and Addiction Displacement*

Varied pathways of heroin dependency were observed with several female participants describing how heroin initiation commenced for them;

*"I started late I was 26 when I started I didn't touch it ... I was going through a stressful time and someone offered something to me to help me through and I took it ...it was heroin... I didn't even know what it was I was taking. When I took it , it did take the pain away, but the pain is always there the next day, that's how I started They say it only takes once ... then its like a vicious cycle." Female aged 48 years*

*"When I moved up here I wasn't an addict and I am up here 15 years, we only became involved in drugs when we moved up. I was 33 when I started, a family member was using heroin, introduced us to it. I started smoking then moved to injecting, I never injected myself, my partner always looked after me in that respect even up to this day I never had the nerve to." Female aged 46 years*

*"No , if I knew what I was getting into , well I suppose I did know what I was getting into but if I knew of different routes to go down, I started taking Heroin when I was 18... because I was a drinker I never really got strung out and when I had my baby I went from working all the time to having a baby, and at home minding the baby and I was bored, I was doing that to fill up my day I didn't know any other routes.." Female aged 46 years*

One male described his reasons for heroin use, with some male participants describing their experiences of a 'revolving door' of drug use, crime and prison when using heroin;

*"Even before I touched my first drug I was wired, I found heroin actually calmed me down, and I was saying to myself ' do you know that this actually helps me' feel more settled in myself. My life was simplified finding the drugs, buying the drugs and using the drugs that's what my day conceived of." Male aged 39 years*

*"Jail back out on the drugs, back into jail, back onto drugs, back to crime , back to the street hood, just got nowhere you know. All my mates used to show me bundles of 20 pound notes and bundles of this and that they were after robbing this and stealing that, I said why should I work for this when I can have that, so it went from this to that.. from then on it was jail drugs jail drugs. I am trying to get in somewhere but I can't get in anywhere...I am trying my hardest to get in somewhere." Male aged 37 years*

In addition several participants observed that methadone maintenance appeared to represent a final connection to drug using circles;

*"I started on Heroin 10 years ago, It takes over your life its like liquid handcuffs, its terrible if you're sick, you want the foy [methadone] and if you don't have enough foy [methadone] you want to use...its a vicious circle. When I was pregnant I would be sick when I took it. People used to say to me you're mad going on that foy [methadone], but I had no choice, but I was never given any other choice." Female aged 28 years*

*"Before I went into prison I wouldn't have got a hello off the neighbours but now I am out and they see me now and they know I am on the methadone now, its no problem for them, they know he's not up to his old tricks getting arrested, they see the improvement in me... but I know the foy [methadone] is still on my shoulder." Male aged 37 years*

*"I came out clean after doing 3 years in prison, when I came out I was out for 1 ½ years.. I got a job when I got out, I started using again, its a vicious circle, when you go into a room and they talk about addiction, they draw a circle and they put all these things in the circle, its one vicious circle, you are going into prison... you're coming back out... you're going back in ...hanging around with people who are actively using, it's not a healthy thing it wasn't healthy for me. I haven't been stopped by the police in a 1 ½ years because I now keep myself to myself. Male aged 36 years*

Other male participants described how prison methadone maintenance gave them the opportunity to commence recovery;

*"Its kept me stable since I came out of prison, in prison it didn't... I was on a high dosage when I came out of prison, I was on 120mls and now I am down to 20mls... A year ago my opinion I was never going to give up the foy [methadone]. I was always kind of afraid, but I cut down gradually, it's kept me stable since I came out of prison since 2004." Male aged 49 years*

A female participant described her experiences of heroin dependency which culminated in homelessness;

*"Towards the end I became homeless , I was living in a hostel in town so I would have to get my bus fare to get to the clinic in the evening, sometimes the doctor would wait, and want to see me, I would be in tears upping my medication, it was a very traumatic time for me , however it was probably the best thing that did happen for me because when I was living in a hostel. I started going to NA meetings and began to see that there maybe a way out of this and began to realise the problem isn't everyone else , its actually me, so the methadone was the last drug I let go of." Female aged 43 years*

Poly drug use and switching of drug dependencies when on methadone were described by participants, with cannabis, prescribed anti anxiety medication and alcohol commonly used;

*"The way I look at it its a substitute for Heroin, if you haven't got Heroin they give you methadone, its just another drug I don't want to be on...I know these problems I have brought on myself through my addiction to drugs. When I went on methadone I thought it made me worse. I was using on top of it, a couple of years ago I was taking 70 tablets a day on top of 110mls of methadone, Male aged 36 years*

*"Its the body that reaches out for the tablets, I don't take heroin, I don't take crack or cocaine, my addiction is sleeping pills that's my addiction, I am after going through 2 packets of sleeping tablets this morning, I am still on methadone.." Male aged 37 years*

*"It helped me stabilise for a period of time but after that period of time has gone, if there is no action being taken on the next step to reduce, I got bored with the methadone, I was able to justify taking other drugs as I was taking methadone.." Male aged 39 years*

*"The clinics have changed... we tell you what you can have, not what you want. My doctor has taken me off a prescription that I need everyday, which means I have to go onto the street and buy it, so the GP is putting me in the position where gangs of drug dealers are to buy these prescription tablets." Male aged 40 years*

*"I am on tablets for 20 yrs they never cut them down, its going to be hard to come off them if I ever do." Female aged 48 years*

*"I wasn't just on methadone I was on crack cocaine, heroin, alcohol, anti depressants, sleeping tablets and anti anxiety tablets. I used to go everyday to get it because I was using and I would have to be breathalysed because I was drinking... If I was over the limit I would only be given half the dose, I felt they were checking up on me, that was my punishment..." Female aged 43 years*

*"They should give another alternative to people and say would you not try and take these steps instead of jumping and putting them onto methadone....they are giving them selves another crisis because they are on methadone and still using and then they have 2 habits, they are injecting heroin and then taking the*

*methadone. Heroin is easier coming off than methadone. Once you're on methadone that's it then you need to go into treatment to come off the foy [methadone]."* Female aged 28 years

A male participant commented on his purchasing of methadone on the street in order to deal with heroin 'droughts' and described switching back to heroin in order to deal with methadone withdrawals;

*"I am not on methadone now...I was on methadone for 12 years and buying it on the street. In the beginning if I was to use it properly, the purpose was to take you off heroin, what I found after a while I just got used to it I felt that I was still missing something I started dabbling in tablets...Then when I wanted to come off the methadone I had to use heroin because the sickness off the methadone is more severe than it is off the heroin."* Male aged 39 years

Several male participants described how methadone maintenance treatment coupled with the prescribing of anti anxiety and night sedation medication contributed to recovery apathy for some;

*"People get their tablets, they get their methadone and have a plasma TV , they are putting in what they want for their dinners, who would want to leave that environment....that's the flip side of it."* Male aged 39 years

*"Methadone is good and bad short term its good but long term, I see friends of mine that are on methadone on years and years taking tablets and having a few cans, they don't look happy. I think methadone helps society more than it helps the addict."* Male aged 28 years

*"People like me but they hate what I am doing to myself with the tablets and the foy [methadone]...and I hate what I am doing to myself. "* Male aged 37 years

Clinics appeared to be a hive of illicit drug and methadone diversionary trading, and represented a very real concern for some participants in their quest for recovery;

*"You see people coming out of the clinic with loads of take away and you know they are going to sell it."* Female aged 28 years

*"The problem is my clinic is a drone for drug dealers its by the fields, always getting asked when I leave the clinic if I want to buy gear , there are plenty of tablets which is ruining more estates than anything else, they are ruining the communities."* Male aged 29-33 years

*"Even if I stay away from all the guys using drugs i am still going to bump into them in the chemist."* Male aged 33 years

### *Detoxification and Treatment*

Several participants observed difficulties in accessing residential treatment;

*"There are hurdles, I think if it was too easy, people could go out and relapse."* Male aged 33 years

*"I can now walk down the road knowing I haven't got warrants. Its not easy getting into a treatment centre there are a few bumps here and there."* Male aged 36 years

*"I know why I had to jump through hoops to get in here having to prove myself to lots of people."* Male aged 42 years

A lack of information around detoxification processes and settings was noted;

*"You would have to make all the arrangement before you went for it , there are ways of doing it but you have to put the work in, nothing is going to happen you have to put the work in. There is not enough information around...there is nothing*

*you can pick up and you can do this, this and this, there are numbers you can ring. ... There are no leaflets telling us how to come down off methadone or reduce there is nothing, there could be people thinking that way and don't want to approach their doctors." Male aged 40 years*

Both male and female participants described self and assisted detoxification attempts when waiting for treatment and frequent experiences of relapse;

*"Tried so many times, always failed." Male aged 37 years*

*"I have tried detox a few times, the first time its a shock I didn't know what I was going into, the second time I knew the rules it was easier for me, I completed it, I came out and still had a lot of stuff I didn't clear and I relapsed." Female aged 46 years*

*"I have done successfully twice." Male aged 33 years*

*"I have done it once stayed clean for a year." Male aged 34 years*

*"Quite a few times, when I was waiting to go into treatment." Male aged 28 years*

*"Twice, tried detoxing off methadone while pregnant." Female aged 34 years*

Tapering and detox attempts were frequently observed to be the client's responsibility;

*"I am with the same doctor for about 10 years and never got on with him, didn't want me to do detox, doesn't want me to get off it, the only reason I am going into treatment is because I had to cut down from 120mls down to 40mls because he wouldn't sign any forms for me, he didn't want me to detox myself, I was throwing foy [methadone] away in the clinic, I was bringing in my own measure....they were giving me my cup of foy [methadone] I was measuring out what I wanted to drink and throwing the rest away into the bin. I had to come off the tablets myself, the hash myself and the foy [methadone] myself. The doctor told me I was a junkie for life, I have heard that he has said it to a load of people.... just think he wants people on his list so he can get paid for them" Male aged 33 years*

*"Every time I went to my previous doctor he was putting me up 10mls... instead of trying to talk or put me onto a counsellor, my previous doctor never spoke to me about recovery, where as now my new doctor said to me I can see you off everything in the next couple of months because your doing so well...I don't want my kids growing up seeing me on drugs..I am comfortable on the 30mls I don't want to be taking 80mls." Male aged 36 years*

*"Been on methadone since 1998, kind of left on, it depends on the doctor, the first doctor pushed for me to come down off it, but the doctor I am on now is content to leave me what I like I could do with a push you do get a lack of motivation when your on it for a certain amount of time and end up falling into a routine." Male aged 34 years*

*"Methadone is like a ball and chain around your ankle, the GP I was with was not happy for me to go into detox, no matter how many times I asked him, I was put up to 80mls by the doctor even though I was coping on 40mls I wasn't ever encouraged by my doctor and its only because I choose between living and killing myself, that I am here talking now..." Female aged 43 years*

Female participants in particular described personal attempts to reduce methadone dosage without medical assistance;

*"Sometimes at the weekend I would take 40 mls instead of the 70 mls and I get through it. Yes, I forget too many, but I have always tried to do it on my own."*  
Female aged 49 years

*"I tried a 2 week programme, but I think the reason it failed you are meant to have total peace and quiet, I tried to do the detox and look after the house and the kids it just didn't work so I just gave up."* Female aged 46 years

*"Detox its tough the first week was really tough, you get used to waking up knowing you're not going to be taking it, no more doctors, no more chemists..."*  
Female aged 28 years

Several male participants described prison detoxification;

*"Yes in prison, went through the detox, this was before the maintenance.. it was a crash course over 2 weeks."* Male aged 37 years

*"Sometimes I would go a year on methadone or the gear, then I would get fed up and try and detox, but I was detoxing wrong, I was doing it real fast to come off it. I was locked up in \*\*\*\*\*, I didn't want anything to do with drugs or methadone so I just came off it, I was doing great inside as soon as I came outside the world was totally different to me, I was only in there for 3 months, mentally my head I was seeing things differently, I couldn't function in the world, so I ended up going back to the same situation, that's how I ended back on the drugs. For some reason I didn't know where to fit in, I just didn't know how to speak, I could get on but I didn't know how to get on, when I had a conversation I didn't know how to hold a conversation. Since I came off the methadone outside everything is a lot clearer and easier."* Male aged 41 years

Only one male reported never having detoxed before and said;

*"This is the first time ever, it's taken me a while but looking forward to it."* Male aged 33 years

## Part 2: Experiences of Recovery, Progression and Special Community Employment Schemes

### *Perceptions of Recovery and Rehabilitation*

Most participants, and especially females observed how methadone maintenance treatment and daily consumption opened the door to a revised and positive day to day functioning which replaced prior drug seeking, purchasing and using patterns and also the opportunity to make plans with regard to family and future goals;

*"I am clean now, I knew why I was taking it.. it wasn't a long term thing... I had expectations where I was going; it was a means to an end. At the start it got me stable, it helped me function better in life; it took the madness out of being active and out there looking for heroin."* Male aged 28 years

*"I feel that if I hadn't had methadone I wouldn't have the stability or the life I have now, I was able to continue to be a mother and work, have a normal life, if I hadn't had methadone I would have had that."* Female aged 46 years

*"Its not nice its very dependable, you have to depend on it and going to the chemist everyday, especially if you have children but its helped me a lot, from being on drugs most of my life, its settled me down, got me through my life, I have been in it since 15years old...Its not nice having to go the doctors for 14 years every week and then going to the chemist every week as well, its a routine its like a little job."* Female aged 28 years

Recovery appeared to mean different things to each participant and ranged from simply getting onto 'methadone maintenance' towards 'complete life change involving new friends, new environments, new relationships, employment prospects';

*"Two years ago it would have just meant, going into detox and coming off drugs, but recovery to me is a lot more than that, recovery to me is getting back to the issues, that led you to the drug taking...There are all different reasons. I don't believe anyone can just stop foy [methadone] without putting everything into order before hand, otherwise you still have the civil war in the head that you have had for years...use or not use. Recovery is an individual thing, recovery isn't just coming off methadone, its a hell of a lot more than that, its about occupying time, trying to get back into society, trying to get back to the normal things, its filling the void that the heroin and everything that comes with the heroin use, the friends , parties." Male aged 29-33 years*

*"It means my life back it means getting something that I want ...it means I have a future of some kind a happy future, no depending on nothing." Male aged 41 years*

*"Recovery to me, means clean, to be clean a change of friends , a change of scenery, they are not your friends, they are your drug partners.....your drug associates, they will stab you in the back for their next fix, they are not your friends. Your friends are the ones that work Monday to Friday and ring you up at the weekend and ask to meet for a pint or we are going for a game of snooker, they are what you call friends, their wives invite you over for dinner, your kids play with their kids, they are what you call friends, not the ones that when you overdose they are going through your pockets. You need to change your friends and your location and your way of living and if you can do all three." Male aged 37 years*

*"It means getting my life back, getting back into working I have lost 15 years of my life over this stuff...I could have my own house , my own everything, but I don't have any of them, still living in my mothers, no job at the moment, no car I am on the welfare. Treatment means getting back to what normal people do." Male aged 33 years*

*"The recovery process is within me it is what I bring to the table, its now giving back, its giving love to my child instilling values into her, its not material. I have structure, direction and routine now.... something I never had. Male aged 39 years*

Participants observations around 'being clean' were mixed with some observing that 'clean' meant on methadone maintenance therapy (not using heroin) but using other drugs such as alcohol, tablets and cannabis, and others observing 'clean' meant 'drug free';

*"When people find out you're not using heroin, if I say to someone I am clean...I am clean means I am on methadone and I am not on Heroin, a lot of people are very supportive of you. " Male aged 29-33 years*

*"Breaking the old habits, getting off all drugs and having help there to do it." Male aged 37 years*

*"The process of coming off methadone, that's what I see as my recovery. I hate the hold it has over my life. I feel like I will never be able to move away from this part of my life while I am on methadone." Male aged 33 years*

*"Learning to cope to live life without drugs, the emotional side of it, I would have thought at one time that getting off drugs would have been enough but then when I was off drugs up in my head, I just wanted to go back using , I would sit down and watch the telly and be thinking of drugs the whole time.....This time now I am*

*on methadone and stopped taking everything, I kind of have some of the work done, so that when I do come off the methadone I will be more prepared." Male aged 34 years*

*"Coming off all drugs and getting back to normal, just live a normal life, I take everyday as it comes." Male aged 49 years*

*"No methadone, I would like to be off everything." Female aged 48 years*

*"Recovering from Heroin , to be clean, clean to me means not touching heroin, last time I wasn't touching Heroin but I was still on the foy [methadone] and I felt like I was clean, that was clean to me." Female aged 28 years*

*"Before it was being heroin free and now its being heroin and methadone free , just being able to get up and not taking it and not having to get up a hour before the young feller, take it to try and get some energy." Female aged 28 years*

Relapse was observed to be inherent part of recovery processes and intensely reflected on by each participant;

*"I have had a multiple years of slipped and relapsed, each time I am learning a little more about myself....In recovery you go through a process of making mistakes and realising your boundaries and certain things I can't do. I used to think if I didn't take heroin.. I would be grand have a few Pints have a few E's and I would be grand, people told me I couldn't do that stuff but I had to experience it myself .....There is a lot of pain involved in relapse." Male aged 28 years*

*"Recovery means staying clean, just taking one day at a time and get to the core of the problem why I took drugs." Female aged 34 years*

Female participants appeared more reflective as to personal definitions of recovery and very much grounded in personal development and mothering roles;

*"I can spend more time with my son, give him more time than I have with my other 4 kids, I can give him more attention, I am seeing more of life doing more things I didn't think I could do, I didn't think I had brains but your brain does wake up." Female aged 49 years*

*"Getting your life back, building a life, getting your confidence back. I have been in and out of recovery for a long time for a good few years, there was no aftercare support, there was never any of that, recently I have started going to NA meetings, I find they are very good. I don't want to go back into the drinking scene again. I don't want to go back into the drug scene again. I just want to have a normal life and with NA they are on the same wave length." Female aged 46 years*

*"Trying to become something of a person before I became an addict, you never actually clean unless you're clean of everything....Before hand I was a wife , a mother , a carer , a homemaker I am still some of those things but not to the ability I could be. I could keep a better house; I could be more proactive with the boys." Female aged 46 years*

*"First of all get stable then my goal is to get clean and live a life without drugs, I have no huge expectations I just want a small home where I can come and go and not have to drink something every morning to make me feel good." Female aged 28 years*

*"I want to be a mum that picks them up from school they don't see alcohol in the house I want my children to experience a happy safe home. I have had to work very hard on relationships it's effected all my family." Female aged 43 years*

Views on rehabilitation appeared mixed and similar to that of recovery but utilising methadone maintenance therapy for rehabilitative medium. The connection between recovery, rehabilitation and participation in the Special Community Employment Schemes shall be discussed in the later section on the Special Community Employment Schemes.

*"In a phase moving into full recovery no methadone no nothing no drugs" Male aged 29-33 years*

*"It's a very personal view; I think that someone in recovery is actively trying to get sorted. I will consider myself fully rehabilitated when I am off methadone." Male aged 33 years*

*"There are 2 groups, one on methadone and the other drug free, the drug free have to work a lot harder....Different people view it differently,...Rehabilitation itself is being off methadone." Male aged 33 years*

*"At times you need to rehabilitate yourself. No matter what you do, you need methadone rehabilitation on methadone to get your head together." Male aged 41 years*

*"The recovery process has started when you're on methadone, now its abstinence from all mood altering chemicals." Male aged 39 years*

*"Being drug free and being on methadone is actually great for me I am more positive in myself." Female aged 49 years*

*"Definitely drug free, I don't consider myself clean because I am on methadone and I still consider myself a drug addict because I am on methadone...Until I stop using methadone and I can sleep at night without the tablets then i will consider myself clean." Female aged 48 years*

*"Being stable is being on methadone rehabilitation is being drug free." Female aged 28 years*

When questioned whether participants felt that methadone had helped recovery and rehabilitative processes, participant responses were positive, and grounded in personal definitions of what being 'drug free' meant, the ability to retain some normality in day to day life, and in its capacity to offer the addict the opportunity to step onto recovery starting points, reflect and consider options;

*"Its helped I gave it a go and it worked and I didn't need heroin anymore, it helped." Male 37 years*

*"It's helped me I would probably be in the ditch from the things I done. " Male aged 29-33 years*

*"Methadone has helped me get off the gear [heroin]." Male aged 37 years*

*"Both , it has helped me in the fact that I didn't have to go off and do things I would have had to do for drugs, but because of the lack of support around the methadone, I am still on it 10 years later, I was never told how to come off it or anything like that its only because I did it myself" Male aged 33 years*

*"It gave me some breathing space when I took methadone, when I was strung out and when I was active, I had no breathing space because I was always trying to get the next fix and always worried about the sickness and the withdrawals and i was always on the go...with the methadone..I was able to calm down, I was able to make appointments, I was able to go to meetings, it stabilised me and there is definitely a place for it." Male aged 49 years*

*"It's helped, it helped... it has its positives and it has its negatives, but it's helped. The positives are I have kids, I couldn't go out shoplifting with those kids, I couldn't do drugs in front of my kids, that's just not right, it's just not normal....and then the medicine helps me look after my kids." Female aged 49 years*

*"Its helped definitely, because if I hadn't been on methadone, I wouldn't have been able to give it up and get them to school or cook or clean the only way I could have done it was to stay on heroin and its an expensive habit. Female aged 46 years*

*"It helped but now I use it as a crutch I can't get rid of...It does help I want to come off it altogether , I have used once in the last year, it's because of the methadone I haven't used, I don't want to be on it either it's just a substitute taking one from the other." Female aged 48 years*

Some participants observed that methadone maintenance treatment had hindered their recovery and rehabilitation in its capacity as replacement addiction, and with some participants continuing to use heroin whilst on methadone;

*"Hindered big time, the current system they have in place at the moment, I understand maintenance...it worked for me for a long time, if I wasn't on the methadone. Half the time I have been on methadone I have been on it so I wouldn't take heroin, its only replacing one with another and one that's harder to come off ." Male aged 33 years*

*"Probably hinder I did try before when I started methadone stopping using gear and it wasn't as bad getting off methadone, I carried on using while I was on methadone for about 9 years." Female aged 28 years*

*"Its hindered me big time when I went on it ,when I went on it , it suited me great because if I didn't have money for heroin, I don't know what my life would be now but its held me back 12 years, I always had it to fall back on. It puts a big stigma on your life." Female aged 28 years*

*"if I hadn't had the methadone i think I would have been off it along time ago, I think its holding you in that environment its holding you back. " Female aged 46 years*

#### *Community Level Encouragement and Support*

Participant observations on support systems and encouragement around recovery were mixed. Most observed the need for improved cohesive service networks to assist in information provision and pathway progression.

*"There are a few courses in the community that are connected with us, No not the doctors he just gives me the urine results, like my doctor doesn't phone up, I think they should connect more." Male aged 49 years*

*"None of the other CE schemes link in, all of the people in the schemes should meet up and share." Male aged 40-45 years*

*"You have to do all the running around they aren't connected, you never get to the main point you see different people each time." Female aged 28 years*

Several participants observed the need for greater visibility around 'drop-in' groups, counselling and treatment information;

*"No support now just here, a talk group not a NA group where you have to do the steps, just a place where you can talk about your experience rather than having to stand up and everyone sit comfortably." Female aged 28 years*

*"The drop in centre is sorely missed when we had the drop in centre, there was always somebody to talk to, always somebody to listen, sometimes you're tired at looking at the four walls , looking at the same people , you need to go out and clear your head, you just had to go up and the drop in was there, there were workers who would offer you a shoulder to cry on that is really really missed." Female aged 46 years*

*"If you want the help there is help out there ..... For people who haven't got the family support it would be nice if people linked in from the clinics. There is no information, even have an information centre or leaflets. When you're first clean even a drop in place and support for your first few weeks, my partner was offered a counsellor but that was back in the clinic which is a contradiction." Female aged 28 years*

*"Its getting the information to them that the support is there... I know a lot of people that wouldn't be aware of treatment centres... that wouldn't be aware of detox services and wouldn't be aware of the services that are out there." Male aged 28 years*

*"I am trying but I don't know where to go next, I am the type of person that needs someone to show me where to go, so no I wouldn't think its that clear, should be more information where you can go." Female aged 46 years*

*"Access the areas where you know they are going to be, have drop in centres, give out information and needle exchanges, go to the clinics. Have workshops for people that are on methadone to provide that information, there are lots of facilities there but its all city based, I don't think people want it in the suburbs." Male aged 28 years*

A number of participants highlighted that they were unable to access counselling outside of the Special Community Employment scheme and those that did, had experiences where counselling staff changed on each occasion;

*"I arranged to meet the counsellor at the clinic but I have been waiting 4 weeks to see him, he has my phone number. I am getting very little support. I can talk to my doctor he understands where I am coming from...I have given counsellors my phone number and nobody has got back to me...I would like to speak to a counsellor , a counsellor that I know is going to be there every week." Male aged 36 years*

*"All the workers on the scheme keep encouraging me, offering me courses, telling me about goals, drawing up plans and looking into the future." Male aged 41 years*

*"I am getting some counselling now, there should be more encouragement." Female aged 49 years*

Others observed the need for improved support for female specific rehabilitation pathways;

*"Its not a straight run I don't think there is enough help there for people who want to become drug free or methadone free, its alright saying go into \*\*\*\*\* for treatment, but there again if someone has children or have other obligations I think extra help from those getting you into \*\*\*\*\*for this treatment a little bit more wouldn't go a miss. Sometimes when you go into treatment you're not quite aware of all the facts some people go in and they are in for a shorter period than they expect or it's not what they expect....Because of my kid the doctor says I can't do this, I can't be pulled back until I am really stable. I wasn't to be brought down I was put up to 75mls from 40mls I was on 100mls. I detoxed myself down to 5mls when I was pregnant. I have asked to clinic to put me on a 'blind ' detox.." Female aged 49 years*

*"I know its my own fault, I know I should have worked better , I think its easy to go up, I was on 15 mls when pregnant...my young feller was born , it was easy to go up after. I think the doctor should support you more, if you get it you're going to take it." It was tough being in detox because I didn't get to see my young feller*

*, I know its for good reasons but I left a bit early out of detox I just wanted to come home to see the young feller. I achieved what I went into do. It's the hardest thing leaving your kids." Female aged 28 years*

*"Not enough support out there definitely not for single mothers...we need another detox centre specifically for single mothers with children, its these people in the clinic that are forgotten about they are put on methadone and that's the last they will hear from them, unless they want to stop using methadone and its very rare that someone on methadone will turn around some day and say i want to stop taking methadone all by themselves." Male aged 33 years*

Greater levels of support and treatment assistance were observed for those partaking in the Special Community Employment Schemes. For those who are not accessing a Special Community Employment Scheme, there was no evident support in the community;

*"I wouldn't say there is a lot of help for people who isn't involved in the scheme, if people are looking to change they need to be given the chance, something needs to be put into place , something that gives them that hope and there are people who just don't want to give it up." Male aged 49 years*

*"There could be a lot more, my friends are lying in bed until 2pm and they are suffering depression and when they come over here they are told to go away and come back, there should be more like a drop in at the end of the day half of them feel hopeless, when they are turned away it makes them feel like the person doesn't want to talk to them, there should be someone to talk to all the time, this is the only service in the area...Not enough support for people who have come out of clean , there needs to be more support for people, there are loads of Heroin addicts in the area, and how many places are there on the CE scheme... 12?, there should be a lot more for people." Female aged 28 years*

*"It [methadone] makes people lazy people who don't have CE schemes they are just taking it and going back to the house and just watching telly, they are not getting any exercise or anything." Male aged 37 years*

### *The Special Community Employment Scheme*

It appeared that each Special Community Employment Scheme seemed to run autonomously and the service it provided to the community was distinctly different. This appeared to depend on the ethos of the co-ordinator not on the needs of the relevant community. The majority of participants observed the Special Community Employment Scheme to be a positive endeavour for them;

*"I like coming to the CE scheme I have been in treatment centres, the scheme has done more for me than the treatment centre has, this has done more for me than any other place because this time I was ready." Female aged 34 years*

*"Positive very positive, an awful lot of people in the community support the scheme because most of their kids would have done a course, they link in with other job centres too. They are actually a very good community." Female aged 49 years*

*"Its brilliant they bend over backwards for you, this place is supposed to be a safe place for everyone...I can understand why people who come in here for the first few weeks find it difficult." Male aged 42 years*

*"Its helping me , I am helping myself, by coming in and talking about things, if you feel like you're going to use you can come in and talk...they change your mind" Female aged 28 years*

Participant observations around the Special Community Employment Scheme appeared grounded in feelings of belonging, improved self confidence and reduced labelling as drug addict;

*"I love it here, I think if I wasn't here I wouldn't be clean, I was using before I came here and I think its seeing people clean , you think if they have it I want it, if they can do it I can do it. Female aged 28 years*

*"I have got my life back, I have my family back thanks to here (scheme) I wouldn't have been able to do it without here. If I hadn't of come here when I did I would either be dead in and out of jail." Male aged 49 years*

*"I know some people come and just for the money but I am telling yer they soon turn around, when you see other people doing so well." Female aged 28 years*

*"I like it here, it is a good course, like people who I never thought would walk up to me when I went on drugs especially and now walking up to me saying fair play to ya, you look great, you are doing brilliant, I am getting the reaction off my kids , they just used to call me a junkie and that used to hurt. Its helping my recovery knowing that people are respecting you, once I get my self respect back, I get the respect back from my kids." Female aged 49 years*

Several participants observed how the Special Community Employment Scheme encouraged them to develop new day to day structures;

*"Its helped me by giving me a structure where I can come in, I have to get up and have to go somewhere and almost held accountable for how I behave." Male aged 28 years*

*"I look forward to coming in here everyday, coming in my daughter is on a summer programme here , I can do my bit and then collect her, its great I love it." Female aged 28 years*

*"I want to be independent, I never had a routine because I was on drugs, it's helped me and that way." Female aged 28 years*

Several participants remarked on the effect of partaking in the Special Community Employment Scheme in challenging participants personal definitions of recovery and being clean, addressing the use of other drugs and stimulating positive decision-making around methadone dosage, reducing dosage, seeking detoxification and treatment;

*"Before I started the CE scheme I was on 90mls I am now on 30 mls of methadone. I am at a stage where I want to move on with my life." Female aged 34 years*

*"I choose to stop the cannabis because of the testing; the rewards have been huge just financially. You can't get away from anything here, you have to deal with everything" Male aged 34 years*

*"For the first 2 years people were saying to me about coming down, I wasn't going to let anyone tell me what to do and then one morning I asked the doctor to cut me, I was aware it was me who wanted to cut, the scheme helps and still helps." Male aged 49 years*

*"I never went into treatment, but you do need a course like this to help you. I came off myself." Male aged 41 years*

The Special Community Employment Schemes seemed to operate in the first instance as a form of personal development and therapeutic self care tool within group settings, with vocational training and job seeking as secondary focus;

*"You're learning how to communicate your learning how to speak, your learning self awareness." Female aged 28 years*

*"It's good therapy it's like we are all interacting, it's helping me now." Male aged 37 years*

*"Its depends on what CE scheme your on, some people come in here not knowing how to read and write, they have no literacy skills so in that sense yes it does help those people, but for me I am learning what I know already. The reason why I love going is to talk to my counsellors my key workers, its somewhere to go, we are all in the same boat." Female aged 34 years*

*"I feel a lot more confident going for a job now than I would have before I started here... the personal skills they have taught me have been invaluable, learning to deal with normal people, you don't realise that when you go into recovery that its like when your all mixed up in addiction you're in your own little world, its like I need these skills to start again just talking to people knowing what to say." Male aged 33 years*

*"Brilliant since day one... getting a routine and then the education, they encourage us, if you're ever feeling low at the end of the day they ask you to stay behind to talk to someone, there is someone to talk to you after hours." Male aged 40 years*

*"There is a humanistic factor about it here .The scheme has helped me immensely this has helped me in my personal therapy, support in going through court cases, they have just been amazing , I am where I am today with the help of the scheme. It's helped me get back my self respect, dignity." Male aged 39 years*

*"Its very good because I find its good... you're learning more about yourself, your working your brain because you haven't been working your brain for so long, its like your educating yourself, its like a baby, they don't know anything but they are learning anyone in the room they can't read or write but because they want to learn, they are working their brain." Female aged 28 years*

*There is a lot of personal development... there is a lot of that going on , how to improve your life, that's what they are doing all the time, they could probably improve it more but I don't know how." Male aged 41 years*

Some participants mentioned skills acquisition in the form of literacy, computer skills, horticulture, life skills and art;

*"Education is what really helped me here." Male aged 42 years*

*"Its good because I have learnt a lot, I have learnt a lot computers, life skills and art, it's set my head right for recovery as well, it's got me thinking what I have got what I haven't got, thinking about the future and making plans, the horticulture is great you can get down here once a week and relax." Male aged 41 years*

*"Its interesting we learn different things we learn meditation, life skills, choice theory, art, computers... it's interesting." Female aged 34 years*

*"I find them helpful they are teaching me computers they are going to try and send me on a course, the classes do help. When I was off for 2 weeks I was bored to death, getting up late and found myself wanting to use again. I like getting up and come over here, it gives you a reason to get up and I like that." Female aged 48 years*

*"Yes I wouldn't know how to use a computer, I have done typing skills, the course has taught me things I thought I could never do, I used to be real negative... wouldn't get a job because of my previous convictions, sure what would I be good at, nothing. Since I started the horticulture I am now teaching my son how to*

*grow at home. I am reading a lot more now about awareness, anger all this is to do with the scheme if i didn't have the scheme I wouldn't be doing this or I would be dead." Female aged 49 years*

### *Progression Pathways*

Definitions of progression varied and hinged on the ethos of the relevant Special Community Employment Schemes or its Coordinator; with some schemes focusing on the reduction of methadone/benzodiazepine use and others on vocational training and job seeking supports. Progressing onto further training on the schemes was seen as a reward and an incentive. Some participants were allocated funds to go onto third education, whilst other participants found it difficult to access other training if they were not 'suitable' or had had a relapse. Several participants observed their aspirations to progress to college attendance;

*"Doing a couple of courses and going to college in a few months." Male aged 28 years*

*They get you training I did a course last year, I have 2 years left." Female aged 28 years*

*"They give me some of my college fees, this is what I have put my training money into, they have helped me with getting my college work together." Male aged 39 years*

For males in particular Junior/Leaving Certification, job specific training and progression onto FAS courses appeared useful;

*"This scheme here helps with your head and education, I did a security course and other courses...this will lead me into employment. I am hoping to do a course later this year, I was to get into a FAS course, the opportunity is there for me at the end of the course I want to be off methadone and drug free." Male aged 37 years*

*"The scheme has helped turn my life around, it's helped me get courses I went to FAS and else where and they couldn't get me on them, step by step everything is getting sorted out. The scheme has been a god send to me..." Male aged 29-33 years*

*"Yes definitely and I want to jump on that band wagon as well... start by allowing Junior and Leaving Certs, people can't get jobs because they have no Leaving or Junior Certs." Male aged 37 years*

Some of the Special Community Employment workers knew those on the scheme and some individuals highlighted this as they were concerned about confidentiality when they left the scheme. A female participant reported a sense of frustration within their time on the scheme and queried the usefulness of having Special Community Employment Schemes operated by Special Community Employment scheme trained staff;

*"I am due to finish soon because I did a year in another place on a CE scheme so they are telling me I am not entitled to another year... On the first year I asked for a personal development course and like that I was told that I had to wait a year to do any courses, now I am finishing in a few months and that is the course they are advising me to go on, but I wanted to do that when I first started.... don't know at the moment I am in between trying to get another year out of them here but I am asking myself would it be a waste of another year, or shall I try and get another place where its more structured.... The staff here are on CE schemes so its different staff coming and going and then they have to pass it all over...I don't think the staff should be on CE they should know what's going on." Female aged 46 years*

Several participants observed the lack of final tangible outcome in terms of employer prejudices against those with community employment scheme attendance, gaps in curriculum vitae and lack of formal training certification. A lack of follow up support for those completing the scheme was observed to contribute to feelings of isolation, time wasting and potential for relapse;

*"I spent the last year of my CE here; the best thing I got from here is the course I was funded to go on, having said that what's gone against me is that I applied for some voluntary work... I put this place down as a reference and when they rang up they spoke to the manager and wanted to know my role and the manager said I was a client, I was really upset and I thought this was a waste of time because I can't put the scheme down as a reference, because people who don't know anything about recovery think we don't want her working up here ...there are 2 gaps in my CV that I can't cover. What I have found that people who have left here before me have gone out and done nothing ....they actually have done nothing, they haven't got work, they haven't got any more training. I think it's a very vulnerable time because you have had all the support on a daily basis, to walk out that door and have nothing. I know the project provides aftercare every two weeks, which enables me to come back and have a chat...Basically after 3 ½ years on being CE schemes I am not trained to do anything. For the first year I was on a scheme in a large organisation I was given no training I was employed as an admin support worker. I am no more employable than I was 3 ½ years ago. It's ok to say you can do a three day course here and a three week course there, it's not going to help. Maybe people on CE schemes should be encouraged to look at what they are going to do when they leave the scheme, I have seen sheer panic, half of their income have gone and what are they going to do." Female aged 43 years*

*"It's you make of it yourself...there is a lot involved and when you do get clean finding a job and to find somebody that will take you with a CV that says you worked 15 years ago, it's not too easy." Male aged 34 years*

*"Getting clean and sorting your life out, job, I would love a job" Male aged 36 years*

Several participants remarked on the lack of aftercare for those participants who had completed the Special Community Employment Schemes. Once a person had left the scheme there was a reported lack of support, in the community and from some of the schemes. It was also highlighted that participants had to leave the Client Forum when their time at the scheme had finished;

*"There is not enough support when you leave a CE scheme, once you leave you're finished your gone, you're thrown out there to fend for yourself, there should be aftercare type service." Female aged 48 years*

*"I don't think the aftercare is very good....I don't know if that's lack of communication or because the programmes are crap. I would like to see a back to work initiative or more follow on CE places." Male aged 33 years*

*"There is a few people who have gone into rehab but everyone of them that I have known are back on heroin again, so I don't know how successful they are. No there is not a lot of aftercare support. There are NA meetings in the area but I wouldn't know where to look for them." Female aged 48 years*

Some participants reported that they had finished the Special Community Employment Schemes and wished to return;

*"I think there should be something out there when they do leave, a place where you could drop in see people if they need to talk." Male aged 49 years*

*"I have an application in for a scheme, I am trying to get on somewhere, the one I was on I loved it ... I would love to go back." Male aged 37 years*

*"I would love to go on another CE scheme; I can't get on one because I am married and have no social welfare payment made." Female aged 46 years*

#### *Client Forum*

Two participants (recent entries onto the Special Community Employment Schemes) had no knowledge of what the Client Forum represented. Observations around the operation of the Client Forum by those clients it represented were generally positive and underscored the need for a consistent external facilitator. There appeared to exist an over reliance on the facilitator to pass on the information. A lack of participant knowledge on the terms of reference and workings of the Drugs Task Force was also evident.

*"I have only recently started so I don't know the in's and out's of it," Female aged 28 years*

Some participants described the lack of Drugs Task Force engagement in the process;

*"So far yes I wished we could find someone more permanent...I don't know anything about the task force I think we have made a bit of head way, as we have got a few things changed but I think there could be a lot more interaction with the task force." Male aged 29-33 years*

*"I am actually very impressed with the new facilitator he is doing a great job, he seems to have got more done in the last couple of months than we have done in the last year. I am looking forward to each one of us attending the task force meetings." Male aged 33 years*

Participants felt that each Special Community Employment Scheme provided varied levels of encouragement and support in the Client Forum processes, with the Co-ordinator of each scheme selecting those who were stable to attend the Client Forum meetings, reflective of control and resulting in a lack of democratic representation which was viewed to compromise the advocacy role of the Client Forum. Others viewed the system of the Special Community Employment Scheme completion leading to termination of participation in the Client Forum as unfair;

*"There was one issue that when people had finished their CE schemes they had to leave the forum one girl who had been on the forum for 2 years she was good but had to leave she put a lot of work into the last report that was done up." Male aged 33 years*

*The next chapter shall discuss the Focus Group and Interview results.*

## 5. Discussion

Qualitative research on individual experiences of overall life functioning whilst on methadone maintenance remains scant (Neale, 1998; Fischer *et al.*, 2002). Focus groups and interviews were selected in order to uncover context specific subjective experiences and personal perspectives (Dale, 1995; Fountain and Griffiths, 1999 Neale *et al.*, 2005) around methadone maintenance for those engaging in Special Community Employment Schemes. The research was led by the Dublin North East Drugs Task Force Client Forum and comprised of three sequential phases, with the forum developing the interview questions through two facilitated focus groups (n=4), the Special Community Employment scheme participants partaking in semi structured in depth interviews (n=25) and with a presentation of results feedback session with the Client Forum. Research has underscored the need for improved client participatory research on methadone maintenance influences on day to day life functioning and where clients are actively involved in this process (Ruefli and Rogers, 2004; Enriquez *et al.*, 2005), and not merely '*spectators on the sidelines*' (De Maeyer *et al.*, 2011). The findings in relation to both experiences of methadone maintenance and that of the Special Community Employment schemes were largely concurrent with the literature (Bruce, 2004; Lawless, 2006; Madden *et al.*, 2008; Winstock *et al.*, 2008; Winstock *et al.*, 2011). However, the research findings must be viewed as exploratory and confined to the localised experiences of this cohort in the Dublin North East Drugs Task Force area.

### *The Client Forum*

Participation rates in the focus groups were low, with two males and two females taking part on each occasion, despite external facilitator encouragement to partake, and the research team visiting the Client Forum to introduce themselves and providing information around the research process. Similar to Schulte *et al.*, (2007) low client involvement in the research process was observed, even though emergent research on service user led research indicates that such peer led research can result in outcomes particularly useful for individual and practice related needs (Faulkner and Thomas; 2002; Rose, 2003).

Both focus group and individual participants observed satisfaction with the Client Forum but underscored the need for additional supports, greater levels of both client and Dublin North East Drugs Task Force involvement and consistent staffing for external facilitation. However, it was observed that control remained in the hands of several Special Community Employment schemes insofar that coordinators selected representatives for the Client Forum, and provided varied degrees of support for Client Forum participation. Research has shown that negative and controlling attitudes to service user involvement on the part of service providers due to fear of criticism, service ambivalence and disillusionment, and power imbalances, can represent barriers to effective two way communication and client participatory processes (Anthony and Crawford, 2000; Soffe *et al.*, 2004; Summers, 2003; Schulte *et al.*, 2007; King 2011). Indeed, provider-client power differentials are grounded in the '*client*' terminology, as opposed to '*user*' with '*client*' inferring weakness, passivity and dependence (Adams, 1996a:1996b; Ridley and Jones, 2002; Lammers and Happell, 2003; Diamond *et al.*, 2003; Vidler and Clarke, 2005; Newman and Vidler, 2006; Fischer *et al.*, 2007). Addiction services traditionally view drug users to be manipulative, resistance, difficult to engage with and gratification seeking (De Leon, 2000; Butler, 2002). On the part of the '*client*' or '*user*' of drug services, evidence shows that mistrust of authority and experiences of drug related stigma contribute to prejudices and tensions within service provider and user involvement relations (Foster *et al.*, 2005; Patterson *et al.*, 2008). '*User*' terminology has been increasingly utilised within harm reduction services, and is supporting an attitudinal shift toward recognition of '*users*' as active, equal and

responsible citizens within a partnership approach (Friedman *et al.*, 2001; Butler, 2002; Kerr *et al.*, 2004).

Indeed, several participants observed that Client Forum representation as dependent on Special Community Employment scheme duration was unfair, with some participants were dropped from the Client Forum on completion of their scheme. None of the individuals on the Client Forum were active drug users. It remains vital to engage with all user groups, most particularly those relapsing, drop-outs and those not engaging with services in order to create support systems and training opportunities for these users to become peer advocates (Croft and Beresford, 1992; Croft and Beresford, 1995; Barnes and Prior, 1995; Lindow and Morris, 1995; Barnes and Shardlow, 1996, 1997; Bowl, 1996; Ferguson, 1997; Forbes and Sashidharan, 1997; Harrison and Mort, 1998; Beresford, 2001; Hodge, 2005; Wylie, 2010). It was notable that two newly recruited Special Community Employment scheme participants were not aware of the Client Forum's existence, and that participants in general were unclear as to the role and terms of reference of the Drugs Task Force. Additional reliance was placed on the Client Forum external facilitator to pass on requests and information. The findings indicate that whilst general observations were positive, the Client Forum was not operating to optimum capacity, was not based on democratic selection of representatives, and equally did not provide clarity to the Client Forum participants around the role of the Drugs Task Force. Research shows '*bottom up*' user involvement in drug and alcohol fields remains limited (Patterson *et al.*, 2008) and that unrealistic, uninformed and '*tokenistic user*' expectations undermine consumerist and democratic user-provider engagement in the forum process (Crawford *et al.*, 2003; Crawford and Rutter, 2004; Rush, 2004; Weinstein, 2006; Patterson *et al.*, 2008; Bryant *et al.*, 2008a; Bryant *et al.*, 2008b; King 2011). However, successful forums with improved service user involvement within a collaborative relationship between provider and client can assist clients in regaining control of their lives (Ruefli and Rogers, 2004; Holt, 2007; Frain *et al.*, 2009).

#### *Methadone Maintenance*

Research has reported on methadone maintenances' effectiveness in terms of clinical efficacy (Dole and Nyswander, 1965; Dole *et al.*, 1968; Sells *et al.*, 1979; Hubbard and Marsden, 1986; Brickner *et al.*, 1989; Glass, 1993; Ward *et al.*, 1999; Faggiano *et al.*, 2003; Amato *et al.*, 2005; Raby *et al.*, 2008; Mattick *et al.*, 2008; Mattick *et al.*, 2009), the reduction of illicit drug use, improved productivity, reduction in HIV risk behaviours and reduction in criminal activity (Hubbard and Marsden, 1986; Ball and Ross, 1991a; Ball and Ross, 1991b; Metzger *et al.*, 1993; Booth *et al.*, 1996; Simpson *et al.*, 1997a; Simpson *et al.*, 1997b; Metzger *et al.*, 1998; Rhoades *et al.*, 1998; Sorensen and Copeland, 2000; Kwiatkowski and Booth, 2001; Corsi *et al.*, 2002; Sheerin *et al.*, 2004; Teesson *et al.*, 2006; Gowing *et al.*, 2006; Millson *et al.*, 2007; Coviello *et al.*, 2011). Other research has reported on improvements in individual and social functioning relating to family relationships, employment and community integration (Ball *et al.*, 1981; Ball and Ross, 1991a; Ball and Ross, 1991b; Strain *et al.*, 1991; Lowinson *et al.*, 1992; Farrell *et al.*, 1994; Hubbard *et al.*, 1997; Kidorf *et al.*, 1998; Murray, 1998; Silverman *et al.*, 2002; Sheerin *et al.*, 2004; Teesson *et al.*, 2006; Knealing *et al.*, 2006; Corsi *et al.*, 2009; De Maeyer *et al.*, 2011; Coviello *et al.*, 2011). Social cost benefits have been recorded (Simoens *et al.*, 2006) with those not on methadone maintenance having an increased mortality risk (Esteban *et al.*, 2003). Dropout remains high, with research recording high dropout rates of 30-65% within the first year of methadone maintenance (Mattick *et al.*, 2001; Darke *et al.*, 2005; Bell *et al.*, 2006; Mattick *et al.*, 2008) and with frequent relapse to opioid use (Zanis *et al.*, 1996; Magura and Rosenblum, 2001).

Research commentaries have observed that critiques of methadone maintenance remain centralised in its status as simply substituting one drug for another, restricting optimal delivery, alternative treatment service expansion and clashing with abstinence focused treatment ideals (Joseph *et al.*, 2000; Bell *et al.*, 2002; Vigilant, 2004). The need to utilize harm reduction such as methadone maintenance in conjunction with abstinence based approaches to treatment has been extensively proposed (Broekaert and Vanderplasschen, 2003; McKeganey *et al.*, 2004; McKeganey, 2005). The participants described the presence of drug displacement patterns (switching of addictions) occurring once on methadone maintenance, in the form of continued heroin use, cannabis and prescribed medication use in some cases. Participants appeared unclear as to the purposes for methadone maintenance treatment, with diversionary sales and purchases of street methadone common to precipitate heroin withdrawals. Some participants viewed methadone maintenance as '*temporary stopgap*' when street heroin could not be sourced. In other cases, methadone maintenance was viewed to represent the final link to drug using circles. Similar to research by De Maeyer *et al.*, (2011), the participants observed difficulties in '*letting go*' of their previous drug addictive lives. Anecdotal reporting of drug dealing outside clinics, pharmacies and on bus routes contributed to difficulties in remaining drug free and appeared to represent contexts for drug dealing.

Research has underscored the presence of public, institutional and private stigma associated with methadone maintenance on the part of heroin users themselves, treatment staff, the public, employers and within NA/AA (Bell *et al.*, 2002; Vigilant, 2004; Ormston *et al.*, 2010). The findings are similar to recent research which identified conflicting community views on methadone treatment as facilitating dependence, and which reinforce public views that methadone should act as short term treatment prior to detoxification (Magura and Rosenblum, 2001; McLellan *et al.*, 2003). Instances of community and neighbourhood stigma were common, and centred on the public labeling of clients as '*junks*'. Indeed, public attitudes to heroin use have reflected '*a negative view of drug addicts*' (Luty and Grewal, 2002:94) with stigma blanketing other members of the users' family (Corrigan and Shapiro, 2006). Participants in many cases hid their methadone maintenance from family members. In addition, it appeared that treatment stigmatization occurred (Luoma *et al.*, 2007) with some clients accessing clinics and pharmacies outside of their neighbourhoods in order to remain anonymous, and to avoid meeting their family or neighbours. Indeed, Radcliffe and Stevens (2008) observed the presence of ambivalent attitudes toward services, with many clients attempting to disassociate themselves from being seen as '*junkies*'; with other research underscoring the relationship between expectations for rejection and treatment avoidance (Semple *et al.*, 2005).

Clinic and pharmacy staff were observed to act disrespectfully to clients, and contributed to intense feelings of discrimination each time clients accessed these settings. Medical and pharmacy staff as members of the public are inadvertently affected by wider addiction discourses at that time, and with the majority holding negative stereotypical attitudes to drug users which prevents them providing quality unbiased care (McLaughlin and Long, 1996; Miller *et al.*, 2001; Landy *et al.*, 2005). Underlying medical staff preferences for abstinence based treatment and generalised lack of knowledge around harm reduction forms of drug treatment are evident (Van den Brink and Haasen, 2006; Ford, 2010). Research shows that pharmacy layout and staff attitudes to supervised methadone consumption and concerns around aggressive intoxicated behaviours and shoplifting contribute to client experiences of prejudices (Sheridan *et al.*, 2000; Neale *et al.*, 2008; Anstice *et al.*, 2009; Simmonds and Coomber, 2009) with research by Lawrie *et al.*, (2003) observing greater public support for needle exchange services, as opposed to supervised methadone consumption in pharmacies. Other research has

observed that pharmacy designated times, areas or '*hubs*' (in this case identified alcoves) or methadone consumption contribute to user feelings of humiliation (Radcliffe and Stevens, 2008). According to Vigilant (2004) methadone maintenance restricts on both medical and criminal grounds (supervised consumption of methadone in pharmacies and clinics; urine analysis). The majority of participants described the supervision of urine samples as degrading, however, '*double standards*' were observed with some doctors' not requesting supervised urines. Lawless (2006) observed client support for threatened sanctions with urine samples taken several times per week, as assisting them in their reduction of illicit drug use.

Similar to other research on methadone maintenance (McKeganey *et al.*, 2004; Potik *et al.*, 2007; De Maeyer *et al.*, 2010; De Maeyer *et al.*, 2011), a majority of participants observed how methadone maintenance treatment created a window of opportunity for them to get life back on track. In contrast to research by Shah *et al.*, (2000) who found that recent incarceration was predictive of lack of methadone maintenance treatment engagement, participants in this research observed how prison methadone maintenance and the continuation post discharge offered a catalyst for change. The participants viewed methadone as an opportunity to get '*headspace*' and reflect on future intentions and plans. The participants observed the need for more clinics and doctors to prescribe methadone, due to greater numbers of prison discharges requesting methadone continuation, greater numbers of heroin addicts in the area seeking methadone when withdrawing, and anecdotal reporting of street methadone sales. Several participants observed the need to make access onto treatment easier for potential participants with treatment seeking restrictions in terms of detoxification. However, of concern is that many participants described the lack of information on health outcomes, side effect and addiction potential of methadone provided on commencement of methadone maintenance, which compromised instances of informed consent which were additionally poor due to the addictive state of the individual in question. Information around alternatives to methadone maintenance, detoxification and residential treatment settings were also scant.

Although initial client satisfaction with methadone maintenance treatment is reported in a majority of clients (Madden *et al.*, 2008; De Maeyer *et al.*, 2011) over time the medical emphasis on client retention within the treatment continuum appears at odds with client requests to come off treatment (Lenné *et al.*, 2001; Stancliff *et al.*, 2002; Winstock *et al.*, 2011). Indeed, in this research the effects of methadone on daily life were grounded in frustrations relating to lack of control, the necessity to consume methadone each day, attend clinics and doctors and frequent rejection of participant requests to reduce methadone dosage, all observed to impact on perceptions of personal freedom. Participants indicated their frustrations in terms of frequent long term methadone maintenance, and difficulties in achieving a reduced dose over time. Research has identified a long term methadone maintenance cohort, considered by themselves to be '*stuck*' in treatment (see also Madden *et al.*, 2008; Winstock *et al.*, 2011). Disappointment lay in the lack of control of treatment care pathways, and repeated attempts in some cases to detoxify without medical assistance. Similarly, Lintzeris *et al.*, (2007) describe the fear of remaining on methadone contributing to attempts of clients to avoid higher doses of methadone, and attempting to seek out short term treatment modalities. However, unbeknownst to these participants, research shows that longer duration treatment is associated with improved addiction and psychosocial outcomes (Sees *et al.*, 2000; Kakko *et al.*, 2003; Mattick *et al.*, 2009). Notwithstanding these observations, research also shows that methadone maintenance with higher doses of methadone (>60mg) incurs greater positive effects in terms of treatment retentions, than dosage tapering and detoxification (Amato *et al.*, 2005; Bao *et al.*, 2009; Mattick *et al.*, 2009). Combined pharmacological and psycho-social treatment intervention along with supportive family relations and employment are associated with positive

outcomes, and most likely in clients receiving higher doses (>80mg) (Siassi *et al.*, 1977; Hargreaves, 1983; Ball and Ross, 1991a; Ball and Ross, 1991b; Caplehorn and Bell, 1991; McLellan *et al.*, 1993; Strain *et al.*, 1993; Saxon *et al.*, 1996; Gerra *et al.*, 2003).

Research has described heroin using mothers as socially isolated, marginalized, emotionally absent from their children, possessing poor parenting skills, compromised coping skills and difficult partner relationships (Barnard and McKeganey, 2004). Other research is suggestive of the influence of social and familial factors in stimulating women to hide, alter and cease their drug use (Jackson, 2002). Research by Ettorre (1992) underscores how women's self worth is centred on ability to care for others, with female addicts (and especially mothers) doubly stigmatized (Denton, 2001; Ettore, 2004; Banwell and Bammer, 2006; Simpson and McNulty, 2008; van Olphen *et al.*, 2009). Several females described the presence of a '*double standard*' of public acceptance for male methadone clients as opposed to females, which were additionally stigmatised due to their socially defined roles as mothers and caregivers. Humphreys *et al.*, (1997) observed that females were more likely to seek treatment due to familial pressures and gender defined social stigma. Women in particular appear to have greater rates of treatment engagement (Shah *et al.*, 2000; Luchansky *et al.*, 2000). In this research however, treatment progression and experiences of detoxification for female participants appeared hampered by child welfare and mothering roles, with most females reporting that they hid their addiction, and their methadone treatment from both children and their parents. Indeed, research has also observed higher treatment failure rates for women (Mino *et al.*, 1998). Completion of the Special Community Employment schemes for females also appeared less structured with post completion for females additionally complicated due to child minding issues.

The majority of participants described methadone maintenance treatment as a '*government holding pattern*', and sought information regarding dosage tapering, treatment centres and modes for self detoxification themselves via informal methadone using groups (see McDonnell and Van Hout, 2010 for similar Irish findings). The majority indicated preference for an opiate free life (or in some cases low dosage methadone) similar to Granfield and Cloud, (2001), but with the relapsing nature of opiate dependence, this was often very problematic (Van den Brink *et al.*, 2003; Van den Brink and Haasen, 2006, Schuckit, 2006; Raby *et al.*, 2008; De Maeyer *et al.*, 2011). The disparity between medical service provider and client experiences remains evident in the current literature base (Winstock *et al.*, 2011) with medical supervision promoting treatment retention, and clients wanting treatment completion. In this research, client-doctor relations appeared subservient in most cases, and the lack of client involvement in treatment planning served to heighten such feelings of disempowerment. Conflicting evidence appears in relation to client satisfaction with doctors (McLaughlin *et al.*, 2000; Neale *et al.*, 2008). This is frequently mentioned in the literature and co-occurs with repeated experiences of prejudice and discrimination (Link *et al.*, 1997; Holt, 2007; Järvinen, 2008). Similar to research by Winstock *et al.*, in 2011, participants in this research described attempts to come off treatment without medical assistance ('*jumping off*') which contributed to frequent relapse, with many observing that methadone was harder to come off than heroin, and with some using heroin again, to come off methadone. The restriction of freedom and anxieties around chronic dependence is reiterated in other research (Fischer *et al.*, 2002; McKeganey *et al.*, 2004; Holt, 2007). Requests to come off methadone maintenance treatment in this research appeared largely grounded in negative attitudes and stigma relating to methadone, unpleasant side effects (sickness, teeth problems and withdrawals) and negative treatment and clinic experiences (Koester *et al.*, 1999). Research has underscored how client expectations affect the personal management of withdrawal symptomatology (Eklund *et al.*, 1997; Karasz *et al.*,

2004; Winstock *et al.*, 2011). Many participants described a fear of withdrawal from methadone in particular and utilised peer networks for support and advice. Only one female participant observed partaking in a blind dose reduction. Speed of treatment reuptake post relapse and length of treatment are additionally predictive of positive long term outcomes of methadone treatment (Simpson *et al.*, 2002; Scott *et al.*, 2003). Although participants observed varying definitions of being *'clean'* (i.e. not using heroin but using other drugs; on methadone and using other drugs; not using any methadone or drugs), rehabilitation was reported to be (ideally) drug free and not on methadone, with some participants describing how methadone maintenance treatment could commence the process. However, for some individuals remaining on methadone for life was a desirable option (Magura and Rosenblum, 2001).

### *The Special Community Employment Schemes*

The majority of participants described how methadone maintenance treatment represented a movement away from typical drug seeking, purchasing and using daily scenarios, toward a more positive day to day existence, with methadone utilised as rehabilitative medium for participation in the special community employment scheme, and the precursor to life changing relationships, new environments and employment prospects. Research has shown that isolation, stigma, and feelings of depression associated with drug use act as barriers to resuming a normal lifestyle (Woods, 2001). Some participants observed that methadone maintenance treatment had both hindered and helped their recovery, whilst providing the opportunity to resume some normality in daily life, it could also carry potential for switching of addictions, in terms of difficulties to withdraw and frequent prescribed medication abuse. However, proponents of vocational training for those in treatment note that improvements in self esteem and decision making are seen (Shepard and Reif, 2004). The support of ex addicts through such training whilst in receipt of welfare payments increases feelings of control, empowerment and autonomy (Frain *et al.*, 2009) and incurs a peripheral effect on social functioning as mothers, fathers, wives, husbands and partners (Neale *et al.*, 2007). In this way, and in the absence of engagement in a positive intervention such as the Special Community Employment Scheme, positive day to day individual functioning for those participants on methadone maintenance had the potential to become compromised and stifled (Ahern *et al.*, 2007; Radcliffe and Stevens, 2008; Simmonds and Coomber, 2009). Indeed, the evident restructuring of daily patterns relating to both attendance at the methadone clinics, and Special Community Employment schemes provided opportunity for the participants to revise daily addictive patterns. In this research, being on methadone maintenance (and in some cases dependent on prescribed medication) for some participants was seen to contribute to generalized apathy and lack of engagement with counselling and training services, with those not on Special Community Employment schemes observed to engage even less. Indeed, Bell *et al.*, (2006) have observed the *'revolving door'* of treatment entry, relapse and re entry, with Coviello *et al.*, (2011) underscoring the need to engage with those out of treatment contexts.

Lilly *et al.*, (2000) have underscored the possible presence of adverse effects unrelated to methadone maintenance as pharmacological intervention, and related to its functioning as social mechanism. Psychosocial support is a vital component to methadone maintenance (Amato *et al.*, 2009; World Health Organisation, 2009). That said, participants complained of the lack of counselling supports coupled with long waiting lists to see counsellors, and a lack of continuity of counselling staff which was viewed to disrupt treatment care planning. Research observes the need for continuity of staff (Ball and Ross, 1991a; Ball and Ross, 1991b). However, most participants on the Special Community Employment schemes observed how methadone maintenance treatment and engagement in the Special Community Employment

Scheme created 'a new life' for them, a sense of group cohesion and togetherness, feelings of purposefulness and personal growth. Feelings of stigma relating to scheme attendance appeared to minimize over time, as community perceptions of the schemes purpose improved. Indeed, De Maeyer *et al.*, (2011) has underscored how purposeful living is paramount to increased quality of life (Davidson *et al.*, 2006) and improved treatment outcomes (Gourlay *et al.*, 2005). Several participants described learning to be assertive and speaking in public situations whilst partaking in the Special Community Employment schemes, which had a reciprocal positive effect on client-doctor relations. This development of independence in mental health has been highlighted (Michalak, *et al.*, 2006; De Maeyer *et al.*, 2010).

Similar to recent evaluations of the Special Community Employment (Bruce, 2004; Lawless, 2006) vocational training in these schemes had become a secondary focus in the place of personal development and relapse management training. Some participants had become clean earlier in their Special Community Employment scheme pathway, with two years remaining on the scheme, thereby raising the question as to the appropriateness of 'one size fits all' approach to the Special Community Employment scheme. The majority of participants were dissatisfied with completion outcomes, with many untrained with no formal certifications; difficulties with curriculum vitae gaps; attempting to deal with employer bias relating to Special Community Employment scheme stigmas around drug addiction, and lack of aftercare supports. Research shows that three quarters of methadone maintenance clients desire further training and certification for professional or technical jobs (McLellan *et al.*, 1998). However, even though the Special Community Employment scheme did not seem to offer further training or specific employment initiatives, it did serve to provide pathways and supports toward detoxification and rehabilitation. Common outcomes were observed to include the reduction of methadone and other drug use, and improved attempts at dosage reduction and detoxification seeking. Several participants also observed concerns for confidentiality on completion of the Special Community Employment schemes, with Special Community Employment scheme clients additionally stigmatised by public labeling as places for addicts. However, research has described the benefits of using such 'paraprofessional' workers as centred in the ability to relate to other drug dependence via familiar forms of speech, relating through real life experiences providing support and garnering trust (Robert *et al.*, 2003; Hossack and Wall, 2005; Schulte *et al.*, 2007). Only some schemes offered college fee supports with progression onto course seen as an incentive, with other participants observing intense frustrations and disappointments in being blocked access to training courses and being 'stuck' on the Special Community Employment scheme with no progression. The findings are further complicated by evidence that each Special Community Employment scheme operated autonomously and provided varied degrees of service and support to its clientele. This was observed to be dependent on the coordinators ethos, and not on individual needs, with some schemes focusing on reduction of methadone and drug use, and others focusing on vocational training and job seeking support. The lack of follow up and after care on completion is worrying, given the concerns for relapse, isolation, boredom and lack of productivity. It appeared that some Special Community Employment schemes offered some community level support due to their placement within community projects, whilst others operated in isolation.

### *Conclusion*

It appeared that not only was methadone maintenance treatment a 'holding pattern' for heroin users, but Special Community Employment schemes also operated in a similar fashion, with little real life employment preparation, assistance in seeking and securing employment or vocational skills development. Similar to Lawless (2006), participants viewed methadone as vital to initial stages of stabilisation, and as methadone alternatives were not available to

clients, it had become the only solution and representative of the 'one size fits all' phenomenon. Indeed, De Maeyer *et al.*, (2011) underscore the need to support clients function normally by consideration of all elements of potential pharmacological, psycho-social and environmental support. Contemporary literature has observed the lack of employment counselling as adjunct rehabilitative therapy in community treatment programmes. (Etheridge *et al.*, 1995; Henderson *et al.*, 1999; Friedmann *et al.*, 2000; Young, 2000; Lee *et al.*, 2001). It is a shame that this situation has occurred in these Special Community Employment schemes, despite the worthiness of stimulating personal growth within a therapeutic work environment, with research underscoring that the stimulation of control and personal independence in those on methadone, is very much related to finding and getting employment, gaining financial independence and self worth (Ruefli and Rogers, 2004). Once drug stabilisation is achieved, employment represents an important adjunctive therapeutic focus for those partaking in methadone maintenance treatment (Zanis *et al.*, 2001). Research shows that unemployment is associated with negative treatment outcomes (Svikis *et al.*, 2011) with employment incurring a host of individual, social and integrative benefits in both methadone maintenance (McLellan, 1983; Platt, 1995; Kidorf *et al.*, 1994a, Kidorf *et al.*, 1994b; Jenner, 1998; Wong *et al.*, 2004a; Wong *et al.*, 2004b; Kidorf *et al.*, 2004) and abstinence based treatments (Rosenheck and Seibyl, 1997; Reif *et al.*, 2004; Kemp *et al.*, 2004). Employment represents a compensatory day today alternative to drug activity (Simpson *et al.*, 1997a; Simpson *et al.*, 1997b; Koo *et al.*, 2007) and can act as a reintegration medium (Platt, 1995; Kerrigan *et al.*, 2000). Research shows that drug dependents often (depending on prior education and employment levels) show job related ambivalence and lack of future planning, do not display employer required job skills, often seek employment unsuitable to their training and educational levels and are not satisfied with low wages, often cite treatment times, literacy issues, depression transport and childcare issues as making employment impossible (Brewington *et al.*, 1987; Deren and Randell, 1990; French *et al.*, 1992; Zanis *et al.*, 1994; Silverman *et al.*, 1996; Kidorf *et al.*, 1998; Shepard and Reif, 2004; Dunlap *et al.*, 2007; De Maeyer *et al.*, 2011). Employer related stigma is perceived by the addict, even though they are able to perform tasks and duties for which they are qualified, with methadone incurring little impairment (Joseph *et al.*, 2000; Klee *et al.*, 2002; Spencer *et al.*, 2008). Equally speaking, securing employment may represent a barrier in itself to the continued engagement with methadone maintenance treatment (Coviello *et al.*, 2011). Indeed, some male participants described having money as trigger for relapse. In light of this, Wong *et al.*, (2004a:b) underscore the need to include job search, structured placement opportunities and on the job skills training within therapeutic work modalities (like the Special Community Employment schemes) and case management approaches for those experiencing drug dependency.

*The next chapter shall conclude and present recommendations for practice and research.*

## 6. Conclusion

The findings, whilst exploratory and context specific to the Dublin North East Task Force area are indicative of methadone maintenance offering participants the opportunity to commence recovery, with additional participation in the local Special Community Employment schemes acting as therapeutic support mechanism. However, the Special Community Employment schemes whilst experienced in a positive therapeutic manner did little to provide specific vocational training, work placement, and the acquisition of employment related skills, with many participants left with little aftercare on completion of their time on the scheme. Issues relating to lack of visibility of methadone health related material and treatment options, lack of informed decision making around client-doctor dialogues around treatment care pathways, lack of continuity of counselling provision, continued drug and prescribed medication use, whilst on methadone and concerns around long term methadone use are evident. Improved discourse between clients and medical support staff is needed, and most particularly with regard to alternative forms of treatment and the final goal of coming off treatment. Treatment services in the Dublin North East Task Force area must endeavour to recognise client desires for being opioid free, and that many clients are afraid of remaining on methadone long term and self detoxify. Instances of community, family, medical and pharmacy discrimination and prejudice were common and served to stifle treatment progression. The research highlights the need for improved anti discrimination and psychosocial support training for medical, clinic and pharmacy staff working in the addiction field in the Dublin North East Drugs Task Force area. Improved interagency cohesiveness in the Dublin North East Drugs Task Force is also vital in order to create supports at all stages of methadone maintenance, treatment and vocational rehabilitation, and promote client centred care planning, the provision of individualised vocational and employment training interventions, and specific female rehabilitative supports. Greater transparency is also needed for Client Forum members in terms of the Dublin North East Drugs Task Force remit, terms of reference, advocacy procedures and capacity to create change.

## 7. Recommendations for Practice and Research

### Practice

#### *Clients*

- Development and distribution of an information leaflet in conjunction with the Client Forum, with regard to what services are available as it relates to methadone maintenance and progression pathways;
- Development and distribution of information leaflets in conjunction with the Client Forum, advising pre methadone entrants of health side effects, addiction potential and typical pathways for methadone maintenance;

#### *Stigma*

- Development and implementation of community and family awareness interventions in conjunction with the Client Forum, on methadone maintenance and Special Community Employment schemes in order to reduce community and family related stigma;
- Development and implementation of awareness training for medical, clinic and pharmacy staff in the Dublin North East Drugs Task Force area;

#### *Supports*

- Provide client support for those experiencing difficulties with doctor prescribing and long term methadone maintenance, and set up a system, where key support workers can attend client-doctor meetings to advocate on behalf of methadone maintenance client for treatment progression.
- Develop women specific drop in and additional female specific counselling and childcare assistance in the Dublin North East Drugs Task Force area;
- Develop more drop in and counselling for those on methadone maintenance and considerate of both those partaking and not partaking in Special Community Employment Schemes;
- Develop an aftercare pathway of counselling, treatment, vocational and employment related supports for those on completion of the Special Community Employment schemes;

#### *Special Community Employment scheme*

- Revise Special Community Employment scheme goals in each project, and identify whether the project is dedicated to therapeutic and relapse prevention supports; or dedicated to specific vocational training and employment initiatives;
- Improve each Special Community Employment scheme in relation to the development of timely assessment procedures in order to provide individual care planning, specific vocational training and employment related skills base, provision of work placement or volunteering supports and assistance in curriculum vitae and interviewing skills;
- Ensure Special Community Employment workers adhere to confidentiality protocols;
- Create a network of potential employers or volunteer placements with local employers in order to reduce instances of Special Community Employment stigma.

#### *Client Forum*

- Increase client awareness as to how Client Forums operate and its relationship with the Dublin North East Drugs Task Force;
- Create greater transparency for Client Forum members in terms of the Dublin North East Drugs Task Force remit, terms of reference and capacity to create change;

- Select Client Forum participants to act as forum advocates at Dublin North East Drugs Task Force meetings;
- Allow the Client Forum to select its own participants, which should include those currently using, those on methadone and those in full recovery.

## Research

### *Qualitative*

- Qualitative research on the development of addiction displacement patterns (drug or addiction switching) in the form of prescribed medication abuse or other drugs, whilst on methadone maintenance;
- Qualitative research on client self detoxification experiences in the Dublin North East Drugs Task Force area;
- Qualitative research on women's experiences of methadone maintenance, detoxification and rehabilitation pathways in the Dublin North East Drugs Task Force area;
- Qualitative research on emergent drug trends and potential trajectories of modes of use (IDU/smoking/oral) among the heroin using population in the Dublin North East Drugs Task Force area;
- Qualitative research on the doctors experiences of long term methadone maintenance in the Dublin North East Drugs Task Force area;
- Qualitative research on pharmacy and clinic staff experiences of long term methadone maintenance in the Dublin North East Drugs Task Force area;
- Qualitative research on Special Community Employment staff experiences of long term methadone maintenance in the Dublin North East Drugs Task Force area;
- Qualitative research on the needs and experiences of methadone maintenance clients not attending Special Community Employment schemes in the Dublin North East Drugs Task Force area;

### *Exploratory*

- Exploratory research on the need for, implementation of a local Community Drugs Team in the Dublin North East Drugs Task Force area;
- Exploratory research on the need for, development and placement of '*Drop In*' services in the Dublin North East Drugs Task Force area.
- Exploratory research on the need for, development and placement of '*Supported Work Placement*' services operating as adjunct to existing Special Community Employment schemes in the Dublin North East Drugs Task Force area.

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