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Bhaile Átha Cliath
Dublin City University

Dual Diagnosis: A Community Perspective



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Dual Diagnosis: A Community Perspective



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Executive summary

“Human beings are complex, you can’t just say I’m going to work with you but not this part” (SP3)

This report presents a community inquiry project concerned with addressing Dual Diagnosis needs in the urban communities of Finglas and Cabra, North Dublin. The study was funded by the Social Inclusion/Addiction Service, CH09, Health Service Executive and Finglas/Cabra Local Drug & Alcohol Task Force. This Participatory Action Research study involved a process in which the research participants were in partnership with the research team for the duration of the study.

This project had two research cycles over a nine-month period. In the first month of the study, the community research group (CRG) was established to oversee, support and participate in the research process. This group included members of the community such as service users, their family members and service providers. Throughout this inquiry, central to all activities, was the importance of ensuring that there was a shared community conversation about the local Dual Diagnosis needs. This study achieved this using Participatory Action Research methods. The first cycle comprised of an Open Dialogue Community Forum and three focus groups. Participants included local residents, service users, community representatives, local health, and social care professionals. During this cycle, participants shared personal experiences of Dual Diagnosis and the

difficulties in accessing appropriate treatment and care, which often lacks compassion for individuals seeking help. Family members spoke about the effect Dual Diagnosis has had on their own and on their relatives’ lives. Professionals shared their experiences of working and supporting clients with Dual Diagnosis. Findings in this cycle mirrored those from the international literature. For example, no joined up policy, restricted and inappropriate service access, limited family support, a lack of intra agency collaboration, organisational struggles for professionals to liaise across services and agencies in relation to collaborative care.

Cycle two focused on how the communities and local organisations can provide effective care for people with Dual Diagnosis and their families, along with required government directives. A second Open Dialogue Forum identified the required actions at community, organisational and governmental level. The findings are summarised across three main domains in the following table.

DOMAIN	WHAT IS NEEDED	HOW CAN IT BE ACHIEVED
Community Response	Interagency Collaboration	Networking, Improved Communication, Identify Liaisons & Establish Community Groups
	Integrated Services	Agreements between mental health and addiction services & Implement Integrated Practices
	Information Sharing	Protocol for Information Sharing, Directory of Services & Improved Record Keeping
	Develop Referral Pathways	Standardised Referral Pathway, Improve Screening & Establish an Online Portal
	Develop Supports	Online forum and Resources, Phone Support & Access and Outreach Teams
	Family Support	Develop Family Support Services, Social Events & Support Groups
	Partnership Approach	Collaborative Approach between service users, families and service providers
Organisational Requirements	Training	Staff could attend a Dual Diagnosis programme & upskill in deficient areas
	Response to Trauma	Raise Staff Awareness, Training in Trauma Informed Care & Respectful Approach
	Develop Assessment Tool	Develop an Evidence-Based Tool
Governmental Responsibility	Care Pathway	Re-establish National Clinical Programme & Mimic Similar Policy Documents
	Change of Policies	Amend Mental Health Act and Clinical Governance Policies & Adopt 'No Wrong Door Approach'
	Improved Case Management	Online Database, Co-Working & One Case Manager per Service User
	Changes to Education	Develop Training and Education Programmes Which Can Incorporated Into Interdisciplinary Academic Programmes

This research provides a community insight into the impact of Dual Diagnosis. It highlights ways to address Dual Diagnosis through a series of interconnecting actions supported by governmental and policy change. Additionally, the findings have implications for the two communities and national policy makers. Notably, this work contributes to the dialogue surrounding the unmet needs of those who experience Dual Diagnosis. Of particular relevance to this research is the process by which the community was galvanised and the representative stakeholders brought together in dialogue. Crucially, this process was deemed a significant outcome of this research in that it facilitated the emergence of mutually agreed findings. The community stakeholders can now establish a process towards enacting the required changes to develop provision for people with Dual Diagnosis and their families.

This research demonstrates that the community experience of Dual Diagnosis is complex and impactful. Importantly, it appears that there are systemic issues effecting the two communities' ability to respond to Dual Diagnosis. It is rare for research to present the shared voices of service users, their families and those they seek help from about the impact of a challenging condition like Dual Diagnosis. This collective voice needs acknowledgment as it is grounded in the shared desire to address the needs of those with Dual Diagnosis from a community and local organisational level while signposting both policy and operational changes to drive and facilitate this.



Introduction

Dual Diagnosis as a term is often used interchangeably with others. Garbare (2015) refers to the term Dual Diagnosis being interchangeably used in practice and literature with other terms including co-morbidity and concurrent disorders (Expert Group on Mental Health Policy, 2006; Department of Health, 2017, 2009). In particular it has continued to be used in relation to substance use and mental health difficulties, despite the very medical connotations of the term. Arguably by adopting a branded term it carries a visibility that perhaps other more suitable terminology, such as 'complex needs' does not presently have in the relevant literature and practice contexts. Equally, Dual Diagnosis continues to be used in mental health, substance use and addiction policy documentation in Ireland. A composite definition based on international literature was adopted to the Irish context in 2004 by Mac Gabhann & colleagues and as it remains contextually relevant today will be adopted for this study as the

“Co-existence of both Mental Health and Substance Misuse Problems for an individual” (Mac Gabhann et al. page 11 2004).

The predominant challenge in the Irish context for people with Dual Diagnosis is not only dealing with both mental health and substance misuse problems but the almost complete lack of co-ordinated Dual Diagnosis service provision with separate

government departments, policy and service provision/orientation (Mac Gabhann et al. 2010). Despite the known increased prevalence rates of Dual Diagnosis in both populations and challenges with separate service cultures and treatment protocols, there have been few attempts to provide an integrated approach to people with Dual Diagnosis in Ireland (Connolly et al. 2015).

The impact of Dual Diagnosis can be wide ranging for an individual and the lack of established service provision contributes to this, as it affects a client's life, their families and the communities they live in.

To date in Ireland, policy and strategic service development has consistently omitted to identify how and what services will address the increasing problem of Dual Diagnosis (Connolly et al. 2015; MacGabhann et al. 2010). However, in 2017 the HSE set up a steering group and clinical lead within mental health services for the development and implementation of a clinical programme to address Dual Diagnosis. The outcome of this development process remains imminent and it is expected that a clinical programme will be ready for implementation within the next 12 months.



This study was a collaborative endeavour between the research team at the School of Nursing, Psychotherapy and Community Health at DCU and Finglas Addiction Support Team (FAST). FAST is a community addiction support service funded by the Finglas/Cabra Local Drug & Alcohol Task Force. FAST was set up in 2004 and current services include a drop-in service, addiction counselling, aftercare and recovery programmes and family support. FAST often has to respond increasingly to the Dual Diagnosis needs of their clients. A key strategic priority for FAST is to develop recovery focused integrated care pathways to better meet the needs of clients presenting with Dual Diagnosis (Mc Crann, 2017). FAST advocates for people with mental health and addiction issues to access the appropriate treatment when they initially present by facilitating clients to be assessed and treated simultaneously in one location.

The aim of this study was to conduct a community stakeholder needs analysis and service response to people with Dual Diagnosis in Finglas/Cabra. The research adopted a Community Participatory Action methodology (PAR) which may result in the transformation the community under observation, (Reason & Bradbury 2008; Connolly et al. 2015).

The study objectives were to:

1. Complete a targeted review of Dual Diagnosis and effective needs based community services in Ireland and other similar jurisdictions.
2. Explore the community experience, knowledge, capacity and resources to respond to people with Dual Diagnosis in their community.
3. Investigate the experiences of people with Dual Diagnosis and their unmet needs from statutory and other community services/agencies.
4. Explore of the wider impact of Dual Diagnosis on the community/families/ local statutory and non-statutory organisations.
5. Identify ways/service developments that will better support those who are experiencing/affected by Dual Diagnosis.

This report contains four chapters. Chapter one presents literature relating to Dual Diagnosis (DD) which frames and informs the research and in chapter two the study methodology is discussed. Chapter three focuses on the findings from both research cycles and the developments suggested to better support those who are experiencing/affected by Dual Diagnosis. Chapter four has a discussion on how the findings relate to existing research and policy and concludes the report.

Chapter One: Literature review



Introduction

The focus of this report is an account of a participatory action research study concerning Dual Diagnosis in two North Dublin urban communities. In order to set the context for this research study and to provide the reader with sufficient information to interpret the findings, this chapter reviews the concept and treatment of Dual Diagnosis within the context of international and national evidence. This review draws on a variety of sources.

Literature relating to Dual Diagnosis will frame and inform this research report. However, an in-depth exploration of Dual Diagnosis is beyond the scope of this report. Within this chapter the following will be considered: defining Dual Diagnosis, its impact on an individual's health, International and Irish Dual Diagnosis policies, the current treatment options in Ireland and community responses to care of individuals. Finally, the scope for the adoption of integrated care is discussed.

Dual Diagnosis affects morbidity, mortality and quality of life and psychosocial wellbeing as demonstrated by the number of early deaths and years lived with disability (Canadian Centre on Substance Abuse, 2009). However, the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5; American Psychiatric Association, 2013) does not provide specific criteria to diagnose Dual Diagnosis. Substance use disorders and co-occurring mental illnesses are listed separately with comorbidity highlighted in the diagnostic criteria of each. Nevertheless, a large proportion of people living with a mental illness also have substance use disorders, and vice versa. Given this apparent connection between the two conditions, it appears appropriate that there should be a distinct term and diagnosis for this condition. However, a lack

of conclusive assessments, the overlaps in substance use and mental disorders, and the complexity of understanding the causal link make this challenging (Farrell et al., 2003; Strehlau et al., 2012). In this review, the term 'Dual Diagnosis' will be used to describe the co-existence of mental health and addiction issues. However, even this term is not completely appropriate as 'dual' suggests that there are only two problems when often individuals have multiple health and social needs.

In practice, people are more often than not only given a formal diagnosis of Dual Diagnosis if they have an addiction and severe mental health needs that meet the criteria for specialist services. A separate issue then arises for people whose problems are not considered serious enough to meet the threshold for specialist care to gain access to appropriate care. Evidence from service user and provider surveys suggests that people with co-occurring conditions are often unable to access the care and treatment they need from both mental health and addiction services (Simpson et al., 2015).

Prevalence and factors influencing Concurrent Disorders

Research has shown that those experiencing Dual Diagnosis often require more service access from a variety of healthcare settings in comparison to those with a single diagnosis or disorder, (Kessler et al., 2005, Kessler et al., 1999). Serious mental and physical health disorders are commonplace among individuals who use substances (Koeogl & Rush, 2011; Chan et al., 2008). Substance users may also find it difficult to engage in and continue treatment, especially for their medical needs.



Rush & Koegl (2008) noted that individuals with substance use disorders often present to non-specialist services such as A&E, GPs and inpatient services which are often not adequately equipped to effectively respond to those with complex and severe needs (Babor et al., 2008). However, at the same time there are not many services that offer comprehensive treatments, especially in relation to the treatment of substance use disorders (Fletcher et al., 2003; Timko et al., 2003). Furthermore, exclusionary criteria for specialist treatment programs often restrict admission to patients with one primary disorder (Gil-Rivas & Grella, 2005).

Mental and physical health disorders are more common among individuals who use substances (Public Health England, 2017). Individuals with Dual Diagnosis can be perceived to be a burden on health services and resources due to the inadequacy of the treatment at their disposal. One UK study reported 54% of all suicides in people experiencing mental health problems had a drug or alcohol misuse history (Health Quality Improvement Partnership, 2016). It is difficult to establish the prevalence of co-morbidity of mental health and addiction in the Irish population due to a lack of recent prevalence studies. Garbare (2015) suggested that it could range between 30 – 55 % but this was from a small amount of studies that differed significantly methodologically. Anecdotally, Dual Diagnosis is becoming increasingly evident across Irish health and social care settings. Evidence shows that people with Dual Diagnosis are more at risk of developing other health problems and early death (Hayes et al., 2011). Individually, alcohol and drug use and mental ill-health are associated with physical health

problems and early death (Hayes et al., 2011). People experiencing mental health crisis may even experience difficulty in accessing and engaging with care due to intoxication despite the heightened risk of harm that this brings (Darvishi et al., 2015). Dickey, Normand et al. (2002) found that individuals with co-occurring psychotic and substance use disorders were at a higher risk of experiencing five of the eight physical disorders assessed for than persons with mental illness alone. These disorders included diabetes, asthma, skin infections, hypertension, heart disease, gastrointestinal disorders, acute respiratory disorders and malignant neoplasms.

Dual Diagnosis policy and care developments in other countries

To contextualise this study a brief overview of some international Dual Diagnosis policy and care approaches are now presented. The approaches to address Dual Diagnosis taken by the UK, USA, Australia and New Zealand have evolved over the last two decades.

United Kingdom

In the UK a substantial amount of funding and a significant body of work has been focused on improving outcomes for people with Dual Diagnosis. There was a policy mandate which stated that service users with Dual Diagnosis are 'a mainstream responsibility for mental health services', which has been particularly influential and was supported and reinforced by the publication of the mental health policy implementation guide the 'Dual Diagnosis Good Practice Guide' (Department of Health, 2002).

This guide considers substance misuse to be a normal occurrence rather than the exception to the rule among individuals suffering from mental health problems and it also acknowledges the complex relationship between the two. 'Mainstreaming' is one of the key policies of this approach and is based on the principle that people with Dual Diagnosis deserve high-quality, service user-focused and integrated care. One of the key beliefs of this approach is that service users should not be passed between different sets of services or put at any sort of risk of dropping out of care. It is made clear that 'mainstreaming' will not reduce the specialist roles of mental health and addiction services but it is stated that people with a Dual Diagnosis need to be dealt with proactively in an integrated manner or these services as will fail to work effectively (Department of Health, 2002). Recently Public Health England proposed a collaborative approach to the care of those with Dual Diagnosis across mental health and addiction services (Public Health England, 2017).

USA

The Substance Abuse and Mental Health Services Administration (SAMHSA) has been working on Dual Diagnosis since 2002 when a report was produced which included a 'blueprint for action' that has guided the country towards best practice service delivery. Since 2002 SAMHSA has developed a range of support documents and practice manuals to enable organisations to build their Dual Diagnosis capability. The most relevant of these is the Treatment Improvement Protocol Series (Center for Substance Abuse Treatment, 2005). SAMHSA identified the

improvement of treatment and services for individuals with Dual Diagnosis as one of its highest priorities and invested substantially in improving the treatment systems' response to Dual Diagnosis. There have been numerous developments in the USA which include:

- The development of the *Co-Occurring Center for Excellence* which provides the technical, informational, and training resources needed for the dissemination of knowledge and the adoption of evidence-based practices in systems and programs serving persons with Dual Diagnosis
- The promotion of integrated treatment of low-prevalence mental health disorder type comorbidity as one of six evidence-based-practices identified for mental health services
- The development of widespread state-based promotion and dissemination of practical, clinician-focused treatment manuals around best practice responses.

Australia

Australia has a national policy specifically aimed at improving service coordination and treatment outcomes for people with Dual Diagnosis. The National Comorbidity Initiative aims that Dual Diagnosis is systematically identified and responded to in a timely, evidence-based manner as core business in both mental health and alcohol and other drug services (Department of Human Services, 2009). In 2009, the National Drug and Alcohol Research Centre (NDARC) published guidelines for the management of co-occurring alcohol and other drug and mental health conditions in

alcohol and other drug treatment settings. These guidelines inform policy development at state level and include improved early identification and mental health outcomes for young people with mental issues; 'no wrong door' service delivery, raising awareness of Dual Diagnosis with health and social care professionals. Similar to Australia, the integration of mental health and addiction care has been a priority area in New Zealand for a number of years.

New Zealand

The Dual Diagnosis focus is reflected in a range of NZ health policies, including the most recent Te Kōkiri: The Mental Health and Addiction Action Plan 2006-2015 (Minister for Health, 2005). This plan identifies specific actions, key stakeholders and organisations responsible for coordinated care, outlines milestones and sets timeframes for achieving the 10 leading challenges identified in the Te Táhuu (Improving Mental Health Strategy). The integration of care and treatment approaches for Dual Diagnosis internationally demonstrates that despite its complexity it is possible to develop services to meet the needs of those with Dual Diagnosis. While not all of these practices could be implemented in the Irish Health System, it exemplifies how serious other countries view the problem of Dual Diagnosis and their attempts to respond to the needs of those who experience it. However, there is no doubt that the care of those with Dual Diagnosis can be challenging for service providers and policy and service development.

Irish Dual Diagnosis policy

Notwithstanding the lack of co-ordination and joined up thinking between services in relation to Dual Diagnosis, a number of policies have been developed in Ireland to progress mental health and Dual Diagnosis care. In 2006 *A Vision for Change* (Government of Ireland, 2006) provided a number of recommendations in relation to Dual Diagnosis, which include service provision and strategies to manage those experiencing Dual Diagnosis and the development of services for clients with complex substance misuse and mental health issues. Central to these recommendations are clear linkages with local community mental health teams. The Health Service Executive produced the *Transformation Programme 2007-2010* (Health Service Executive, 2006) which emphasised the reformation of mental health services including collaboration of the mental health services with primary care addiction services. *The National Drugs Strategy* (Government of Ireland, 2009) produced similar recommendations in relation to Dual Diagnosis treatment and more recently *The HSE National Service Plan 2016* (Government of Ireland, 2015) highlighted the need for investment in Dual Diagnosis.

Even though many Irish policy documents assert the need to develop Dual Diagnosis services, its implementation has been challenged periodically. However, the *HSE's National Service Plan 2016* (Government of Ireland, 2015) emphasised the need for investment in clinical programmes for Dual Diagnosis. In the third Irish Drugs Strategy, launched in 2017 (Department of Health 2017) the move to a more health-orientated approach to substance misuse

is explicit. It includes a specific strategic goal to address the Dual Diagnosis issue. However, progress has been slow with the development of an evidence-based care programme for those experiencing Dual Diagnosis. This is despite the assertion by communities, consulted by the policy developers, of the continued impact of Dual Diagnosis on individuals and their families. Importantly, the development of a clinical care programme for Dual Diagnosis noted in the *HSE's National Service Plan 2019* (Government of Ireland, 2018) again offers hope that service change may be imminent even though there are no national guidelines on service provision for Dual Diagnosis in Ireland. The current treatment options for those experiencing Dual Diagnosis in Ireland are now discussed.

Dual Diagnosis, the Irish context

In Ireland, there are the three main treatment systems which people experiencing Dual Diagnosis access. Each one is separate and has distinctive strengths, weaknesses and different clinical approaches (Garbare, 2015). The three systems are: Mental Health Services, Primary Care and Addiction Services including Community Based Organisations.

Mental Health Services

Irish mental health services comprise of a wide range of mental health practitioners including psychiatrists, mental health nurses, psychologists, social workers, occupational therapists, and many other specialised practitioners. For example: alcohol counsellors and Cognitive Behavioral Therapists. Mental health services are present in a wide variety of settings and include a broad range

of perspectives and approaches to the treatment of mental health issues. However, despite this wide range of professionals and mental health facilities, many mental health personnel report deficits in knowledge and experience concerning illicit substance use and the bio-psycho-social factors of addiction (Connolly, 2018). Many of those experiencing Dual Diagnosis may seek help in their local primary care service.

Primary Care

Practitioners working in primary care services such as GPs are often the first point of contact for people with mental health and addiction issues. However, GPs are primarily involved in treating medical issues in the community and managing emergency situations and may not have capacity to support those who present with both mental health and addiction problems. Byrne (2006) suggests that because of their contact with such large numbers of the public, they may be ideally positioned to initially screen and identify people experiencing Dual Diagnosis. In relation to Dual Diagnosis, GPs working in primary care often prescribe medications such as anti-depressants, antipsychotic and benzodiazepines and liaise with the individual's mental health team in this regard. Additionally, primary care practitioners mainly concentrate on the medical-physical issues of addiction, such as overdoses or detoxification. In Ireland, presently GPs and nurses work with allied health care professionals within primary care teams in order to treat the bio-psycho-social components of addiction and mental ill health, which is beneficial for those experiencing Dual Diagnosis (Irish Medical Organisation, 2015).



Addiction Services

Similar to the varied model of care adopted by mental health services, there appears to be no evidence of any one optimal addiction treatment response in Ireland. There are a diverse range of services which use a number of different models including the medical, behaviour modification and detox models drawing on a variety of treatment philosophies and programmes in both residential and community based settings. Similar to the mental health services, a wide range of disciplines and practitioners are involved in the treatment of substance use disorders such as: addiction counsellors, psychiatrists, psychologists, general practitioners, mental health nurses and a variety of other professionals (Roberts & Bell, 2013). Addiction services generally use multidisciplinary, bio-psycho-social and/or the twelve-step approaches to addiction. Some services advocate for methadone prescriptions and medications for addiction-related concerns such as overdose, withdrawal and maintenance whereas others work towards ultimately eliminating all drugs (EMCDDA, 2014). Those working in these addiction services often may lack knowledge concerning treatment approaches for mental health issues (Evans-Lacko et al., 2010). Additionally, in terms of training, Roberts & Bell (2013) said that service providers in addiction services report minimal training regarding medications required for mental health conditions.

In Ireland, Community Based Organisations (CBOs) carry out the majority of the treatment services for substance use. CBOs can be either statutory or non-statutory organisations. A recent review of Irish drug and alcohol treatment services, reported that when staff in CBOs were questioned

about Dual Diagnosis many stated that they were not capable of providing treatment for both substance use and mental health despite the service need to respond Dual Diagnosis (Clark & Eustace, 2016). Importantly, some reported having poor experience of referring individuals to mental health or psychiatric services or getting in-patient access to hospital. Often healthcare psychiatric teams refuse to accept individuals from addiction services due to the fact that the mental health issue is associated with substance use and therefore the addiction needs to be addressed first. Services often won't accept a referral unless the individual is drug or alcohol free (Clark & Eustace, 2016). However, services have noted that often addiction masks an underlying mental health issue, and that the substance abuse may have been used as a coping mechanism, which only becomes apparent as the person detoxes. Therefore, in order to appropriately support an individual's recovery, they need to be linked in with mental health services. In an attempt to address Dual Diagnosis some organisations have developed in-house capability (Clark & Eustace, 2016) and/or have developed good working relationships and appropriate referrals with GPs and psychiatric teams to ensure access to mental health services when required.

This separation between mental health and addiction has resulted in differences in service provider's attitudes towards specific disorders and in overall treatment philosophy being reinforced. Differences between the mental health and addiction fields in clinician beliefs, training, behaviour, and ideology pose significant barriers to the effective treatment of Dual Diagnosis (Sterling, Chi & Hinman, 2011).

There are a number of issues regarding individual motivation and responsibility, as well as treatment focus. In general people who are referred to a service, are required to attend the appointment they are given in order to demonstrate their motivation for change (Bailey et al., 2010). However, people with mental health or addiction issues often find it difficult or are reluctant to attend appointments. It is in this motivation to change where addiction and mental health services differ to quite a large extent. Many addiction services feel that it essential that service users take responsibility for their actions, which includes asking for help and attending appointments (Beattie, 1992). Addiction services often measure motivation through challenging services users about particular realities of their addiction (Thombs & Osborn, 2019). This challenging process is often viewed as a necessary component of the treatment process which helps services users to understand their behaviour patterns and the consequences of their actions. Therefore, it is not uncommon for individuals referred to the addiction services to not receive treatment if they do not show motivation or are unable to cope with the treatment practices. Conversely, mental health services use a case management and care planning system in order to counteract this lack of motivation or treatment seeking. These systems were designed to help with engagement and to support people in a range of community-based services (Hughes, 2006). Individual's limitations, strengths and weaknesses are identified and their complex needs are responded to proactively. Additionally, if a service user rejects professional help then a case manager may attempt to employ alternative approaches to assist and motivate the service user to accept help (Connolly, 2018).

Additionally, from a mental health perspective, it is often argued that substance misuse issues are symptoms of deeper psychological distress/trauma and that when those other disorders are properly treated, the substance misuse problems will lessen or subside. This conceptualisation has reinforced a hierarchy in which substance use disorders and their treatment are seen as less legitimate and less deserving of attention and resources. Contemporaneously, the addiction treatment field frequently is ideology driven, and its disagreements with the mental health field on appropriate diagnosis and treatment often have been contentious (Sterling et al., 2011).

Irish treatment programmes

As a result of these differences, service users with Dual Diagnosis are left with unmet needs and often experience a lack of coordination across mental health and substance use disorder treatment systems, as well as certain exclusion criteria that prevent them from receiving appropriate treatment. These problems are primarily as a result of administrative and financial policies that maintain the separation of mental health and substance misuse treatment into independent service systems. As a result, these individuals are often referred back and forth across services or fail to receive treatment for either disorder. Internationally, previous research by Drake et al., (2001) and Friedmann et al., (2003) both argue that comprehensive services are required for individuals with Dual Diagnosis.

Ideally, each treatment programme would integrate multiple sectors, such as healthcare, criminal justice, education and social welfare in a comprehensive system of support and service. These treatment programmes should be provided for areas with high rates of substance use and should also include health care policies such as those defined by World Health Organization as “decisions, plans, and actions that are undertaken to achieve specific health care goals within a society, within the same system framework” (Karapareddy, 2019, pg 57). However, to date a lack of guidance for service providers in Ireland in developing Dual Diagnosis care has resulted in continued fragmented care. Previous research has noted the need for multifaceted treatment, such as combining pharmacotherapy with cognitive behavioural therapy, psychotherapy and behavioural treatments (Morley et al. 2007). Kelly et al., (2012) also found that a combination of treatments results in better overall outcomes through the integration of psychological, physical and social therapies.

Even though recognition and awareness of Dual Diagnosis has increased, there is little evidence on which to base recommendations for a particular mode of management (Evans & Baker, 2012). As these are often lifelong illnesses, it does not come as surprise that a chronic disease model which uses the simple principles and models of chronic care have been used in the treatment of people suffering from Dual Diagnosis (Donald et al., 2005). Nevertheless, a consensus regarding the most effective model has yet to be reached. Presently, the most ubiquitous models of service delivery are parallel, sequential, and integrated models. However, results from research which investigated the most

effective models of care are inconclusive, from both a clinical and a scientific perspective (Drake et al., 2000; Hunt et al., 2013).

Canaway & Merkes (2010) described three primary models of service delivery for Dual Diagnosis, sequential, parallel, and integrated. In sequential models, different specialists provide treatment in different services. One condition is treated initially and then this is followed by treatment of the second condition. Parallel models are those in which specialists provide treatment concurrently in different settings. There may or may not be communication among these service providers. In integrated models, treatment for mental health and substance use disorders is provided together. Outcomes from these models have not been researched to a great extent. Additionally, the complexities associated with defining Dual Diagnosis as well as the methodological challenges for research in the area have resulted in little agreement on what constitutes a good model for delivery. Nevertheless, integrated care is increasingly seen as an effective Dual Diagnosis model of treatment.

Community response to the care of those with Dual Diagnosis

In Ireland, presently there are about seven community Dual Diagnosis programmes in different communities in the country, they are in: Cork, Tipperary, Clondalkin, Dublin City, Kilkenny, Limerick and Waterford. These communities took it upon themselves to engage in integration efforts across mental health services and the drug and alcohol task forces. These developed to address unmet needs of those experiencing Dual Diagnosis. These are the first

integrated programmes for Dual Diagnosis in the country. Galvin (2019) provided recommendations as to how to develop integrated services through a review of these services in addition to a synthesis of related contemporary literature. The recommendations in relation to policy included:

- Provide financial incentives for services to develop integrated care of individuals with Dual Diagnosis.
- Analyse how the system functions in terms of access to psychological services and align providers with service needs.
- Exploration of methods in resource allocation to support a holistic approach to care.

From an organisational perspective, it was recommended that services:

- Build a knowledgeable and integrated group of personnel who places the service user at the centre.
- Examine training needs for service providers.

In terms of treatment, some of the recommendations were to:

- Build a Dual Diagnosis learning community between the current integrated programmes.
- Conduct an evaluation of the services to improve current programmes and develop others.
- Assign resources to support the formation of comprehensive new integrated programmes.

Finally, in terms of service users and their families Galvin (2019) asserts that partnership systems need to be incorporated into each level of the system such as in treatment design, individual care and policies. This review demonstrated how policies and resources could be aligned in order to provide integrated care to respond to the needs of those affected by Dual Diagnosis and their families/communities. Nevertheless, in an Irish context further research needs to be carried out on how best to integrate care on a national scale; presently, it is motivated by local communities who are tasked with developing these cultures of integration and co-production. Integrated care programmes are currently being introduced nationally on a phased basis for older people, children and chronic disease. However, an integrated care programme is yet to be implemented for Dual Diagnosis despite the severity and impact of the condition.

On top of the models of service delivery, there is a need for policy makers to add different concepts such as “no wrong door,” (Prendergast et al. 2015), which aims to provide appropriate and consistent services, irrespective of where the patient enters the treatment system. The ‘no wrong door’ approach is based on the principle that every door in the health care system should be the ‘right’ door, i.e. it is the responsibility of every service provider to try and help an individual, wherever and whenever someone presents for care. This approach provides people with, or links them to, appropriate services regardless of where they enter the system. It is the responsibility of the service to navigate and negotiate the network of service providers on behalf of the service user and to ensure seamless service delivery between agencies.

Adopting an integrated approach to Dual Diagnosis

Nationally, the move to integrated healthcare across the lifespan is central to the vision of Sláinte Care (Houses of the Oireachtas, 2017) which is the all-party approach to health service reform. Integrated care involves the coordination of interactions and relationships within and across services to provide the best treatment for an individual with Dual Diagnosis. A common misconception is that a structural realignment of service systems is necessary for this approach to be successful. Ideally, the provision of mental health and substance use services would be in a single setting; however, if this is not possible then prearranged clinical pathways can and should provide links with others services within local health areas/communities. Integrated care requires a focus on the provision of holistic and coordinated care, liaison and advice, and the development of clinical pathways between and across an array of services. (Alcohol, V., & Drug Association, 2011).

Research has demonstrated that the cost of integrated systems does not vary greatly from the cost of standard care (Domino et al., 2005; King et al., 2000; Morse et al., 2006). Domino et al. (2005) revealed no significant difference in the cost of treating Dual Diagnosis, between integrated and usual care models, and the integrated approach produced better clinical and social outcomes. Similarly, Morse et al. (2006) and King et al. (2000) showed that although the treatment cost for Dual Diagnosis is higher than that of mental health on its own, the costs of the integrated model are similar to those of standard care. Therefore, it can be posited that as well as being a more

effective treatment for Dual Diagnosis, integrated models are not a financial burden. It can even be said that integrated care may be more cost-effective in the long run as a result of the reduced burden of disease in individuals who recover and also taking into account the additional costs of inadequately treating Dual Diagnosis. Given the continued impact of Dual Diagnosis and the social costs it engenders, an integrated co-produced approach to people with Dual Diagnosis in Ireland is necessary (Galvin, 2019, Connolly et al. 2015) however at this point in time aspirational.

Summary

Those who experience both mental health and addiction problems deserve appropriate evidence-based treatment. This discussion foregrounds the contemporary dialogues about Dual Diagnosis in Ireland; the challenge of effective Dual Diagnosis treatment and care is apparent. Evidence-based care has much to offer those living with Dual Diagnosis although its development by statutory services in Ireland has yet to become a reality. Importantly, in Ireland now there exists examples of successful community endeavours to address Dual Diagnosis. The complexity of Dual Diagnosis has influence beyond the individual and their immediate families and there is scope to assess the role communities have in the response to Dual Diagnosis. This research set out to explore the community experience and impact of Dual Diagnosis and to consider strategies that may shape a local response to this multifaceted health and social challenge. The study methodology is presented in the next chapter.

Chapter Two: Methodology

Introduction

In this chapter, the research methodology employed in this study is described, including the participatory action research approach, the two research cycles, participant recruitment and a profile of the research sample, data collection, and analysis strategies. This research project was concerned with exploring the impact of Dual Diagnosis within two north Dublin city areas through a community needs analysis. This participatory action study began in Jan 2019. In this section the following are discussed; Participatory Action Research, the development and role of the CRG, study processes including ethical approval, recruitment, sampling, data collection and analysis.

Participatory Action Research

As the research was undertaken with stakeholders, as opposed to being about them and the research was expected to transform the community under observation, a Community Participatory Action Research methodology (PAR) was utilised. This was the most effective approach to address the research aim (Reason & Bradbury 2008; Connolly et al. 2015). This approach involved working with the people in the system as co-participants in the inquiry with a view to transforming that system from within as a principal focus of the research process itself. PAR is part of the Action Research Worldview and methodological approach. Action research originated in the social sciences with Kurt Lewin coining the term and having a major influence on its development (Lewin 1946). It differs from traditional inquiry in that it strives to generate knowledge and change the environment at the same time. Initial emphasis of action research was to change

the system through social engineering. A later emphasis on participatory research (Whyte 1991) extolling the virtues of empowerment, collaboration and emancipation through collective critical reflection and action attracted health researchers to the methodology. Action research is also appealing to practitioners engaging social systems where power imbalances prevail, where the case is made that it lies in the domain of critical theory (Kemmis 2001). Holter and Schwartz-Barcott (1993) outlined four key characteristics of PAR, which underpinned this inquiry. These are:

- collaboration between researchers and practitioners
- solution of practical problems,
- change in practice
- and development of theory

It is difficult to encapsulate all that PAR has to offer, as by definition it will impact on each individual differently. Ottosson (2003) offers some practical wisdom on the value of PAR; it can offer the unspoken though often important information that more traditional methodologies cannot extrapolate, that research findings can be interpreted for practical use quickly with faster feedback, though it is more demanding and complex than classical research. Central to the aim of PAR is to create social change, which addresses inequalities in power relations, leading to empowerment and a better understanding of all participants' life experiences. As the intention with this research was to engage with all of the community that wished to participate and be part of the change in how they address Dual Diagnosis, PAR was the obvious choice to guide the research process.



Project co-ordination

This study had a project research team led by the Principal Investigator (PI) and its membership included a DCU academic/researcher, the project research assistant, the Chief Executive of FAST and a service user representative. A research assistant was appointed to work on all aspects of the project under the supervision of the PI for the duration of the study. The overall management of the project was led by the Principal Investigator with the project research team in consultation with the community research group (CRG).

The Community Research Group

A community research group (CRG) was established to advise, support & contribute to the study as it progresses. The purpose of the CRG is to ensure stakeholders are integrated into the study from the onset. Membership of the community research group (CRG) was both self-selecting based on stated interest, service interest and/or those who were impacted directly or indirectly by Dual Diagnosis. Additionally there were some invited key local representatives/professionals from health/social care and community organisations. In this instance it comprised of members of the community such as service users, family members, local elected councillors, representatives from local service providers (Appendix 1). A CRG is a central aspect of the participatory research process and this group oversaw the research process, supported recruitment and were consulted on the study findings and final recommendations. Based on existing community knowledge of the

fundings and core research group the CRG evolved and grew according to increasing collective knowledge of other stakeholders in the community of inquiry. During this project the CRG met six times in different venues across the two communities and in DCU. Email was also used to support the consultation process between the project research team and the CRG. All members of the CRG are also study participants as they represent various aspects of the community in which the research was centred in.

Ethical considerations

Ethical approval for the study was received from Research Ethics Committee at DCU prior to the commencement of data collection. Key to this study was that the rights and dignity of all participants were respected throughout the project. All participants in this study participated voluntarily in the various research activities and the data collection events and could withdraw from the study at any time. The participants were varied because as a community research study it included people dealing with Dual Diagnosis, relatives of those who are affected, local community representatives, health and social care professionals e.g. Gardaí, addiction support workers, counsellors therefore the level of investment in the process varied.

Research process and methods

The research process took place over nine months inclusive of two Action Research Cycles. Cycle One focused primarily on the first four objectives of the inquiry drawing on the CRG and wider community as active participants expert in identifying community needs in order to respond effectively to people with Dual Diagnosis. A participant information sheet was designed for the study which described the study objectives and process and was available to all participants. The process was managed through two specific data collection methods. Firstly an Open Dialogue forum was convened and members of the community were invited to participate with recruitment coming through the community networks that CRG members were associated with. Thereafter, through networking, advertising, word of mouth and targeted recruitment of stakeholders, participants in the Open Dialogue forums self-selected as participants. During the dialogue conference, participants were given a series of semi structured questions to answer in relation to the objectives and following group facilitated analysis, a set of themes emerged.

In addition to the Open Dialogue Forum three focus groups were convened. Participants were recruited through the CRG and associated networks. The purpose of these focus groups was to elaborate on themes emerging from Open Dialogue discussions. Findings from both data sets were merged and an initial framework was derived from these to inform Cycle Two.

Cycle Two had a stronger focus on transformation, i.e. what needed to happen to ensure these Dual Diagnosis needs could be met through the process. This cycle comprised of another action orientated Open Dialogue forum where the findings from Cycle One were summarised and a set of semi structured questions focused on Objective 5. *'Identify ways/service developments that will better support those who are experiencing/affected by Dual Diagnosis.'* were asked of the participants. The format for this dialogue was for participants to identify: (a) what was happening and still needed to happen in the community in order for effective Dual Diagnosis provision to be available; and (b) how will the required actions be completed and by whom. Following data analysis because of the transformative action orientated nature of PAR the process itself moved the community response to Dual Diagnosis along. In particular Cycle Two unfolded a community position on Dual Diagnosis with solutions regarding how to continue to respond more effectively in the future.

Conclusion

This chapter outlined the study design and process. As a participatory action research project the establishment and use of the Community research group guided the data collection process. There were three key data collection events the two open dialogue forums and the focus groups and the findings from these are discussed in the next chapter.

Chapter Three: Study findings

Introduction

During this study substantial findings emerged, all of which are relevant to the ongoing response in the participating communities to Dual Diagnosis. The findings represent the opinions and experiences of participating community members, as reported during the study, and do not necessarily represent legislative or policy direction. For the purpose of this report those findings will be condensed, in particular Cycle One findings, though none will be omitted. This first section of the findings relates to Cycle One of transformation in the inquiry during which there was the first open forum and the three focus groups. The demographics for Cycle One are presented in Table 1. The findings for the Cycle One are clearly demarcated by objective, which includes objectives 2 to 5 of the study which are as follows:

2. An exploration of community experience, knowledge, capacity and resources to respond to people with Dual Diagnosis in their community.
3. Investigate the experiences of people with Dual Diagnosis and their unmet needs from statutory and other community services/agencies.
4. Exploration of the wider impact of Dual Diagnosis on the community/families/ local statutory and non-statutory organisations
5. Identification of ways/service developments that will better support those who are experiencing/affected by Dual Diagnosis.

We can see from Cycle One that the issues arising in these communities and the suggested solutions are very similar to what has been identified in the literature from other studies, though the emphasis on some are very specific to this study and particularly in Cycle Two the findings target this community experience. A unique offering and feature of this study is the process which enabled the community stakeholders to come together in dialogue and inclusiveness, meaning it was not just one group from the community that have produced these findings.

Cycle Two will be presented differently as this focused on the transformatory process i.e. what has to happen for an effective response to Dual Diagnosis in these communities The focus in this discussion will be on the findings that will enhance that response, though again, no findings will be omitted.

Quotations from stakeholders who took part in the data collection phase permeate the text and each one is identified by a unique identifier such as Service Provider 1 (SP1), Service User 2 (SP2) and Family Member 3 (FM3). If a quote is not labelled with a unique identifier, it is due to the fact that it originated from written data during one of the open dialogue conferences and thus, it was not possible to attribute it to any one individual.

Participatory Action Process

The Participatory Action Process was used as a transforming agent in this study which allowed different stakeholders in the community to network and build relationships. This process was central to the study and had many benefits for example it gave people the opportunity to build links with people and services they otherwise would not have come into contact with. A number of service providers spoke openly about some of the connections they had built as a result of their participation in the inquiry:

“Being part of this process I realised that we are all in the same boat and we have started talking about meeting up regularly in the future”,

“We swapped numbers because that is where the family support piece comes in, so we can inform families of where they can go to get support, can't talk to parents about their child, it's more about telling them where they can go to get information”

and one service provider spoke of an agreement already in place:

“Someone said they would come and do a talk with our GPs around family support and admin staff could be trained up by the HSE so they could be a support for families and could advise them where to go”.

Furthermore, as a result of the relationships built during the research process, a number of service users stated that they would be more comfortable picking up the phone to talk to another service as a result of now being able to put a face to the name. Additionally, the inter-relational dynamics that occurred between participants in the inquiry, created a process from which knowledge was generated. A number of service users spoke of how they gained information they had not been previously aware of during the inquiry:

“In our group, we found out lots of different things that each other were doing that could help us to support each other”,



It's about where do we go from here,
we keep the network going,

"I know in our own subgroup,
we passed on numbers, and
I've no problem meeting with
any of them. There has to be
a concrete agenda of what
we're meeting for, we have to
start providing a service"

and another reiterated this point:

"We were actually discussing
different types of training
that the community were
funding that the HSE were
funding that I wasn't aware
of. You realise that there is a
lot going on that you wouldn't
necessarily know is going on,
I think that's something we
can action very quickly"

It was also stated by a number of service
providers, family members and service users
that they would like to keep the process
going after the research concludes:

"It's very enjoyable and
invigorating sitting down and
having the conversations but
I would like to think we take
the responsibility to follow
on from this"

"One of the objectives could
be that the process is kept
going and it's more inclusive,
the full 360° voice, from the
services or to the family,
from the statutory to the
voluntary"

and:

"Everyone should advocate
to keep the process going"

It is possible that services users with Dual
Diagnosis who are ordinarily part of a
number of distinct systems, will be united
in one cohesive system as a result of
the relationships built between services
during the research process. It was also
hoped that the creation of these inter-
relational dynamics would aid with the
co-construction of a conceptual framework
aimed at improving the community's
response to Dual Diagnosis. This framework
will be outlined in the findings for Cycle Two.

Cycle One findings

For ease of reading and capturing the extent of findings these will be presented below in a series of tables, one for each research objective. There is overlap between themes across the different study objectives. These will become more clearly related in Cycle Two findings and the discussion chapter. In relation to demographics, there were a total number of 90 participants. Some would have participated in both the Open Dialogue forums and a Focus Group. This is not an issue for the study, as it might be with traditional quantitative research. The methodology allows for the immersion of the participating community members in any and all aspects of the study.

Table 1 Cycle One demographics

	N	FEMALE (%)	MALE (%)
Focus Groups	28	21 (75)	7 (25)
Open Dialogue Conference 1	62	39 (63)	23 (37)
Total	90	60 (67)	30 (33)

Figure 1 An exploration of community experience, knowledge, capacity and resources to respond to people with Dual Diagnosis in their community

This study found that for both communities there were concerns about lack of knowledge about Dual Diagnosis, role of medication in managing symptoms, lack of effective treatment and care pathways and an inadequate acknowledgment of the impact of trauma for those experiencing Dual Diagnosis.

THEME DESCRIPTION

Lack of Knowledge (main theme)

There is a lack of knowledge on Dual Diagnosis amongst professionals and laypeople in the community. In this case 'knowledge' is an all-encompassing term which includes education, information, awareness and training

ILLUSTRATIVE QUOTES FROM PARTICIPANTS

"We were originally working on addiction a few years ago and we were struggling with the barriers for people linked in with mental health services. So as a community, we got trained up and now we do work with people with things like CBT I'm not a doctor or a psychotherapist but I feel like I'm actually doing the work with people" (SP7)

"They didn't have education in addiction and they're working with it. It must be difficult to be in a role supporting people with Dual Diagnosis and not having any education around substance misuse and the impact around that" (SP5).

THEME DESCRIPTION**Lack of Information (sub theme)**

There is not enough readily available information on what services people can access and this was highlighted by service users and service providers alike

Information Not Provided by Services (sub theme)

Often given inadequate or no information at all when they actually present to a service and upon leaving a service people often have no idea where to go next or what treatment to seek. It has a knock-on effect when they present to another service

Lack of Interagency Cooperation (main theme)**Information Sharing (sub theme)****Disconnect Between Services (sub theme)**

Care for people with Dual Diagnosis is not integrated in the health service and people usually do not receive treatment for their addiction and mental health issues in the same place/service at the same time. Services don't even work together to provide these services separately and there appears to be a paucity of interagency referrals.

Medication Issues (main theme)**ILLUSTRATIVE QUOTES FROM PARTICIPANTS**

"I think it's all about just knowing what is there, I think a lot of people would go to the drop-in services if they knew they existed" (SU1).

"A service user presented to A&E after a crisis, the doctor told the family member that CAMHS would be the best thing for her. She actually went to the pharmacy the next day and bought 'Kalm's', the tablets. She only realised that maybe it was the service CAMHS that was meant after talking to someone else, there was no information given, there was no contact details, nothing" (SP2)

"My experience is that the GPs don't know about any of the supports out there for service users and families. I've had to tell them that this place is here, even if they had pamphlets left out that people who are maybe in a crisis could pick up, it would maybe be a starting point" (SP4)

"Sharing of information is a huge problem. Services are very disjointed and a lot of services work in their own field, often it's very difficult to get information about somebody or give information about somebody. Everyone in services are working independently" (SP13)

"I work with clients who are homeless and they are very vulnerable and you can't get any information about where they're staying from the homeless agency because of data protection and all that, so that is a barrier" (SP15)

"In the past I would have tried to get psychiatrists engaged in care planning for people, people who are actively using and it would be very difficult"; however, on the other side a psychiatrist stated that "people are not linking in with me and I do not know what's going on on the other side. That linking in does not exist, we all talk about linking in and sharing but we don't" (SP2)

See below

THEME DESCRIPTION

Self Medication (sub theme)

There are a number of issues surrounding medication such as self-medicating, over prescription of medication and a lack of medication review. This means that people do not possess the necessary coping skills and information to deal with these issues in a constructive way. Therefore, many people end up using substances to take the edge off or as an emotional anaesthetic

Over Prescription of Medication (sub theme)

Reported by service users and professional providers that there is an over reliance on prescribing medication that is not conducive to effective treatment

Lack of Adequate Treatment (main theme)

There appears to be a lack of willingness to work with this population due to the lack of appropriate policy on the treatment of Dual Diagnosis and possibly also as result of the stigmatisation associated with the condition. This sometimes results in treatment not being offered and inappropriate and rapid referrals on to other services. However, in general it appears that the complex needs of this population are rarely taken into account during treatment.

ILLUSTRATIVE QUOTES FROM PARTICIPANTS

"You learn on the job but substance use is a self-soothing behaviour for some mental health diagnoses" (SP 12)

"I think there is an overprescribing of drugs and an addiction centre might get to meet them a year or two or ten years after being on antidepressants forever and the referral for counselling or that type of service isn't there, it's mentioned but there isn't a solid referral, there is a gap. Some people fall into the belief that a tablet is going to do the work" (SP11)

"When I presented myself I could give the symptoms of depression, and was given antidepressants; I was suffering from depressive symptoms with that was not the problem, it was the addiction" (SU6)

"At least if we can get peace here then we can work on the other issues over there but it doesn't work like that, long-term the medication is more addictive than probably all the other drugs that are out there. You're talking about Ritalin and other things like that and as a parent you think you're helping your child and realise when you look back you would think would I give my child heroin, no. Ritalin is a form of it" (FM1)

"In some services it's like a one hat fits all, particularly if you present with an addiction or substance misuse, they're going through the process for quite some time before somebody realises there is also a mental health issue. What happens then is people get lost in the medicating for the substance use but they are failing to help the people with their mental health issues and referring them to appropriate services" (SP13)

THEME DESCRIPTION

Resistance to Evidence-based practice (sub theme)

There appears to be a resistance to change and embracing evidence-based practice when it comes to treating Dual Diagnosis. The resistance to change and lack of adoption of evidence-based practices has left service providers frustrated and disheartened as they essentially have to work with their hands tied behind their backs

Disparity between Private and Public Services (sub theme)

There appears to be quite a large discrepancy between the services offered in the public sector compared with private services offering broader choice, evidence-based practice and better facilities as highlighted by. Whereas public services do not offer such choices

Lack of Accountability/ Responsibility (sub theme)

It was reported that generally services do not provide quality treatment for those with Dual Diagnosis, that doctors often refuse to work with certain groups of service users and that it is often left up to individual practitioners whether they want to provide treatment for this population or not, as opposed to mandatory service-wide regulations or standards.

ILLUSTRATIVE QUOTES FROM PARTICIPANTS

"There is lots of evidence-based practice and for whatever reason Ireland has chosen to turn a blind eye. Really good practices in other countries that have had to be innovative to get to where you want to be" (SU2)

"There are a lot of old historical attitudes with regards to Dual Diagnosis and addiction "and "there are a lot of evidence-based practices out there, that are met with resistance from some psychologists and psychiatrists in the HSE" (SP3)

"If you go to [private hospital] or [other private hospital], they have an alcohol and MH treatment mixed together and both of them are private hospitals and that's the sad reality. A lot of places don't have it but yet if you have money in your back pocket, you can go over to [private hospital] and get treatment" (FM2)

"There are so many new treatments out there and there is a resistance to them, then you have private services with more people offering it and promoting it, so there is a gap there between private and public services" (SP16)

"If you don't have VHI you can't get anything, it's not good enough" (SU6)

"I don't want to work with... is not an ok answer for anybody. So I think it should be mandatory in all programmes, not an optional 40 hours of unit here or there. Human beings are complex, you can't just say I'm going to work with you but not this part" and "well that's not my department" and it irritates me so much, that's not what I asked you, what I asked you was where do I go" (SP6)

It's left up to the person or practitioner in the service if they want to go that extra mile. I might do it and then some else might say that they can't be bothered" (SP9)

THEME DESCRIPTION

Lack of Continuity of Care (sub theme)

There are also serious issues around continuity of care for people accessing services for mental health issues. This is due to a number of reasons such as the large turnover of staff in the mental health sector, staff such as mental health nurses in these services rotating frequently and often professionals move between services. This is often very disheartening and invalidating for services users as they have to constantly build a relationship with someone new, it also adds trauma to an already traumatic situation. Additionally, there also appears to be serious issues around time between appointments; service users are often left waiting months between appointments during which time they have no contact whatsoever with the service.

ILLUSTRATIVE QUOTES FROM PARTICIPANTS

"It's very impersonal, it's the same questions over and over again, are you suicidal, are you this? Are you that? And that's it. It's very undignified at times and not humanistic at all" (SU7)

"I experienced it first hand and I count myself very lucky to be sitting here in this chair today. People being moved from pillar to post. I was called for my psychology appointment a year after my other one. I was a dead man for all she knew and that's the problem" (SU3)



THEME DESCRIPTION

Absence of a Clear Pathway (main theme)

Ireland lacks a joined up Government policy that reflects the overlapping agendas of both substance use treatment and mental health. A functional integrated care pathway would allow flexible movement between services, in accordance with a service user's changing needs over the course of treatment. However, at the moment, addiction and mental health services are generally separate and service users rarely have access to both at the same time. The lack of a care pathway also means that service providers often do not know what to do with service users with Dual Diagnosis. Service providers aren't aware of what treatment to offer, who to communicate with about the service user, who should be their case manager, where to refer them, how to refer them and numerous other issues which essentially stem from a lack of clarity on what the course of action should be for service users with Dual Diagnosis.

Lack of Referrals (sub theme)

The lack of a clear pathway has made referrals between services much more difficult. It was reported by both service providers and service users that there is a serious lack of referrals to appropriate treatment services, particularly in relation to referrals from mental health services to addiction services, whether this due to a lack of knowledge or trust remains unclear. Additionally, mental health services will not treat service users if they have an addiction so it is incredibly difficult for addiction services to refer to mental health services.

Referrals are not forthcoming even when there is stated capacity to take them on.

ILLUSTRATIVE QUOTES FROM PARTICIPANTS

"There is no clear pathway, that is something that people ask for and there just isn't one" (SP2)

"Even with the Primary Care Centre, it's rolling staff and people don't even have their own doctor and there is no clarity in terms of who you could approach and they would rarely approach us. There is no clarity around how to treat people with Dual Diagnosis" (SP10)

"With these kinds of health problems, you are on your own and you become isolated and that is when the problems get bigger, the more isolated you become the bigger the problems get" and "At the moment it seems like you might have to call three or 4 times to the emergency room before you get to know where you can go, and even then it just up to chance" (SU8)

"If someone presents with a substance issue or a substance dependency, Mental Health aren't referring them onto us, we can refer them to MH which we do but the reverse referral is very weak and it's a weakness within that system" (SP12)

"There is no joining of the dots, we have never gotten a proper referral, maybe just to sober up and they are put in a psychiatric department and is released a couple of days later and we don't even know" (FM3)

"There are very few referrals in from GPs. People usually come in through word of mouth, through a friend, or self-referral, etc." (SP10)

"Sometimes his [psychiatrists] service is empty because there is no referral coming in because the statutory bodies do not recognise the conditions as being what they are, so there is no chance to have an input" (SP8)

THEME DESCRIPTION

Case management (sub theme)

There are serious issues reported around case management. As mental health services and addiction services operate independently, it is extremely difficult to ascertain who is in charge of case management, and the lack of links between both services make this very difficult.

Inadequate treatment of trauma (main theme)

People with Dual Diagnosis often have a history of trauma and which can lead to disruptive attachments and challenging behaviour, as well as a myriad of other health problems. However, there appears to be inadequate treatment provided for trauma and that professionals are not trauma informed or trained to deal with it.

ILLUSTRATIVE QUOTES FROM PARTICIPANTS

“There is no Case Manager because nine times out of ten they’re coming to this service and they’ve been prescribed and they’ve been linked in but with that NDRIC system it is impossible to know who the case manager is. This may be a possible explanation as to why the referrals are not coming through as there is no manager” (SP10)

“We’re not training professionals that trauma is often an underlying feature whether it’s a Mental Health problem or an addiction. If we are bypassing that or not recognising that then we’re doing a disservice” (SP6)

“PTSD is undervalued as well, so many of my clients are experiencing it due to childhood trauma or any other trauma. That is a real Dual Diagnosis in the DSM and affects Addiction and mental health. It is underdiagnosed and undertreated” (SP14)



Figure 2 Investigate the experiences of people with Dual Diagnosis and their unmet needs from statutory and other community services/agencies

The experiences of those with Dual Diagnosis included the following: accessing services can be difficult, receiving a Dual Diagnosis is problematic and a lack of faith in the services accessed which will now be presented.

THEME DESCRIPTION

Difficult to access services (main theme)

Mental health and addiction services are usually separate so generally people only have access to one of the two even though they have both substance use and mental health issues. The problems with this approach was highlighted by a number of service providers. A number of service providers and service users also highlighted the fact that people are refused access to certain services if they are found to have addiction issues. Moreover, it appears that if somebody is diagnosed as having a Dual Diagnosis, it acts as a barrier to accessing services, which is completely counterintuitive

ILLUSTRATIVE QUOTES FROM PARTICIPANTS

“People are not able to get the proper supports that they need, you get either one or the other and if you are put in one or the other, you are left there. You can’t move from maybe having substance misuse issue to a mental health issue. You could only have one or the other which we all know is contradictory to their actual life” (SP9)

“I attended a mental health organisation at the same time as attending another service. I didn’t get the treatment because someone recognised that I was attending another service” (SU1)

“The only way you get linked back into services is to attend A&E and get a paper trail but even if that’s successful you are still left waiting weeks for an appointment, during which time you could be in a very bad way” (SU1)

“A lot of people go to access services. They are so disempowered and oppressed within their illness that they don’t have the energy to be going around looking for different services. Once they hit that initial barrier, of someone saying no, that’s it, they’re at a loss, they’re done” (SP9)

THEME DESCRIPTION

Crisis (sub theme)

There are a number of issues that arise when people try to access services in a crisis. Services are generally open from 9 to 5 and closed on weekends so the ED is the only place where people can present or else they have to be detained by the Gardaí, which is a waste of their resources. Additionally, both Emergency Departments (ED) and Garda Stations are completely unsuitable places for people in crisis; additionally, as a result of the Mental Health Act people cannot be admitted to a psychiatric facility if they are under the influence, so essentially they are just holding the person for a certain amount of time before they release them.

ILLUSTRATIVE QUOTES FROM PARTICIPANTS

“My son thought he was [identifying description omitted] and I brought him down to the Garda station, the Gardaí were brilliant and a Garda came out to me and said you’ll never believe it, the doctor is after finding him fit. Later on at home, I had to get the Garda response unit, that all escalated over 24 hours. That could have been stopped if that doctor had taken my child to safety. He wasn’t safe in his own mind. It’s the saddest part as a mother to watch that” (FM1)

“They wouldn’t help because he was using drugs. In the police station, they said he’s screaming about people coming for him and the doctor came and he knew he was mental and he still didn’t do anything” (FM3)

“I remember I was with somebody like that and he was paranoid, I think he was just voluntary admitted. I sat with him for 8 hours and I had to convince the doctor to admit him, his family were there and they finally took him in but they wouldn’t just commit him because he was addicted to weed. I do find it is a brick wall” (community service provider)

“I just think when you get somebody into services and there is an opportunity to make good progress, it shouldn’t be missed as they may not want to attend services at another time” (FM3)

“I’ve accompanied people to the ED as it’s the closest hospital and when somebody is in Crisis and you are on your toes, you think Hospital. You could be there for hours with somebody that’s very vulnerable and you’re told you’re in the wrong place, it’s the other place you need to go to and you’re like WTF” (SP12)

THEME DESCRIPTION

Difficulties surrounding diagnosis (main theme)

There are a number of issues surrounding the actual diagnosis of Dual Diagnosis. People find it very hard to get a diagnosis as there is a lack of clarity around the definition of Dual Diagnosis. Additionally, medical professionals are often reluctant to diagnose people for a number of reasons. Firstly, there is the possibility of diagnostic overshadowing, i.e. substance misuse may 'mask' an underlying mental illness or vice versa. Secondly, a person may just have mental health issues as a result of an addiction as opposed to an actual mental health diagnosis. Thirdly, there is a Chicken and the egg scenario which is called the "primary diagnosis conundrum" i.e. Which disorder came first?; this in turn leads to other questions such as "Which is more serious?" "Which should be treated first?" and even, "Which service should manage the service user?" However, more often than not, the primary diagnosis reflects the source of referral rather than causation. Also, as a result of inadequate assessments or people presenting to acute services with unrelated health problems, their 'Dual Diagnosis' often may be missed.

ILLUSTRATIVE QUOTES FROM PARTICIPANTS

"Trying to get a diagnosis is very difficult. We are years down the line and we still haven't managed to get a diagnosis. We are always at crisis point where we're in A&E with self-harm and suicide attempts. We're just kind of sent off sometimes. Whenever we go to psychiatry we are told it's an addiction, just told to go and sober up and come back"

and "we've had terms thrown around such as bipolar and then somebody goes who told you that, there is nothing on paper. We're just starting from scratch every time, it is just a continual loop trying to find a diagnosis in order to access services" (FM3)

I see the word diagnosis as the most important part of it because what I see is that people are not getting diagnosed and people are diagnosing themselves; and when people present to services, the people in the services can't really do anything until they are diagnosed by a psychiatric team" (SP8)

"It cost me thousands to be diagnosed with what I was diagnosed with. I was one of the lucky ones who had that, who got a second chance. I fight every day of the week and I see people every day of the week and no one is helping them" (SU3)

THEME DESCRIPTION

Dual Stigma (main theme)

Stigma is another issue that appears to be a barrier to this population accessing care. The general negative attitude or stigma towards people who use drugs and alcohol both in the general population and even in mental health services. The theme of stigmatisation was constant throughout the data collection phase and it appears that people with a Dual Diagnosis are not stigmatised solely for their addiction issues but also for their mental health issues, so there is a sort of dual stigma about the condition.

People losing faith (main theme)

It was reported that people are becoming completely disheartened and are losing faith in getting any help after being let down constantly. When people present to services, they are either told they are in the wrong place, they can't be helped or to come back another time, more often than not without a referral or any information.

ILLUSTRATIVE QUOTES FROM PARTICIPANTS

"the stigma of a substance user or dependent and then you have someone who suffers from mental health stigma so you're a dual again" (SP12)

"Addiction is addiction. They like to push the stigma over there and say they are a dirty addicts over there, I actually only take cocaine so I am a social user, it doesn't affect my family" (SU)

I had left a different Residential Service and taken a break and what actually made me go back into it was how the pharmacist used to treat people coming in to collect their methadone, I couldn't believe it. There would be a queue and they'd be like I just sent him to sit over in the corner. I thought to myself how awful it is how some people are treated because of their mental health and Dual Diagnosis. I used to hate that, I found it very difficult sitting there, how people are treated by services that are supposed to be providing them with services" (SP2)

"We have had a few occasions where young men have presented to A&E and they've gone there with the same idea, A&E is where you go to get fixed if you have broken a bone or anything else, and they are just given a leaflet and they just left standing in the street with a leaflet and they have no confidence, no faith at all in where to go if something else happens" (SP12)

"No wants them on their budget for their year and that's what it comes down to, money. I said it before, people are dying because you won't put an extra 0 in the budget. When you feel that's all you are, an extra zero. Well unfortunately that's what you expect, I'm only a number, I'm not going to be helped, I'm just going to be shoved aside" (SU3)

"...that is where we are at now, we have no faith about where to go this time around We're just starting from scratch every time, it is just a continual loop" (FM3)

Figure 3 Exploration of the wider impact of Dual Diagnosis on the community/families/local statutory and non-statutory organisations

In this study, it was apparent that responding to the needs of those with Dual Diagnosis is challenging for local services and organisations. Families are affected in many ways by Dual Diagnosis.

THEME DESCRIPTION

Local statutory and non-statutory organisations (main theme)

Dual Diagnosis affects local organisations in a number of ways; it is a source of frustration, a drain on resources and trauma invoking. These consequences are not solely a result of attitudes towards people with Dual Diagnosis but more so as a result of the aforementioned lack of resources and pathways. The lack of a clear pathway and dearth of resources is a serious source of frustration for local organisations in the area. Dual Diagnosis has also become a serious drain on resources for community organisations as they feel that they have become a substitute for the mental health service, in particular when it comes to the treatment of addiction

Families (sub theme)

Dual Diagnosis also has an enormous effect on the lives of the families of people with Dual Diagnosis. Family members are essentially also living with the disorder of their family member. Everything that goes with having a family member with Dual Diagnosis can be stress provoking, tiresome, financially challenging and can impact on family dynamics, as well as having a knock-on effect in terms of others family members developing mental health and addiction issues. One of the most striking findings was that a lot of these stressful consequences are as a result of what happens when families present to services with their family member. Even when family members present to the correct services, it was reported that they are regularly turned away and this is incredibly traumatic for them.

ILLUSTRATIVE QUOTES FROM PARTICIPANTS

“It’s really frustrating when I come to a country where, as has been said, millions are pumped into services and yet you walk into one and the door is closed because you have the other condition as well. People are dying because of this. It’s a huge frustration” (SP6)

“You can have the whole family of the person in your service while you’re trying to find the best service to meet their needs, and it’s very difficult when the right service can’t be found” (SP)

“I’ve lived in this community all my life; this community is everything to me but I see a breakdown in systems. I see a disconnect between projects, they’re not coming together” (FM1)

“We were referred to the mental health service, it took us years before he was seen and no contact was made in the intervening period” (FM6)

“If it’s difficult for us as a service then it’s incredibly difficult for the family members themselves who are trying to navigate that for their family member and they spend years trying to figure out what to do and how to access services” (SP10)

“We are years down the line and we are always at crisis point where we’re in A&E with self-harm and suicide attempts and just nothing. We’re just kind of sent off sometimes. Whenever we go to psychiatry we are told it’s an addiction, just told to go and sober up and come back. As a family we are almost telling the staff what needs to be done” (FM3)

THEME DESCRIPTION

Lack of information for families (sub theme)

There are great difficulties around the dissemination of information in the health service and family members in particular are affected by this. When someone is over the age of eighteen, their family no longer has access to any information regarding their treatment and this acts as a huge barrier when they are trying to care for someone. If the service user does not want any information shared with the family, then they are essentially left in a situation of complete powerlessness. This has a seriously negative impact on family members

Knock on Effect (sub theme)

It is evident that caring for a family member suffering from Dual Diagnosis is incredibly stressful and has a knock-on effect for the rest of the family. Often family members turn to drugs or develop mental health issues themselves as a result of the stress.

Financial challenges (sub theme)

As well as being mentally taxing, having a family member with Dual Diagnosis can also become a financial burden. Due to the absence of referrals and difficulties accessing services, families often have to make huge financial sacrifices in order to get treatment for their family member. It appears as if families will do anything to get treatment for their relatives and are being let down by the health system so they have to take action themselves.

ILLUSTRATIVE QUOTES FROM PARTICIPANTS

"When someone is transitioning from an u-18 service to an adult service, the family's level of contact with the mental health service is cut off. A lot of family members really struggle with that, being cut off and not being involved and not having the consistency of the mental health service linked in. They find it very difficult when they can't get any knowledge and that creates other serious problems" (SP2)

"They are being discharged from hospital after a crisis without anybody knowing, it's just very dangerous, when all we're trying to do is keep him safe" (FM3)

"We are always at crisis point, whether it's due to a visit to A&E because of self-harm, suicide or whatever, it's constant and it is rare that something is done about it and never any information given that might help us" (FM4)

"I've seen Dual Diagnosis go through the generations and three or four people ending up with a Dual Diagnosis over a 5-year period. I've noticed that can happen very easily and it's very difficult to support people when they're in that situation, when they find it so difficult that they can't see a way out" (SP2)

"Family members spend years and years going through the process, with no feeling that all the effort they're putting in is going to come to anything or even lead to some sort of improvement, whatever about resolution, even an improvement. They end up linking in with the services for their own mental health" (SP10)

"you're always on the boundary of should I medicate, will that help get me through this" (FM3)

"I always described our life like Christmas, you hear of people saying for Christmas, we always have to say we always had that money because they always have the next psychologist or psychiatrist or therapy or something. We were always financially stretched, it was a horrible time, would I have admitted it? No, but now yes. We were just surviving" (FM4)

"I suppose financially it is a big burden as well, I had the issues with my son, I also have two other children and financially all the resources would have gone into him. I often regret looking back and wonder is my oldest son's alcoholism because of this" (FM5)

THEME DESCRIPTION

Impact on family dynamics (sub theme)

It is clear from some of the accounts given by family members that when there is somebody with a Dual Diagnosis in the family, it has a serious impact on the family dynamics. A huge strain is put on the rest of the family as they are focusing all of their energy into trying to help the individual to get better, often resulting in break ups.

ILLUSTRATIVE QUOTES FROM PARTICIPANTS

“You lose sight of everything else that is normal and you just concentrate on the issue and solving that issue. It affects the dynamics of the family an awful lot when there is a Dual Diagnosis present” (FM4)

I was with somebody with a Dual Diagnosis but it was having a knock-on effect on me and my children, so I made a decision that not everybody would make. I knew that if I didn't that my children would have suffered, I wouldn't been able to look after them and that is the hidden harm piece” (FM5)

Figure 4 Identification of ways/service developments that will better support those who are experiencing/affected by Dual Diagnosis

The findings from Cycle One in relation to Objective 5 will be organised by the group or body that seem most aligned with addressing requirements. In the case of Cycle One, these recommendations will be split between: (1) The Government; which will primarily pertain to changes of policy; and (2) The Community, which will include initiatives that can be implemented and initiated by the community; which is comprised of community, voluntary and statutory organisations, as well as service users, family members and laypeople. These last set of findings provide the bridge and initial dialogue about how to respond to Dual Diagnosis into Cycle Two findings that focus entirely on objective 5.

Governmental responsibility

THEME DESCRIPTION

Implementation of a Clear Pathway (main theme)

The implementation of a clear pathway was one of the primary recommendations made. Service providers and service users need direction. In relation to Dual Diagnosis, at the moment service providers don't know how to refer people, where to refer them, what options are available to them and it is similarly confusing for service users. Overall, a clear pathway would improve quality of services for service users and should help with other areas such as referrals and case management.

ILLUSTRATIVE QUOTES FROM PARTICIPANTS

“In an ideal world you would have a clear contact in all of the services and a clear path to refer people if your current service isn't meeting the person's needs” (SP10)

“I think if we all had the same framework, it makes it very difficult that everyone is working off something different. If everyone worked off the same framework then people would know what they're going to get, what the process of it might look like” (SP2)

“A proper pathway to work with, so irrespective of whether you're working in the community or not everyone that presents, you know what kind of services you can get medically and if somebody presents to A&E or the GP then they know exactly what kind of Community Services they can access” (SP14)

THEME DESCRIPTION

Change of policies and procedures (main theme)

The changes that could be made to policies and procedures are as follows: Addiction and Dual Diagnosis should be treated together as one; evidence-based practices for Dual Diagnosis should be implemented; holistic treatment approach; and a 'no wrong door' approach. All of these changes have been highlighted before and have not been implemented, whether this is due to practical/financial reasons or whether it is due to stigma remains unclear.

Other initiatives (main theme)

Dual Diagnosis service (sub theme)

It was proposed that the establishment of separate Dual Diagnosis specific services could be beneficial. This would essentially entail setting up a service which caters solely to service users with Dual Diagnosis and all the complex needs which go along with it, in one specially designed location which houses all the services they may need such as mental health services, addiction services, social care, etc.

ILLUSTRATIVE QUOTES FROM PARTICIPANTS

Litigation has stagnated progress in every department. I can't do this because the last time this happened there was a claim. People can't make decisions and are held back" (SU1)

"Is there something about it not being the person's fault that they have come to the wrong place. We should be able to respond to the person instead of saying oh can you detox. There should be some level of help or as you said just the power of listening" (SP4)

"The two of them need to come together, not a dual it needs to be a one, to treat the whole person", "I think there is a responsibility to offer a holistic approach and I know sometimes holistic is sometimes a bit cuddly for the statutory services. They're not using it but they're expecting it, you can't treat mental health in one vein on its own and expect do impact the rest of the person, so there needs to be a more holistic approach. Need to get away from dual, there is one person and everything encompasses that" (SP12)

See below

"I think we need to acknowledge the need for services for people with Dual Diagnosis because at the moment they are so separate. Some services are trying to provide that but they're not supported from a statutory perspective" (SP9)

"Human beings are complex, you can't just say I'm going to work with you but not this part" (SP3)



THEME DESCRIPTION

Funding (sub theme)

There is a requirement for increased funding and a restructuring of the approach in which funding is divided. It was also acknowledged that before anything can be actioned with regards to funding a number of precursors must be in place to ensure that the funds are used effectively for Dual Diagnosis. It is clear that the way that services who are dealing with mental health and substance issues needs to be reconfigured and changes made; however, appropriate structures need to be in place if the funding is to be used successfully

ILLUSTRATIVE QUOTES FROM PARTICIPANTS

“Funding also needs to change, my funding has to be addiction, alcohol and drug related but I can’t give my funding to mental health initiatives even though they are intrinsically linked, I think the way the funding is approached needs to be changed” (SP9)

It’s the same with any service I’ve seen, get it efficient, improve their communication and then bring the funding in as it builds” (SP3)

Community response

THEME DESCRIPTION

Education and Prevention (main theme)

People often lack the basic skills to deal with mental health issues when they arise, which means they often have to present to services in order to get some relief. There are huge problems when people present to emergency services in crisis as it is very hard for the emergency staff to process or help somebody when they are in that state. Therefore, it was suggested that more of a focus be placed on prevention of illness rather than managing outcome.

ILLUSTRATIVE QUOTES FROM PARTICIPANTS

See below

THEME DESCRIPTION

Education for adults (sub theme)

Education emerged as the primary intervention which could be effective in preventing mental health issues or at the very least could help people to manage them. This would require education to be provided for adults on mental health and substance issues and teaching them how to build self-care and resilience. Thus, it was recommended that attempts be made to raise awareness around simple coping strategies, basic skills and information on mental health and addiction in general. Education and awareness could also be used to eradicate stigma which is huge problem for people with a Dual Diagnosis as they often also suffer from dual stigma. In a more professional sphere, education could be used to train people i.e. service providers could upskill in whichever area of mental health or addiction they are deficient in. However, it may be more beneficial to reach professionals at a younger age before they are socialised.

Education for young people (sub theme)

One of the ideas proposed was to start educating people on mental health and addiction at an even earlier age, i.e. while they are still in school

Directory of Services (sub theme)

There was general agreement that a directory of services needs to be compiled and actively disseminated on a revolving basis.

ILLUSTRATIVE QUOTES FROM PARTICIPANTS

“it’s not just a health issue, a lot of these issues are also basic life skills” (SP5)

“Sometimes it’s the simple things like learning coping techniques or breathing techniques, even just walking twice a day, decluttering your room, eating well. It is quite shocking that the general public don’t understand these basic things” (SP1)

“In University Programmes (Psychology, Nursing, Social Work, etc.), they need to be cross-trained, so you have the language of Dual Diagnosis and the DSM and you can communicate with the Psychiatrist, that facilitates access to services for the SUs. We’re not training people, they are coming out and saying I work here, I work there. People do extra courses but why aren’t we training them when they are back in college” (SP6)

“Dual Diagnosis can affect everyone in the family. Resilience needs to be built up in our children” (SP5)

Schools have a very important role to play. As a health model we deal with crisis prevention and you’re not going to prevent everything” (SP4)

“Imagine how much time you would save if there was something that could be updated once every 12 months” (SP6)

“The knock on effect would be hugely beneficial for service users; the staff as well would be under much less pressure, they wouldn’t have to be tearing their hair out wondering what should they do and where should they even start” (SP7)

THEME DESCRIPTION

Community groups (sub theme)

It was proposed that interagency meetings could be held to discuss the current state of affairs regarding Dual Diagnosis. As mental health and addiction services in the community are so separate at the moment, and Dual Diagnosis is a condition that requires input from multiple services, it was felt that community groups would be a feasible way of improving this interagency cooperation. These groups will need to have a strong service user presence as there is often very little service user representation in similar groups which are running in the community

ILLUSTRATIVE QUOTES FROM PARTICIPANTS

“We are all kind of working disjointedly but I think if there was some kind of forum where we could come together around Dual Diagnosis, it would improve things” (SP6)

“Within the community, there are steering groups that meet up like the HSE and Barnardos but there are very few local service users at those meetings, people who have experience of it. They are the ones who have the knowledge. I feel there needs to be, especially in terms of MH and Addiction, a group put together where there is service providers but also service users” (SP9)

Summary of Cycle One findings

The findings from Cycle One clearly identify systemic issues affecting the whole community's ability to respond to Dual Diagnosis and in the main these are replicating other studies and community experiences. These findings provided a baseline from which to identify how they can be addressed now and going forward the next section begins to uncover how the community (inclusive of policy, organisations, services and people) can do this. The section provides the impetus and process means by which this can happen.



Cycle Two findings

The findings for Cycle Two relate to Objective 5: Identification of ways/service developments that will better support those who are experiencing/affected by Dual Diagnosis and build on the last section of Cycle One. The demographics for Cycle Two are presented in Table 2. However, representation of people and organisations was still maintained. The findings are organised by three distinct categories based on which group or body is in the best place to action the recommendations.

The three categories are as follows: Community Response, Organisational Requirements, and Governmental Responsibility. The findings for Cycle Two are summarised in Figure 5. below. Quotations are not used to illustrate these findings, as they were action orientated, analysed within groups and collectively agreed. The key questions put to participants following a summary of findings to date and identification of those warranting action were: What needs to happen for positive developments: and how can they be enabled?

Table 2 Cycle Two demographics

	N	FEMALE (%)	MALE (%)
Open Dialogue Conference 2	30	19 (63)	11 (37)

Figure 5 Cycle Two findings

Three key action areas emerged from the findings, they are mobilising and developing a Dual Diagnosis community response, how organisations can respond to the needs of those with Dual Diagnosis and governmental and policy changes to support the development of effective accessible services.

DOMAIN	WHAT IS NEEDED	HOW CAN IT BE ACHIEVED
Community Response	Interagency Collaboration	Networking, Improved Communication, Identify Liaisons & Establish Community Groups
	Integrated Services	Agreements between mental health and addiction services & Implement Integrated Practices
	Information Sharing	Protocol for Information Sharing, Directory of Services & Improved Record Keeping
	Develop Referral Pathways	Standardised Referral Pathway, Improve Screening & Establish an Online Portal
	Develop Supports	Online forum and Resources, Phone Support & Access and Outreach Teams
	Family Support	Develop Family Support Services, Social Events & Support Groups
	Partnership Approach	Collaborative Approach between service users, families and service providers
Organisational Requirements	Training	Staff could attend a Dual Diagnosis programme & upskill in deficient areas
	Response to Trauma	Raise Staff Awareness, Training in Trauma Informed Care & Respectful Approach
	Develop Assessment Tool	Develop an Evidence-Based Tool
Governmental Responsibility	Care Pathway	Re-establish National Clinical Programme & Mimic Similar Policy Documents
	Change of Policies	Amend Mental Health Act and Clinical Governance Policies & Adopt 'No Wrong Door Approach'
	Improved Case Management	Online Database, Co-Working & One Case Manager per Service User
	Changes to Education	Develop Training and Education Programmes Which Can Incorporated Into Interdisciplinary Academic Programmes

Community response

Interagency collaboration

At the moment community services appear to be working independently which is to the detriment of the service users. There is a need to improve coordination and collaboration of services for individuals with a Dual Diagnosis within and between mental health and addiction services. Interagency working should include statutory, community and voluntary services. It was reiterated on numerous occasions that this needs to be put into practice and not just spoken about.

The following proposals were put forward as to how interagency collaboration could be improved:

- (1) Identify liaisons within each appropriate service in the community.
- (2) Good communication is key to successful interagency collaboration. This needs to be formalised with pathways agreed and responsibilities and roles identified for each team.
- (3) Interagency arrangements should be consistent with the right to confidentiality
- (4) Establish community groups; these groups could meet on a regular basis to discuss the state of affairs in relation to Dual Diagnosis in the community.
- (5) Establish networking forums which include all of the appropriate services in the community.

Once these interagency collaborations are established then the different services in the community which are operating independently can agitate around self-identified issues and work to achieve their own goals. These goals, which may or may not coincide with the intentions of the government such as developing integrated services, improved information sharing and standardised referral pathways, will be discussed in greater detail in the following sections.

Integrated services

The need for addiction and mental health services to be integrated in order for those with Dual Diagnosis to receive adequate treatment was a common theme in both cycles of the study. This would essentially involve multidisciplinary teams, consisting of staff from mental health and addiction services, working together in a long-term model with case managers in order to deliver interventions for both mental health and substance misuse at the same time. A number of service providers expressed their preference for integrated services instead of a specialist Dual Diagnosis service:

- (1) Agreements need to be reached between mental health and addiction services in the community regarding their amalgamation or processes identified for integration where persons with Dual Diagnosis are on caseloads.
- (2) Services need to agree on and implement integrated practices.
- (3) Changes need to be made to clinical governance.

Another suggestion was in relation to new Primary Care Centre in Finglas. It was seen as a great opportunity to integrate services from the beginning. It was stated that the new Primary Care Centre could integrate addiction and mental health and to locate them on the same floor in the building. This would mean that it would be a community voluntary statutory Primary Care Centre as opposed to just a statutory one. It was also proposed that the design of the building be different to other primary care centres, in that it should be less clinical.

Information sharing

There is a need for improved dissemination of information between services as it was highlighted that there needs to be clarity about what services exist in the community as well as what each one does. This would aid referral processes and improve service quality for those accessing them. A number of service providers stated that this is something that they would get on board with and feel is achievable.

Overall, a protocol for information sharing could be established between mental health, substance misuse, voluntary and community services as well as health, social care, education, housing, etc. This could involve sharing information on support services between the agencies while ensuring all those involved know about and can provide information on the services all of the other services; this would also require services to provide prompt feedback and communicate regularly about progress. This would allow people with to consistently get help from the most relevant service.

Another idea which was proposed was a directory of services in the community. This would essentially entail the creation of an online database of services in the Finglas and Cabra, accessible to every service in the community. The directory would also include the address and contact details of each organisation. A committee organised by the Finglas/Cabra Local Drug & Alcohol Task Force has begun working on this. This directory should also be made available for public access so services users and family members have information on which service they should present to. Additionally, it was also suggested that a record be kept of the number of people who have Dual Diagnosis in the community.

Develop Referral Pathways

There are serious issues regarding referrals between services in the community. At present, referral processes are causing frustration and fatigue among service providers and feelings of hopelessness among service users and families. Solutions put forward included the establishment of a referral pathway. A number of service providers expressed their desire for the implementation of a centralised referral pathway by the government or designated agency. However, another suggestion which may be more feasible was the establishment of a standardised referral pathway which could be set up by the different services in the community. If a standardised referral pathway was in place, then service users would not be sent to the wrong place and there would be an increase in referrals to appropriate services.



Services in the community could establish a MDT with representation from a range of different services in order to design a standardised referral pathway. The following principles were deemed essential if the pathway was to be effective:

1. Improve screening so referrals can be as accurate as possible.
2. Timely access to consultation for referrers.
3. The referrer should be aided in finding the most appropriate service through discussion with other agencies.
4. Avoid redirecting referrals to another service purely based on what is thought to be their primary diagnosis.
5. Establish an online portal which the different services have access to in order to improve the efficiency of referrals.
6. Each Service user is allocated a case manager.

In terms of a centralised referral pathway, this would involve referring people to one port of call, and an MDT manage everything and also decide which is best for a service user.

Education/awareness

It was highlighted that education, psycho-education and information for service users, families and the general public is essential, in order to facilitate understanding of what the concepts and nuances concerning Dual Diagnosis can be and the potential impact on individuals, families and the community as a whole. It was stressed that mental health knowledge improves the chances that someone will seek help for a mental

health issue or will be more inclined to disclose it to family and friends. Improved education could also help to reduce the stigma associated with mental health and addiction problems.

The solutions as to how education and awareness could be improved are listed below:

- (1) Hold talks in local community buildings on different topics related to mental health, monthly meetings could be organised in order to try and raise awareness.
- (2) Awareness of the available services which can cater to the needs of those with Dual Diagnosis could be raised during community talks/meetings or the information could be open to the public on a website.
- (3) Children taught about mental health and addiction issues while still at school.
- (4) People with experience of mental health and/or addiction could go in and talk to children in schools.

Develop supports

It was proposed that a number of additional supports needs to be developed within the community in order to cater for the complex needs of those with Dual Diagnosis. A number of service providers highlighted the need for supports that are easily available to people and which are also accessible outside of normal business hours.

A number of possible additional supports were proposed:

- (1) An Online Forum: this would act as a focus point where people could access information and direct help. It would help to support people and would reduce issues such as staff burnout in local services.
- (2) Online Resources: a repository with resources such as bibliotherapy and other information regarding coping strategies, behavioural interventions, addiction and general mental health issues.
- (3) Phone Support: A number which people in the community could ring in order to talk to someone about the issues they are having in relation to mental health or addiction issues.
- (4) Access Team: a community mental health team that can be accessed 24-7. A safe place where it is possible to call up and bring someone who is in crisis.
- (5) Outreach Team: a team which can be contacted and that will come out and talk to the person where they are, where they are living rather than going through the sectioning process.

Family support

Family support is a much needed resources for the families of service users with Dual Diagnosis as it also impacts on them mentally, physically, socially and financially. It was stated that it is integral to have separate entities for families and service users as this aids with trust, honesty and the therapeutic relationship. More services need to be developed for family members as they often develop mental health and addiction issues themselves as a result of caring for their relative.

The following support mechanisms were proposed:

- (1) Invite families to access support: there are a number of programs available in the community and families need to be made aware of these such as the Positive Parenting Programme available to people in North Dublin and Suicide or Survive (SOS)
- (2) Social events could be help in local services such as life skills workshops
- (3) Services could develop psychoeducation programs and allow families in the area to attend for a number of weeks.
- (4) The local services need to develop a comprehensive outcomes and evidence-based approach to addressing the needs of service users and their families experiencing both mental health and addiction issues. A whole-family approach could be taken.
- (5) Local services could provide family therapy for the whole family.
- (6) Develop family support services locally which provide access to information about mental health, addiction and the recovery process for family members. These services should also include peer-led support groups and evidence-based skills programmes.
- (7) Group meetings or support groups could be set-up by local services which could then develop into being completely peer-led.
- (8) Develop Supports such as online resources or a phone line which is available solely for family members.

Partnership approach

A partnership approach should be developed between the local services and services users/families in the community. Services users and service providers should be equal partners when it comes to decisions related to the individual's treatment plan. Families should also be seen as key to a person's recovery.

A number of suggestions as to how a partnership approach could be adopted by local services are listed below:

- (1) Local services need to adopt a different attitude so that service users and families need to be seen as key stakeholders in the individual's recovery.
- (2) Service users need to be given some choice and control when it comes to the design of recovery plans are designed, especially with regard to medication, peer support and talk therapies.
- (3) A collaborative approach needs to be taken by local services when it comes to a services user's care plan.

Organisational requirements

Training

The data demonstrated that education and training for all healthcare professionals was essential in order to effectively work with Dual Diagnosis in the long-term. Staff need to be adequately across all areas, this may include nursing staff being trained in addiction related knowledge or addiction personnel up-skilling on matters associated with medication and serious mental health diagnoses. This was described as essential in order to effectively work with people with Dual Diagnosis in the long-term.

Additionally, addressing gaps in knowledge, whether it relates to mental health issues or substance misuse could encourage staff in the separate services to establish links with each other, which in turn may help with the improvement of service delivery.

A number of proposals were put forward which community organisations could put into action:

- (1) Establish a progressive environment where staff feel comfortable taking time to upskill and train.
- (2) Ensure that staff regularly take part in training and professional progression.
- (3) Staff could attend a Dual Diagnosis training programme.
- (4) Ensure that staff are trained in areas where they are currently lacking knowledge e.g. staff at an addiction centre attending training related to medication and mental health issues.

Response to trauma

At present, services aren't always adequately equipped to treat trauma and there are a lot of models of Trauma Informed Care that people are not aware of or do not understand. Therefore, there is a need for services to become more trauma informed and to upskill in that area, due to the fact that trauma is likely prevalent in service users with Dual Diagnosis.

The following proposals were put forward:

- (1) Raise staff awareness that people with mental health and addiction issues may also be suffering from trauma.
- (2) Ensure they can meet those needs by making sure all staff are adequately trained with regards to dealing with trauma.

- (3) Service providers should make sure to adopt a respectful, non-judgemental and dignified approach when treating service users suffering from trauma.
- (4) If staff are unable to treat trauma then it is paramount that they make appropriate referrals once it becomes evident that there may be some underlying trauma issues

Develop assessment tool

As well as raising awareness around Dual Diagnosis, there is also a need for a standardised assessment tool for the condition as at present it is often missed during assessment:

- (1) Develop an assessment tool for Dual Diagnosis based on evidence-based models already in use
- (2) Train mental health and addiction service staff how to administer this tool

Governmental responsibility

Care pathway

The necessity for a care pathway was once again highlighted. The primary reason why a care pathway is necessary is due to the fact that there is a clear divide between community services and state services which results in difficulties in communication and working relationships between the two. Additionally, there is a need for common standards and content of treatment, a consistency of first contact, a proper diagnostic system, standardised training and an adequate case management system.

A number of recommendations were given as to how this could be achieved and should be actioned:

- (1) Re-establish National Clinical Programme for Dual Diagnosis
- (2) Mimic policy and action practice documents on integrated care pathways which have already been implemented such as that for chronic illness which like Dual Diagnosis is based on complexity
- (3) Ensure service users have prompt access to local services including direct referrals if possible.
- (4) Ensure referral processes and care pathways within and across services are consistent and that governance arrangements are in place, including local care pathways in order to meet other needs such as social care, housing and physical health.
- (5) Ensure that there are follow-up protocols in place
- (6) Ensure continuity of care to support people at different transition points in their lives.

Policy changes

At present, a number of policies are placing constraints on service providers' ability to treat people with Dual Diagnosis as outlined earlier in chapter two. Firstly, restrictions in relation to clinical governance mean that mental health services are unable to treat addiction. Additionally, under the current Mental Health Act people cannot be committed to a psychiatric facility if they are under the influence, this is particularly problematic for service users with Dual Diagnosis and often results in more extreme

consequences. The necessity for the adoption of a 'no wrong door' approach was also mentioned on a number of occasions as often service users present to a service and are turned away without a referral or any information.

In order for these needs to be met the following proposals emerged:

- (1) Restrictions could be lifted in relation to clinical governance when it relates to service users with Dual Diagnosis. Thus, allowing medical practitioners to treat more than just a person's mental issues.
- (2) The Mental Health Act could possibly be amended so that a person could be committed to a psychiatric facility even if they are under the influence if they have a documented history of mental illness.
- (3) Adopt "No Wrong Door" Approach. This would mean that also services need to provide individuals with, or links them to, appropriate services regardless of where they enter the system of care. Community organisations can do this to an extent through networking but it needs to be a state wide policy for it to work effectively.

Improved Case Management

There are serious issues relating to case management for service users with Dual Diagnosis due to mental health and addiction services being separate. This often means that service users are left without an assigned case manager and are passed from service to service. It was also claimed that since the introduction of GDPR that it has become incredibly difficult for services to share information.

The following recommendations as to how case management could be improved were proposed:

- (1) The introduction of an online database with information on a service user's care plan/engagement with services. For example the NHS has a database called OASIS for sharing of information across services so as not to breach data protection, the HSE could implement a similar system.
- (2) Services could consider co-working rather than excluding individuals with co-morbid conditions.
- (3) Should be one case manager per service user, not multiple.
- (4) The introduction of a case management team could also be another option.

Changes to education

In particular service providers proposed that changes be made to third level education, i.e. students should receive some cross training in different disciplines while still studying so as to avoid having to upskill later on:

- (1) Develop training and education programmes which could be incorporated into interdisciplinary academic programmes
- (2) Mental health nurses, psychiatrists and other medical personnel could be educated on addiction.
- (3) Social Care and addiction counsellors could receive education on mental health conditions and medication while they are training.

An ongoing transformative participatory community process

Throughout the participatory research process, participants decided that the approach that brought them together was effective in getting an inclusive community dialogue and mutually agreed findings in place. Because of the mutuality owned and created network approach it was deemed more likely that agreed actions and recommendations would be effectively implemented. Moreover, in both Cycles One and Two findings indicate the need for interagency collaborations and joint working on making the recommendations a reality. Therefore, one of the key process outcomes of the research is that participants agreed to continue meeting in the open dialogue forum that was created for the research itself. Already plans for the next gathering are under way.

Conclusion

Whilst the findings from Cycle One generally mirrored international evidence, they were derived from and tailored to the communities participating in this research. Moreover, the methodology garnished the resources of the community and gave voice to all who might be effected by Dual Diagnosis. In Cycle Two these findings were analysed within the Open Dialogue forum and using the relational knowledge generated through the research process, solutions were created that can insure Dual Diagnosis does not have to be relegated to the shadows of marginalisation anymore.

The conceptual community response model is possible, even without major government shifts in policy and departmental responsibility. However, at senior management levels in statutory and voluntary sector services there needs to be a shift in priorities towards Dual Diagnosis and an openness to work in partnership with each other. These communities have demonstrated what is needed and how to respond to that need. A process is underway that can take the necessary step create an effective care pathway for people with Dual Diagnosis, though buy in and a willingness to engage in cultural change will likely be required to bring the solutions to fruition. The following chapter will discuss some of the ramifications and implication of these findings for organisations, people, these communities generally and government action.

Chapter Four: Discussion and implications for service provision

Introduction

This report discussed community participatory action research about the impact of Dual Diagnosis in Finglas and Cabra. To follow is a discussion about the study methodology, the process of community engagement research. It presents a conceptual framework of the implications of this research and some reflections on the current community responses within this study's context. Importantly, this work highlights the continued unmet needs of those who experience Dual Diagnosis. Its uniqueness is the shared voice of stakeholders across two communities dealing with the reality, burden and consequences of Dual Diagnosis.

Review of study methodology

The value of this study's findings are compelling because this study is context bound within the two communities. This collaborative research process represents community data and includes personal experiences of Dual Diagnosis, the family/carer impact and insights from professionals who work with clients with Dual Diagnosis. As noted previously, the findings mimic those in previous Dual Diagnosis research however this study's collective actions are owned by its participants i.e. the communities of Finglas and Cabra. This allows for change and in time transformation in the local Dual Diagnosis response. The voluntary nature of participation in the open forums and focus groups may be suggestive of bias towards interested parties who may be affected by Dual Diagnosis either personally, professionally or both. Also the study time-frame was short which may have resulted in a lack of participation

by some. This study aimed to consider ways to address Dual Diagnosis in the two communities so was not about generalising its findings to other areas. However, we believe the shared dialogue created in this process may have resonance for other communities struggling with the challenge of appropriate care and treatment of those with Dual Diagnosis.

Process of community engagement and participation

Findings from this study not only once more repeat the challenges experienced internationally in terms of fragmented care, ineffective appropriate care provision and lack of joined-up policy thinking; they also provide a contextual basis to this area of North Dublin for what effects every other researched jurisdiction in relation to Dual Diagnosis. What differs in this research to most published research in the area, is what emerged in Cycle Two of the process. The required transformation process by which this can take place was identified. Of particular relevance was the identified process outcome finding '*An ongoing transformatory participatory community process*' and a commitment by community stakeholders to embrace this process in order to bring about these required changes to how people in the community experience service provision for Dual Diagnosis. The very nature of the dialogical collaborative process established in this research brought all relevant participants together where mutual needs and responses were agreed, and actions produced will ensure they will be met.

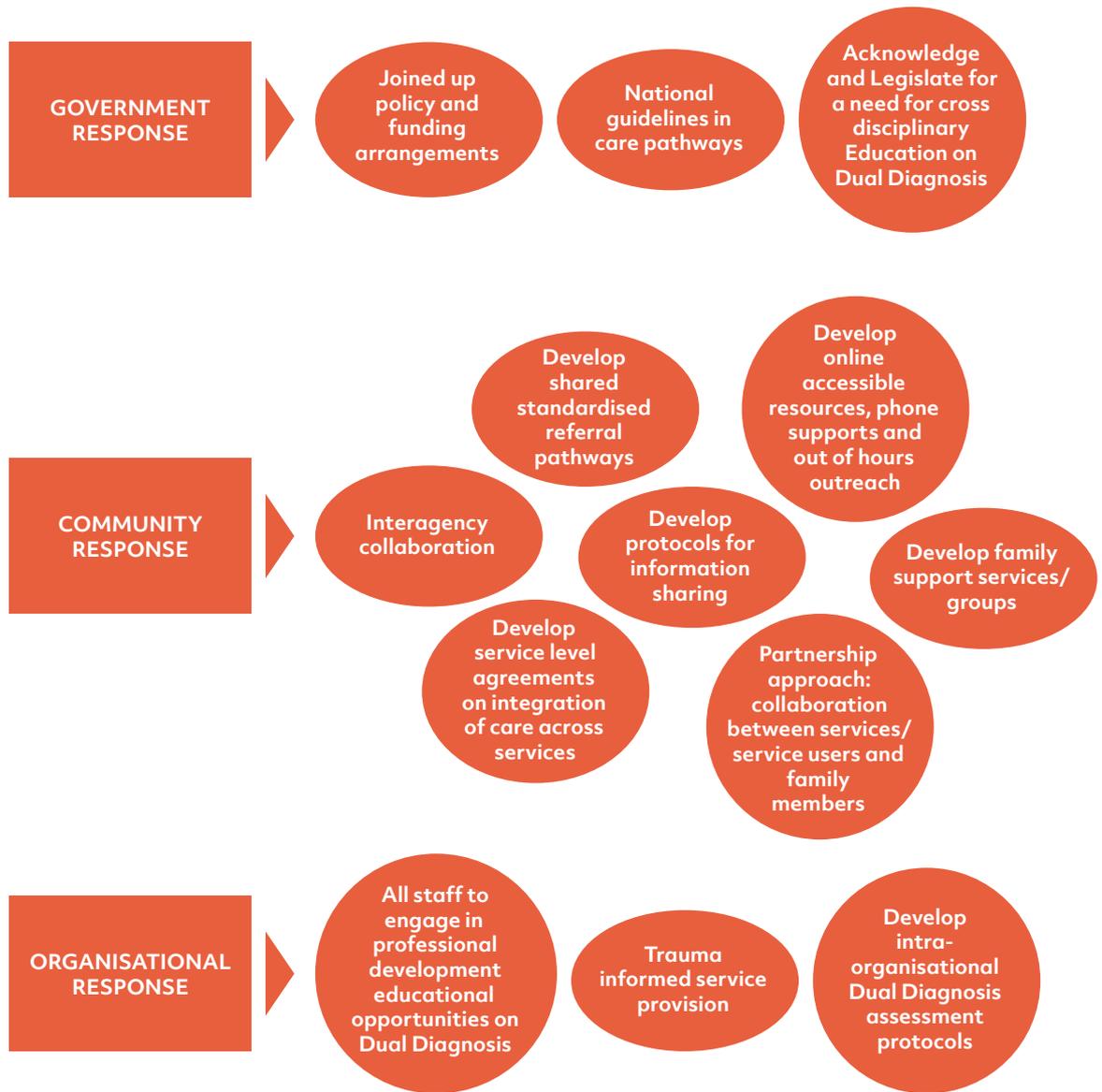
At a Community and Organisational level this dialogical process will continue so that the required changes and developments can occur so that there is an effective community response to all of the complexity associated with Dual Diagnosis. Critically, Government and Statutory Agencies need to also respond to the findings, given that within this large catchment area the challenges identified in international literature and indeed Irish literature (MacGabhann et al. 2004; MacGabhann et al. 2010) remain current. Moreover, within this study context, the solutions to these challenges are owned, have been agreed and are possible, though need government intervention to enable full organisational and community transformation.

Implications of action orientated findings

Contrary to traditional research methodologies, where there is knowledge generated that enable recommendations to be made and implications to be discussed, PAR and the findings of this research bring about concurrent transformations in the system under inquiry. The required changes to existing service provision have already begun for example improved interagency communications and thus there are consequences for the various community representatives requiring ongoing action. Stakeholders recognised and owned these changes, which is why they have agreed to continue with the dialogical process, in the first instance to explore how to create improved interagency collaboration. Figure 6 provides an illustration of the actions, i.e. a conceptual framework required of the specific transformations that need to occur for Dual Diagnosis to receive the required service, community and government response.



Figure 6 Conceptual Framework: A Community Model – National/Community/Organisational Response for Dual Diagnosis



Dialogue on Dual Diagnosis community developments in Ireland

So far, we have seen from the literature that there has been a limited response to what is a huge complex need in communities across Ireland due to the fragmented government policy. Even where a process for developing a clinical programme was started, it emerged into nothing and presently there are no guidelines for any services in Ireland to provide a Dual Diagnosis service. This is not to say that communities and services are not trying to respond effectively. We have seen in other jurisdictions, for example England, where much research, lobbying and local developments occurred for nearly ten years before clear guidelines and concurrent resources were made available (DOH, 2002). Ireland is not necessarily any different, albeit repeating history when the required response is already known is frustrating. The limited research has shown that even as far back as 2004 attempts have been made by services to respond to Dual Diagnosis (Mac Gabhann et al. 2004) though the amount of research and development has been slow. A commitment to Dual Diagnosis is evident in the current Irish drug strategy (Department of Health, 2017). We can see from the literature reviewed here that there is a slow increase in researching Dual Diagnosis and in recent years an increase in active service development at local level (Connolly et al. 2015; Garbare 2015; Galvin 2019) has been progressing. Each study, each development has progressed a small emerging community of practice and dialogue that if government and statutory services choose to engage with, could provide the blueprint for an effective affordable national response to Dual Diagnosis.

The findings and implications of this study are not surprising. There are a number of emerging service models in Ireland that are best practice both internationally and at local and national contextual levels. Despite the duplications in research knowledge and identifiable evidence-based practice, local communities are still left without national guidance, resources or the remit to deliver effective services. This research has once more shown what is needed, what is possible and what is already in place to meet the needs of people with Dual Diagnosis in these two communities.

Conclusion

These findings emphasize that a timely response to address Dual Diagnosis needs is necessary. The complexity of Dual Diagnosis is far reaching as it affects more than an individual and their families, its impact can be community wide. This study underscores the community impact of Dual Diagnosis within Finglas and Cabra. It provides some solutions/ways forward to tackle this multifactorial issue from the communities in tandem with structural and policy improvements.

Importantly, the needs of those living with Dual Diagnosis matter as much as those with other complex health and social issues. We hope this study can be a catalyst to the development of an effective Dual Diagnosis community response in association with governmental policy changes.

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Appendices

Appendix 1: Community Research Group

Membership included:

- Dual Diagnosis Ireland
- Health Service Executive
- Finglas Addiction Support Services
- Finglas community representative
- Service User representative
- Public representative
- Local Outreach Family Therapies (LOFT – Cabra)
- Mental health nursing, Dublin North City Mental Health Services
- Finglas/Cabra Local Drug & Alcohol Task Force
- Finglas Traveller Development Group
- Sankalpa Addiction Services
- Dublin North West Area Partnership (DNWAP)
- An Garda Síochána
- Better Finglas
- Community and mental health advocate
- Family member representative
- Dublin City Council
- GP Finglas
- Castlevue Mental Health Service
- Psychology Service, Primary Care.



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