

The Evolution of NICHE: Assessing the challenges and opportunities for a community health organisation in Cork City

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CARL Research Project

in collaboration with

NICHE



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Community Academic Research Links (CARL) is a community engagement initiative provided by University College Cork to support the research needs of community and voluntary groups/ Civil Society Organisations (CSOs). These groups can be grass roots groups, single issue temporary groups, but also structured community organisations. Research for the CSO is carried out free of financial cost by student researchers.

CARL seeks to:

- provide civil society with knowledge and skills through research and education;
- provide their services on an affordable basis;
- promote and support public access to and influence on science and technology;
- create equitable and supportive partnerships with civil society organisations;
- enhance understanding among policymakers and education and research institutions of the research and education needs of civil society, and
- enhance the transferrable skills and knowledge of students, community representatives and researchers (www.livingknowledge.org).

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How do I reference this report?

Author (year) *Dissertation/Project Title*, [online], Community-Academic Research Links/University College Cork, Ireland, Available from: <http://www.ucc.ie/en/scishop/completed/> [Accessed on: date].

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Declaration of Originality

I wish to state that the work on this thesis, “The Evolution of NICHE: Assessing the challenges and opportunities for a community health organisation in Cork City” is all my own. Where I have referenced the work of others, I have cited it using approved academic referencing.

Catherine Majella Canty

4th May 2020.

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Abstract

This study was proposed by NICHE, a community health organisation based on the North side of Cork City. NICHE wanted to capture and reflect on the role that it has played in that community for the last 20 years. This research provides an analysis of how the NICHE model has evolved over these years and the role that the community health worker has played for the people in this community. The study is contextualised within wider changes that have affected communities and community development in Ireland. The story of NICHE is set against the impact of a neoliberal policy agendas on community organisations. As a result, this research also explores the effects of neoliberalism on NICHE.

This is a qualitative study combining a review of the literature with 10 semi-structured interviews documenting the thoughts and experiences of people who have worked at NICHE. Their voices and stories highlight a number of issues: first, interviewees reflected on the impact that wider policy changes have had on NICHE as a community health organisation over the years. Findings indicate that the shift from participatory democracy to a neoliberal policy agenda has had a negative impact on community development in Ireland. The top-down approach to community development, a feature of neoliberalism appears to be ineffective in reflecting the needs of a community. Community organisations would benefit from the re-introduction of structures which once supported communities in influencing policy. Secondly, in relation to the role of the community worker, this research reveals the importance of community health workers being local. However, in contrast with findings from the literature review, this study also points at some difficulties encountered by workers who live in the communities they serve which may be worthy of further investigation.

Based on the findings, this study points at the need for NICHE to return to community consultation in order to assess the needs of a changing community and to determine what role NICHE may play in addressing these needs.

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Chapter 1: Introduction

1.1 Introduction

This thesis is the result of a collaborative project between NICHE, a community health organisation located in the North side of Cork City, and the researcher. This collaborative study emerged as a CARL (Community Academic Research Link) project, an initiative that facilitates students to undertake research projects that address community research questions and concerns. This chapter addresses three main things: first of all, it provides some background to CARL (Community Academic Research Link) and the role the researcher has played in the context of this project; secondly, it gives an introduction to NICHE; and finally, it also outlines the rationale, aims and objectives and the methodology adopted by the research.

1.2 Background to CARL Project

This study is a collaboration between the researcher and NICHE, and it emerged as a Community Academic Research Link (CARL) Project. CARL is committed to working with community/voluntary groups who would not normally have the resources to carry out their own research, facilitating and empowering those groups. Northside Community Health Initiative (NICHE) celebrated their 20th Anniversary in 2019. This milestone was considered an ideal opportunity to chart the journey of NICHE over the past twenty years and to reflect on the future challenges and opportunities for the organisation. The manager of NICHE proposed the study to CARL and as part of my masters, I applied to work with NICHE on the project. CARL facilitated a meeting between NICHE, the student and the supervisor, and as a result of a number of conversations that followed this meeting, we finally agreed on the scope of the research and its main objective, which was to capture and document the experiences of key members of the team at NICHE over the past two decades.

1.3 Introduction to NICHE

NICHE is a community health initiative working within Knocknaheeny, Hollyhill and surrounding areas of Cork City to improve the health, wellbeing, and quality of life of community members. NICHE was established in 1998 when it operated from a prefab behind the nun's convent in Hollyhill. The organisation has seen significant growth and development over the past 20 years and now operates from 2 sites: the NICHE building on Harbour View Road and the community garden, which is located in Hollyhill. The NICHE building has facilities to host workshops, meeting rooms and therapy rooms; the community garden in Hollyhill allows community members to grow and cook fresh vegetables and benefit from the company of other community members. NICHE's work is primarily facilitated by Community Health Workers (CHWs) of which there are five. Groups such as the Men's Group, Young Mothers' Group, Women's Group and the Environment Group were all established as a result of community consultation by NICHE. All these groups responded to some of the diverse needs that were identified by community members. Community consultation took many forms, such as outreach where CHWs went door to door engaging with locals, community meetings and focus groups. The CHWs have mostly focused on bringing different groups of people together and enabling them to voice their concerns and experiences. CHWs also empower these groups to come up with solutions to address local and individual health needs.

1.4 Rationale

I first heard about CARL during a presentation to our social policy class and I knew instantly that this was the research path for me. CARL embodies the principles which I value most with regard to community: it is participatory, inclusive and enables even those who are disadvantaged and under-resourced to benefit from research. When I read the proposal from NICHE I was immediately drawn to the organisation because it was community-based, and its core aim was to improve the health and wellbeing of community members. I also loved the fact that NICHE is strengths focused and encourages community members to work with the resources within the community. The manager of NICHE mirrored my own passion for people, community, and health. We quickly agreed that a reflective study on the experiences of those who had worked for NICHE was appropriate for the study.

1.5 Aims of Research

This research aims to reflect on 20 years of NICHE and how the organisation has developed in that time. The study will document the experiences of key workers and discuss the challenges and opportunities for the organisation in a wider policy context.

- The main objectives for this research are to look at the NICHE model over the past 20 years and map how it has evolved over time.
- A core element of the NICHE model is the role of the Community Health Worker (CHW). As a second research objective, this study also aims to explore how CHWs have shaped the organisation, what role they have played and how this role has changed overtime.
- Finally, this research also wants to analyse some of the current and future challenges and opportunities for NICHE in the face of a changing societal and policy environment. It will explore how NICHE has responded to these changes.

As such this research aims to answer 3 specific questions:

1. How has the NICHE model evolved over the past 20 years?
2. What role has the Community Health Worker played in the organisation?
3. How has NICHE been affected by changing wider policy developments?

1.6 Methodology

This is a qualitative study: primary research was conducted in the form of 10 semi-structured interviews with people who have worked at NICHE. Purposive sampling was used to ensure that interview participants had the experience and knowledge relevant to the study. The data was analysed using a thematic approach and emerging sub themes were also identified and discussed.

1.7 Contribution to Knowledge

This research project makes an important contribution to knowledge about community health projects in Ireland. Drawing on the voices of 10 participants who have worked for NICHE for many years, it tells the story of a community organisation that has played a key role in a disadvantaged area of Cork City. The study also raises a number of key challenges in a rapidly changing policy and societal environment. Documenting the evolution of NICHE has identified two crucial elements which are key to its success and longevity; firstly, the model on which NICHE was developed and secondly, the role of the CHW in the organisation. The study also explores the difficulties and challenges identified by participants in the context of these two key elements. Finally, the research highlights the impact of a neoliberal policy environment on community organisations particularly in the context of funding and the dismantling of community structures.

1.8 Chapter Outline

Chapter 1

The first chapter outlines the background to this collaborative study. The chapter also details the rationale and aims of the research.

Chapter 2

The second chapter reviews the literature on community development and provides the academic and policy background to this study.

Chapter 3

The third chapter details the epistemological position and theoretical perspective which underpin this study. The methodology and research methods adopted are also discussed in this chapter.

Chapter 4

The fourth chapter outlines the findings that emerged from the interviews. Using a thematic approach, the findings are presented under 3 headings: community health organisations, the role of the community health worker and the impact of a neoliberal agenda on NICHE.

Chapter 5

The fifth chapter provides a summary discussion of the three key findings. The discussion is organized under these 3 main themes; the NICHE mode; the role of the community health worker; and the impact of a neoliberal agenda.

Chapter 6

The final chapter concludes the study by reflecting on the research aims. It also presents a number of recommendations informed by the data analysis. The chapter also highlights some of this study's limitations and includes a reflective piece on the research process.

Chapter 2: Literature Review

2.1 Introduction

Community Based Health Organisations have emerged and evolved as a response to health inequalities in society and are typically seen in areas where health services are deemed inadequate and/or inaccessible (Chillag et al., 2002; Lyons, 2001; Wilson et al., 2012). Reflecting on the literature on community health organisations (CHO) allows us to assess the opportunities and challenges ahead for such organisations and how they are impacted by government policy. A systematic literature review was deemed appropriate for this study and the researcher identified two key themes which emerged from the literature: 1. The importance of CHO's in addressing inequalities in health; and 2. The role of the community health worker in community-based organisations. The following chapter reviews the literature and discourses on these key themes.

The literature that I will refer to here looks at key debates around CHOs, including a history of these organisations, how they have evolved and what the future looks like for the sector. The literature review will also discuss how these organisations are funded, how these funding arrangements have changed overtime and the impact these changes have had on the sector. In addition, the chapter also explores how these organisations work and examine the issues and challenges facing them, as discussed by the literature. Furthermore, this chapter will also discuss the radical change in the Community Development model in Ireland, which has been transformed from one of participation and partnership, to one built on a neoliberal agenda where communities have been essentially silenced into submission.

In the second part of this chapter, I will focus on reviewing the literature on the role of the community health worker, a central element in discussions around CHOs. The role of the community health worker (CHW), according to the literature cited here, is paramount to the work and success of a CHOs (El Arifeen et al., 2013; Swider, 2002). Specifically, the chapter will examine key debates around the role; describe the specifics of the role; and highlight the centrality of relationships and partnerships attached to the role at local level. The literature on this topic also highlights the need for adequate and ongoing supervision and training for CHWs and also tells us a great deal about the challenges for people in the role.

2.2 Community Health Organisations

In order to get a better understanding of what CHOs are, what they do and how they work, it is crucial to provide a definition of the concept of community in the first place. A useful definition of community appears in the WHO report *Strengthening the performance of community health workers in primary health care*, (WHO, 1989). Here, community is described as a number of people living in the same area who also share “common interests and a fellowship”. The report while acknowledging that it is not always easy to achieve community involvement, nonetheless community involvement is essential in the context of primary health care. The report also highlights that an understanding of community structures and dynamics coupled with faith in the community's ability to learn and manage are essential for successful community engagement and involvement. In Ireland, the Government describes community as a place, identity or interest, while community development refers to both a sector within the overall voluntary and community sector and a distinctive approach to working for social and economic development and change (Government of Ireland, 2015).

The WHO identified five key characteristics of CBOs, indicating that they must be 1. Organised, 2. Separate from the government, 3. Non-profit distributing, 4. Self-governing, 5. Voluntary (WHO, 1989). CBOs are often referred to as non-governmental organisations, voluntary organisations or faith-based organisations (Bhan et al., 2007). Wilson et al. (2007) also noted that CBO have also been described as ‘third sector’ or the third way, which refers to the gap filled by these voluntary organisations between what is provided by the state and the private sector. Milligan and Conradson (2006) state that organisations working within this sector can be viewed as organisations that are formal, non-profit distributing, constitutionally independent of the state and self-governing. According to the literature, community-based organisations have held a central role in representation and advocacy for marginalised groups and individuals for some time. It is widely recognised that they are able to provide services and support to marginalised and disadvantaged sections of the population which governments find difficult to reach and engage with (Lyons, 2001). Furthermore, according to Carey et al. (2009), professionalised third sector spaces can still be ‘community’ spaces where individuals may give and receive care and services (Carey, Braunack-Mayer and Barraket, 2009).

2.2.1 Inequalities of Health

Improving the conditions in which people are born, live, work, grow and age can help close the health gaps that are evident globally, nationally, and locally within our communities (Marmot, 2011). Wilson et al. (2012) state that community-based organisations often provide services and support to the most marginalised, disadvantaged, and stigmatised sections of society (Wilson, Lavis and Guta, 2012). According to the literature I will be referring to here, Community Health Organisations are often pivotal in encouraging people to engage with health services. This seems to be even more important in areas with low participation rates in health promotion activities and low levels of help seeking behaviour. These organisations form a crucial go between and can bridge the gap between service users and health service professionals. For example, according to Wilson, Lavis and Guta (2012), community-based organisations play a key role in the provision and promotion of health care services. As they highlight, one of the reasons for this is that service users often find it easier to seek help in their own communities where they feel safe and the familiarity of surroundings offers a sense of security. Furthermore, according to Chillag et al. (2002) breaking down the barriers to help-seeking behaviour is fundamental to the success of health care initiatives. An understanding of local issues and a knowledge of challenges faced by local people is key to provision of effective health care initiatives and for service user participation (Chillag et al., 2002). They also assert that Community-based organisations (CBOs) are well positioned to deliver such services because they understand their local communities and are connected to the groups they serve. Furthermore, Chavis and Florin (1990) state that voluntary community organisations are geographically based, represent residents of a particular area, volunteer driven, locally initiated and are multi-purpose and flexible allowing them to address a broad array of issues.

2.2.2 Community Development in the Irish Context: a historical background

Community Development in Ireland originated in the rural cooperative movement and was promoted by Muintir na Tire, which can be translated as “The People of the Country” (Government of Ireland, 2019). In urban areas, community development grew out of local responses to high levels of unemployment, educational disadvantage, poor

housing, and lack of public services. (Government of Ireland, 2019). Influenced by the 1942 Beveridge report in Britain (report on Social Insurance and Allied Service), which proposed a universal scheme of social insurance and a National Health Service free for all citizens at the point of entry, the Irish government published two white papers, Outline of proposals for the improvement of the health services (1947) and Social security (1949) which advocated for improved health services in Ireland. In 1948, Dr Noel Brown's Mother and Child Scheme proposed free healthcare for mothers and their children up to 16 years of age. Proposals for improving health were met by opposition from the Church and the medical profession. Dr Browne's Scheme was vehemently opposed by the medical profession who feared loss of income and the church who were fearful of the dangers to faith and morals (Barrington, 1987). Some argue that the opposition to the Mother and Child Scheme, coupled with the failure to adopt the Medical Insurance Act of 1911, which was also opposed by the Church and the medical profession, signalled that Irish health care would never be universally provided (Adshead and Millar, 2003). The establishment of Voluntary Health Insurance (VHI) in 1957 effectively cemented this two-tier system of public and private health care in Ireland (Harvey, 2007; Adshead and Millar, 2003). To this day, the Irish healthcare system is a two-tiered system of healthcare that provides faster access to private patients for hospital care, and is characterised by a primary care system that fails to provide free universal access to GP care for all.

In the 1980s and 1990s, there were some positive developments regarding the community and voluntary sector in Ireland. Specifically, in 1986 the Irish Government established the Combat Poverty Agency to promote and resource community development as a strategy to respond to poverty and social exclusion. With government support, Ireland developed an internationally recognised community development sector. Community work was a critical feature of work in the fight against poverty and social exclusion. In 1996, we saw the creation of a Community and Voluntary pillar which would sit alongside the trade union, farming and business pillars for the "partnership 2000" discussions this increased participation in the policy field for the sector (Meade, 2011). Historically, community organisations were funded under section 65 of the 1953 Health Act, which as of 2001 had invested 486 million euro in the sector. Critics of section 65 grants deemed them inconsistent, inadequate, and suggested that

they had high entry barriers (Harvey, 2007). The Health Act 2004 aimed to make the health system more unified, efficient, and less vulnerable to local pressure (Harvey, 2007). The 2004 Health Act changed community funding to section 39 grants, however, no role in decision making was given to community organisations in the context of this change. Historically, the service level agreements of the 1990s set down a system of mutual obligations and responsibilities between the health sector and community organisations in exchange for a grant. Since the introduction of the 2004 Health Act, the obligations on community organisations have lengthened and there is a lack of access by community organisations to the decision-making system within the health service (Harvey, 2007). According to the literature, significant characteristics of voluntary organisations are that they are separate from government and self-governing. Funding without decision making powers disabled organisations and essentially stripped them of autonomy. This lack of autonomy features predominantly in the literature, with many questioning how community organisations can be described as bottom up or participatory when they are so reliant on the state for funding (Harvey, 2007; Meade, 2011). The failure of the Health Act 2004 to give decision making powers to community and voluntary organisations appears to have limited the opportunities for these organisations to have a formal voice within the health service (Harvey, 2007). Critics also point to the lengthy time community health workers spend on managing their relationships with the state, which has led to less autonomy and a more bureaucratised community sector. Meade (2011) also argues that the sector is vulnerable to the needs of the economy which was evident in the public sector cutbacks and funding cuts following the 2008 recession where cuts of more than 40% were inflicted on the sector. According to Harvey (2015) while government spending fell by -7.1%, the community sector was disproportionately hit with cuts to local community development by -43%, youth organisations by -44%, sports grants by -60% and drugs prevention by -37%. The cuts experienced by the community sector have impacted most negatively the most vulnerable members of our communities. Meade describes community development as a technique of anti-poverty policy and points to the launch of the Community Development fund in 1990 as a key moment in asserting community development as a technique of government (Meade, 2012). In 2015 the Government once again promoted, in theory at least, the notion of working “with” rather than “on ” or “for” people as

central to proactive and progressive processes in seeking changes in social and economic conditions (Government of Ireland, 2015).

In 2016, the Irish Government approved the creation of a healthy Ireland fund with an initial investment of 5 million euro in 2017 to establish programs and projects at community level. Communities could avail of this funding if they applied through local community development committees LCDCs to address local priorities through projects which had a health and wellbeing outcome or if they wished to engage in a programme or project from the healthy Ireland strategic plan. Furthermore, the healthy Ireland policy framework highlights the need to “strengthen participation in decision making for health and wellbeing at community level.” For example, through local authorities, community services funded by the government or through the health service user involvement strategy” (Government of Ireland, 2013). Furthermore, in 2017 the Irish government reiterated once more the role that community can play in meeting people's health needs locally. The government announced that a major investment in health infrastructure would be guided by the recognition that the best health outcomes can be achieved by reorienting our health services towards primary and community care (Government of Ireland, 2017). Local issues however do not always align with national policy, community groups struggle with people from outside the community telling them what the priorities of the community are (Government of Ireland, 2019).

Healthy Ireland policies certainly demonstrate an emphasis on community-based health provision, many in the literature however argue that this is not enough and that more needs to be done at government level to utilise these community organisations for health service provision (Healy et al., 2019). Critics of Irish public health policies argue that strategies for health promotion often target the individual and blame individual problems for health inequalities (Wilson and Lindsay, 2017). Fernandez (2017) argues that putting responsibility for health on individuals and particular groups has led to stigmatisation of these people. Fernandez elaborates on these tensions in her description of Irish Health Policy as being embedded in a series of complex relationships between different agencies and bodies (Edwards and Fernández, 2017). Meade (2011) as already highlighted, discusses the relationship between the state and community organisations and stresses the co-dependant nature of the relationship as they cooperate for funding and policy implementation on the ground. In 2019, the

Government restated its commitment to community development and stressed its intent to provide communities with a voice and the power to influence, shape, implement and plan policies and actions that affect them and to involve them in capturing learning and feedback from performance and outcomes (Government of Ireland, 2019).

According to Social Justice Ireland, the need to focus on community-based health services has never been as urgent. The Irish health service is over reliant on hospital services which has resulted in an extreme and chronic shortage of beds and crippling waiting lists. Now more than ever the government needs to look more towards expanding community services and providing access to services at local level (Healy et al., 2019). Improving the health of disadvantaged and underserved populations is the cornerstone of public health policies and initiatives. As highlighted above, the involvement of CBOs and the public has been shown to increase the likelihood that policies will be appropriate, acceptable, and effective (Dupre et al., 2016). According to the Healthy Ireland Report, Ireland is, like many other developed countries, facing serious challenges within the economy, society, and the health system. The current health status of people living in Ireland and their lifestyle trends are leading us toward a costly and unhealthy future (Department of Health, 2013). Health is not evenly distributed in Irish society, with prevalence of chronic conditions and accompanying lifestyle behaviours being strongly influenced by socio-economic status.

Another issue regarding public health is the imbalance of social investments in medical care compared with prevention activities (McGinnis et al., 2002). Health comprises the second largest component of public expenditure in Ireland after social protection. From 2000 to 2009, the Irish public healthcare expenditure more than doubled in real terms to €15.5 billion per annum. Spending is mainly directed towards diagnostics and treatment services for diseases and injury. Chronic diseases and their risk factors are major drivers of healthcare costs, as well as associated economic losses (Department of Health, 2013). There is an overwhelming economic argument for action: national and international evidence shows that health is an economic good in its own right and is a key factor in employment, earnings, productivity, economic development, and growth (McGuinnis et al., 2002). Better health can lead to economic growth, not only through an increase in total GDP as the population increases, but also, more importantly, through

long term gains in human and physical capital that raise productivity per capita. Protecting health and putting in place targeted, cross-sectoral and cost-effective prevention programmes and policies will play a central and supportive role in Ireland's short and longer-term economic recovery programme, as well as reducing the prospect of unaffordable future health costs, which will certainly arise if current health trends are not addressed (Department of Health, 2013). As highlighted above, community-based organisations are ideally placed to implement these types of prevention and health promotion programmes. Health is powerfully influenced by education, employment, income disparities, poverty, housing, crime, and social cohesion. The choices we make every day with respect to diet, physical activity, sex, substance abuse and our coping strategies are also important determinants of health. The growing knowledge and evidence base in the areas of behavioural patterns and social determinants of health provides important opportunities for targeted action and strengthening of policies that directly affect these influences (McGinnis, 2002). If we wanted to expand our investments on promotion of population health as opposed to spending to restore health, what type of policy interventions might work are the questions posed by McGuinnis et al., (2002).

“Public investments in health seem to require evidence that future savings in health and other social costs will offset the investments in prevention”
(McGinnis, Williams-Russo and Knickman, 2002, pg. 85).

Given present pressure on health systems and their proven inability to respond adequately the existing evidence suggests that CHW programmes are not cheap or easy but remain a good investment, they need political leadership and substantial provision of resources to be effective and sustainable (Lehmann and Sanders, 2007). Rosenthal (1998) argues that knowledge of CHW programmes' effectiveness among policy makers and health care providers is likely to increase, given growing public attention to issues of outreach and cultural competence and suggests that collaboration with CHW at all levels is essential to promote the field. We are advised that strengthening public policies in support of these programmes by ensuring sustainability through financing and linkages among state agencies are essential for the programmes to reach their potential. Health Impact Assessments (HIA) have been put forward as a tool to evaluate the impact of policies on communities. HIAs have been described as a tool for furthering

“better informed and inclusive policy making” (O'Mullane, 2015). According to Harris et al. (2014) HIA can be utilised to put health on the policy agenda but it requires a partnership approach (Harris, Sainsbury and Kemp, 2014). Further literature is needed on HIA and their potential for influencing health policy particularly for community organisations where the partnership aspect of HIA makes them an ideal tool to assess potential health impact of a CHO.

2.2.3 The Partnership Model and Community Development

The late 1980s and 90s saw an increased focus on local economic development involving a partnership of local public and private socio-economic interests, including the community and voluntary sector. Kelleher and O'Neill (2018) argue that State support and funding of the community sector in the 1980s and 1990s led to the development of a vibrant community development sector which was supported by government policy and underpinned by the principles set out in the White Paper on the Relationship between the Community and Voluntary Sector and the State (Department of Social, Community and Family Affairs, 2000).

The growing focus on local social partnerships was influenced by significant changes in EU policy. The Single European Act (1986) provided a context for more effective approaches to dealing with problems of persistent disadvantage. There were growing concerns that economic growth was not being evenly spread and concentrations of deprivation were developing. The programme for Economic and Social Progress 1991 - 1993 provided for the establishment of partnerships in areas of high socio-economic disadvantage, by 2004 there were more than 60 partnerships. *Supporting Voluntary Activity* (Government of Ireland, 2000) confirmed the Government's commitment to the voluntary and Community Development sector. It affirmed the independence and critical role of the sector, set down a programme of multi-annual funding and much improved funding support for research and training within the sector. It also stated that there should be voluntary activity units in every government department to facilitate access to government (Harvey, 2015). According to Harvey (2015), the funding promised in 2000 was not only delayed until 2002 but was cut by 53%, this was an

early indicator of a strategic shift in policy which would impact on the community sector.

2.2.4 The rise of Neoliberalism and its impact on community development

As the community sector grew in strength, Kelleher and O'Neil (2018) argue that the sector became a key concern of the political establishment. Policy makers and governments have often struggled to move beyond a control or disciplinary style of engagement to a more democratic one (Meade et al., 2016). In 2004, voluntary and community agencies were given warnings that their work was “too political” and they were discouraged from having social policy posts (Harvey, 2015). Local disadvantaged communities build up their own leadership, capacity, knowledge, education, which according to Harvey (2015), would be a nightmare for the government, “an educated working class” able to argue their case.

According to McCrea and Finnegan (2019) funding functions as a connector between communities, the state, practitioners, and other institutions. Additionally, funding influences ideas and practices, can determine goals and can also impact on the democratic potential of an organisation. According to McCrea (2016), state funding regimes have proved hostile to dissent. The growing tensions between the community sector and the government gave key politicians the opportunity to promote a new model for managing community programmes. The transformation which occurred in the sector can be described as a shift from Participatory Democracy to Neoliberalism. This paradigm shift was imposed on the sector from 2002 and had profound consequences for the community and voluntary sector as a whole (Kelleher and O'Neill, 2018). The main changes occurred under the Health Act 2004, as mentioned in my earlier section, when community organisations were faced with an increasingly bureaucratic system which imposed lengthy obligations on the community organisations but granted no access to decision making systems within the sector.

Harvey (2015) argues that the Government's commitment to the community and voluntary sector took a strategic turn in 2002 when the new Fianna Fail/ Progressive Democrat government cancelled a new community development policy unit that would

bring issues from the community development sector to government. This proposed community development policy unit had taken 2 years to design and agree but was gone in days. Funding promised in the White Paper 2000 was delayed by 2 years and cut by 53%. Research funding and funding for training were also cancelled. Funding for anti-poverty networks and community development was also cut. The promised voluntary activity units did not happen and there was little annual funding. There was no shortage of money as this was pre-recession, which means these decisions were politically motivated, a response to dissent. In 2007, in one of the most telling signs of the Government's changing commitment to the sector, the Fianna Fail/ Green Party Government decided to abolish the Combat Poverty Agency which had been established in 1986 to promote a just and inclusive society by working for a poverty-free Ireland (Cousins, 2007). The abolition of this statutory body that had supervised anti-poverty and community development policy and research was of major significance in that it led to twenty years of expertise being destroyed overnight. In December 2009, in response to the financial crisis, 14 of the 180 community development projects were closed; the following year, most of the rest were transferred to local partnerships. From 2008 - 2014, government spending fell by 7%, the community sector, however, suffered disproportionate cuts, local community development fell by 43% and community organisations national funding fell by 41% (Harvey, 2015).

Employment in the voluntary/community sector has fallen by 31% from 53,000 in 2008 to 36,000 in 2015. Harvey (2015) states that privatisation marked the end for community development in Ireland. Community development projects were transferred into the local community development programme and then into local authorities on 1st July 2014. Competitive tendering, a feature of a neoliberal agenda is considered a threat to the community and voluntary sector in Ireland. Community Work Ireland (2015) describe competitive tendering as a competitive process where responses are invited for the delivery of a predetermined service for a predetermined price. The dominant ideology according to Community Work Ireland (2015) is that through competitive tendering, efficiencies will be gained through competition and engagement of market forces and the private sector in the delivery of services. Community Work Ireland (2015) argue that not only is competitive tendering counter to the objectives and fundamental principles of community work, it is a threat to the independence of

community organisations and limits their ability to identify and address local needs. Cuts and increased government interference have severely limited the scope and impact of community organisations (Forde et al., 2015).

Overall, in post 2002 Ireland, many elements of neoliberalism were imposed on the community development sector. Business and managerial models which were out of alignment with the needs of the working class communities were enforced and undermined the concepts of citizenship, social solidarity and a commitment to the most vulnerable (Kelleher and O' Neill, 2018). These business and managerial models did not align with the concept of community development, they were a cost per unit model, using key performance indicators to assess the success of programmes which gave an accounting value and excluded qualitative indicators such as the extent to which the wellbeing of a participant had increased as a result of the programme (Kelleher and O'Neill, 2018). According to Kelleher and O'Neil (2018) community development no longer meant building cohesion and solidarity and responding to community needs. The meaning of these words was replaced to describe the "self-activation of individuals" decontextualized from their economic and community context. This, they argue, carries a powerful underlying story of the deserving rich and the undeserving poor, producing inequalities that justify disadvantage as personal failing (Kelleher and O'Neill, 2018).

To conclude, the literature on community-based health organisations while limited in scope is emphatic on the need for organisations which are underpinned by principles of partnership and participation as opposed to those which are vulnerable to shifts in policy and the economic climate. Crucial also to the success of these organisations is the role of the community health worker.

2.3 Community Health Worker Role

According to the literature, central to the facilitation of health promotion and increased engagement with community health services is the role of the Community Health Worker - CHW. The WHO *Global Strategy on Human Resources for Health: Workforce 2030* encourages countries to adopt a diverse, sustainable skills mix, harnessing the potential of community-based health workers. As part of broader efforts to strengthen

primary health care and the health workforce more generally, there is growing recognition that CHWs are effective in the delivery of a range of preventive, promotional and curative health services. According to the WHO (2018), they can contribute to reducing inequalities in access to care. Furthermore, by employing members of the community, the health sector contributes to job creation and economic growth (WHO, 2018).

The World Health Organisation defined CHW as workers who live in the community they serve, are selected by that community, are accountable to that community, receive a short defined training and are not necessarily attached to any institution (WHO, 1997). The roles and activities of CHWs are diverse and range from preventive, curative to developmental (Lehmann and Sanders, 2007). CHWs have been described as agents for community change, as they make important contributions to social capital and build networks, partnerships, and trust with their clients (El Arifeen et al., 2013). In areas with low participation in health initiatives and where there are perceived barriers to access, CHWs act as a bridge between the service and service user. Rosenthal's (1998) U.S national survey of CHWs and those working with them identified 7 core CHW roles: cultural mediation, informal counselling and social support, providing culturally appropriate health education, advocating for individual and community needs, assuring that people get the services they need, building individual and community capacity and providing direct services. The Centre for Public Awareness in the United States (1999) describes several global functions of the CHW including: decreasing health care costs, increasing health care access, strengthening the local economy, and strengthening the family and the community. The role has proliferated in communities where people are hard to reach and have been missed by traditional health care systems (Rosenthal 1998). Furthermore, the literature highlights the importance of the community health worker role and identifies key sub-themes under which the role needs to be examined. First of all, there is the issue of the effectiveness of community health workers. Secondly, there are debates around the importance of the workers being local. Thirdly, there are the issues of training and development. The literature also raises the issue of support and supervision. Connection, participation, and relationships with the community are identified as fundamental to the success of the community health worker and feature prominently in the literature.

2.3.1 The role of the community health worker in relation to poverty

According to Swider (2002), CHWs are promoted as a mechanism to increase community involvement in health promotion efforts and there is some support for CHWs' ability to increase access to care, particularly in disadvantaged areas. Others maintain that CHW programmes should only be implemented where basic issues in health care have already been resolved, and there are also those who regard CHW programmes as the only possible alternative to no care at all in communities (WHO, 2018). One of the most important functions of the CHW is the bridging of the gap between service providers and service users. It has been extensively documented that people from disadvantaged or marginalised areas are hard to reach and engage through traditional health care services. CHW aid and support the provision of service and the promotion of health in these communities by advocating for people and through referrals. CHW can be trained to work with communities to bring about the kinds of change that strike at the causes of disease and ill-health in a community and at an acceptable cost. At the same time, they are also agents of community participation in health which is essential for managing the causes of ill-health.

2.3.2 Being Local

Dr Mahler, Director General of WHO at the time of the Yaoundé Conference emphasized the importance of the CHW link to the community; "Community health workers must be of the people they serve, they must live with them, work with them, rejoice with them, suffer with them, grieve with them and decide with them" (WHO, 1989). The literature highlights that in order to ensure community acceptance, CHWs must respond to local, societal, and cultural norms and customs (Lehmann and Sanders, 2007). CHW have been described as actors who can empower and mobilise and be agents of change in their community (Dupre et al., 2016). Furthermore, according to Dupre et al (2016) they are considered vital to the effectiveness of health improvement initiatives at local level.

2.3.3 Effectiveness of role

Another issue raised by the WHO report *Strengthening the Performance of Community Health Workers in Primary Care* (1989) is that community involvement must be supported by the creation of links between the community and the health services at the planning stage, and that the impact of community health programmes is largely determined by the strength of the relationship between the community and the health sector (WHO, 1989). In the late 1980's in Ireland, the Eastern Health Board adopted a novel approach to public health by replacing the Public Health Nurse with an experienced mother from the same community and of similar social status as the client. This became known as the Community Mothers Programme. The programme was evaluated in 1989 and evidenced that it was successful in achieving its aims of improved health care, nutrition, and development of babies. This success raised important questions for policy makers in Ireland around health promotion and engagement with health services (Fitzpatrick, Molloy and Johnson, 1997). It is an example of the value of community programmes at local level.

While some of the literature is very positive about the effectiveness of CHWs in impacting on health at community level, there are also others who raise questions about their effectiveness. For example, Swider (2002) suggests that there is little consensus about the role and its effectiveness and warns that it can often be doomed by overly high expectations, lack of clear focus and lack of documentation. Documentation of the effectiveness of the role is essential to gain support for institutionalisation of the role. Swider (2002) also argues that it is still unclear whether CHWs are the most effective means for delivering health care interventions or even the least costly ones, and suggests that further study comparing if the same intervention delivered by different types of health care worker could help determine if the CHW adds a unique benefit to the health care delivery system. In small projects supported by various donor agencies, and in some exceptional cases, CHWs have been successful; on the other hand, the experience with national projects has been different, and with a few exceptions, it appears CHWs' contributions are not always achieving their potential (WHO,1989). Despite the wide recognition and evidence of their potential for positive input, support for CHWs is ad hoc and uneven across and within countries, which may partly explain the differences in rates of success and impact.

According to the WHO (2018), good practice examples are not always replicated. The literature suggests that CHW programmes and policies need to be further monitored and evaluated over time and adapted as informed by evidence (Cometto et al., 2018).

2.3.4 Sustainability

Swider (2002) warns that CHW roles vary from very specific functions to global community health and development efforts and cautions that such breadth can make it challenging to sustain the role. A national survey of CHWs and their usage in the U.S called for a national policy agenda including refinement of the role, development of CHW evaluation guidelines, establishment of certification for CHWs and the development of means to sustain the role through public policy and financing changes (Rosenthal, 1998). According to the WHO (2018), successful CHW programmes are integrated in the communities they serve and the health system to which they connect. Optimising the value and impact of CHW programmes requires appropriate planning, implementation, and measurement of performance as well as adequate resources and supplies. Integration of CHWs in health systems is vital for them to thrive (Ajuebor et al, 2019). Additionally, countries should plan for their health workforce as a whole. CHW initiatives and programmes should be aligned to and be part of broader national health and health workforce policies (Cometto et al., 2018). According to Bach-Mortensen et al (2018), community organisations often face capacity and capability issues which are primarily driven by a lack of support and expertise. They suggest that funders should assess these organisations before providing funding, and once the decision to fund an organisation has been made, continuous training and support for that organisation should be provided (Bach-Mortensen et al., 2018).

2.3.5 Resources

The WHO says it has become apparent that in many countries CHWs had been assigned or appointed with almost no facilities or resources to support them. The WHO has questioned whether the concept of CHW is still valid, as in many instances the

expectations were so high that failure was inevitable. People have seen CHWs as a means to solving health care problems which they were not equipped to solve and are often beyond their scope. According to the WHO (2018), engaging communities in defining needs, selecting, and holding CHWs accountable and mobilising local resources can improve community ownership and satisfaction as well as the motivation and performance of CHWs.

2.3.6 Selection/Training/ Development

Back in 1987, the WHO determined that many countries had adopted and strengthened programmes for training and deployment of CHWs and that while overall the concept of the CHW had been successful, selection, training, supervision and relationships with the health system were all identified as areas which required more attention (WHO, 1987). Thirty years later, selection and training continue to be central, and the WHO (2018) recommends that CHW programmes should select CHWs based on educational level, membership and acceptance by the community, personal attributes, and skills. Training should balance theoretical knowledge and practical skills. Competency based certification can improve quality of care and influence CHW motivation. Some of the literature highlights failure to address selection, training and supervision issues at the planning and implementation stages for a lack of broad success (give references here) and despite the diversity of opinion on the complex nature of the CHW role, there is consensus on a number of issues: first, CHWs can make a valuable contribution to community development and can improve access to and engagement with health services for their community; second, for CHWs to be effective they must be carefully selected, appropriately trained and more importantly, continuously supported through adequate programmes of supervision; third, CHW programmes are neither the solution for weak health systems or a cheap option to provide access to healthcare for underserved populations. Numerous programmes have failed because of unrealistic expectations, poor planning and underestimation of the effort and resources to make them work. This has undermined and damaged the credibility of the role. According to the WHO (2018), CHW programmes should be supported by appropriate supervisors to CHW ratio; performance evaluation and meaningful feedback should be provided by

trained supervisors; CHWs should be paid in-line with job demands and number of hours worked; and retention and motivation of CHW can be increased by linking performance to opportunities.

In conclusion, CHW programmes are vulnerable unless they are driven, owned by and firmly embedded in communities, otherwise they are affected by the moods of policy swings and are often fragile and unsustainable (Lehmann and Sanders, 2007). Public health policy would benefit from an expansion of CHW provision, but it will require the commitment of governments, funders, and programme managers to retrain and refocus large CHW workforces (O'Donovan et al., 2018). While there is extensive literature on the Community Development sector in Ireland, the scope of literature which focuses on Community Health Workers is limited. It is however explicit on the importance of the CHW in health promotion particularly in disadvantaged and hard to reach communities.

2.4 Conclusion

In conclusion, the literature is overall positive about the potential role of community health organisations as a tool to combat health inequalities. Furthermore, it is generally also supportive of the role of the community health worker in enabling this process, as long as these organisations and workers are properly led, funded, and supported. The neoliberal agenda which emerged in Ireland in 2002 appears to have suffocated, disabled, and disempowered community development with cuts, managerialism and increasing bureaucracy. It is surely time to revisit the participatory model of community development of the 1980s and 1990's in Ireland, which enabled and nurtured community organisations and facilitated them in addressing health and social inequalities.

Chapter 3: Methodology

3.1 Introduction

The following chapter will outline the epistemology and theoretical perspective that underpin this study, while also describing in detail the research process undertaken. As this is a collaborative project between the researcher and NICHE facilitated by CARL (Community Academic Research Link), I will discuss community-based participatory research and the ethical issues which need to be considered for such research. The chapter also gives an in-depth look at the methodology and methods used and the rationale for selecting them. The importance of reflexive positioning will also be discussed as an essential component of rigorous qualitative research.

3.2 Epistemology and Theoretical Perspective

The world is constituted in one way or another as people talk it, write it, and argue it (Bryman, 2012). A constructivist epistemology was appropriate for this research as it was primarily concerned with the experiences of the participants. According to Gray (2014), truth and meaning are created by the subjects' interactions with the world. Interpretivism is the theoretical perspective underpinning this study because similarly to constructivism, it is focused on the experiences of individuals. Interpretivism asserts that natural reality and social reality are different and that the social sciences often deal with the actions of individuals (Gray, 2014). Coupled with interpretivism there will also be an element of critical inquiry underpinning this study. Critical Inquiry is not content to simply interpret the world but also seeks to change it (Gray, 2014). Critical inquiry research designs work toward transformative action, it respects the experiences of people's lives and is concerned with speaking *with* rather than *to/for* marginalised groups (deMarris and Lapan, 2003). A critical inquiry perspective was therefore also appropriate for this collaborative research as we explored the thoughts and experiences of participants with the view to making recommendations for improvement.

3.3 Community-Based Participatory Research

Community-Based Participatory Research (CBPR) is a collaborative enterprise between academic researchers and community members where they work together throughout the process (Bates and Burns, 2012). This collaborative study is a CBPR project, a CARL project, a collaboration between the researcher and NICHE. There is an ideological rationale in terms of the value placed on this type of research, which is sharing power with those who are usually the subject of research and working towards progressive social change (Connected Communities, 2011). Decisions on the scope and focus of the study were made jointly following discussions between the researcher and the manager of NICHE. We met and discussed the scope of the research and agreed that the study would capture and document the experiences of key members of the team at NICHE over the past two decades.

3.4 Methodology

The researcher conducted primary research for this study. A systematic literature review was also carried out to review and reflect on published literature deemed relevant to the study. In fitting with the qualitative nature and constructivist paradigm of the study, primary research in the form of 10 semi-structured interviews were conducted to capture and document the thoughts and experiences of participants. The researcher sought to capture a narrative account of those who have worked for NICHE.

3.5 Methods

3.5.1 Purposive Sampling

Purposive Sampling is the selection of only those participants who can provide the researcher with the information needed for the study. This study required the experience of those who had worked for/with NICHE over the past twenty years. People who have knowledge of the organisation as service users were excluded for interview as

documenting their experiences would have gone beyond the scope of this study. In consultation with the manager of NICHE, it was decided that interviews would focus on the experience of Managers, Community Health Workers, Administrative Staff and Board Members. The final sample included 3 Community Health Workers, 3 Managers, 3 Board Members and 1 Administrator all of whom had experience of the organisation from an operational perspective.

3.5.2 Semi-Structured Interviews

Semi-structured interviews were deemed appropriate for this study for two reasons. First, the researcher was able to prepare in advance a set of guide questions to help steer the interview. Secondly, semi-structured interviews afforded the interviewee the freedom to discuss their own views based on their own experiences.

3.5.3 Thematic Data Analysis

Deductive analysis was used to identify 3 core themes in the research data. These 3 core themes were predetermined by the research questions and the literature review. Inductive analysis was used to identify sub themes which emerged from the interview data through coding. This involved attaching a label to an excerpt from the data and grouping the commonalities.

3.6 Ethical Considerations

The research was evaluated under university ethical guidelines, in consultation with my supervisor and was deemed low risk given that:

- The research topic is not sensitive.
- Participants were all adults and not considered vulnerable.
- Participation was voluntary and there was no pressure to participate.

- Interviewees were given an information sheet and a consent form (included in appendices) in advance of interviews and were reminded that participation was totally voluntary.
- The study posed no risk of harm to participants or the researcher.
- Names have been anonymised to protect the identities of the participants.

The research study was therefore given approval by my supervisor and the collaborating community organisation - NICHE.

3.7 Reflexivity

Reflexivity is a major strategy for quality control in qualitative research and this is particularly important when the researcher shares the experience of study participants (Berger, 2013). The researcher having grown up in the community served by NICHE was mindful of bias. Buetow (2019) argues that unconscious bias can prompt us to see and value what we expect to find in our research. According to Oancea (2016), sometimes when research is conducted in a disadvantaged community, it can be very tempting to extend the role of the researcher into advocacy and support, in other words to prioritise voice and reciprocity over the communication of knowledge. The question according to Oancea is how to maintain a balance between rigour in research and care for participants (Oancea. A, 2016). The researcher strived to be mindful and conscious of bias throughout this study by engaging in discussion with my supervisor to ensure objectivity.

3.8 Conclusion

This study is a community-based participatory research project, a collaboration between the researcher and NICHE which seeks to capture and document the experiences of interview participants. The constructivist epistemology and interpretivist perspective which underpin the study are appropriate for reflecting the experiences of interviewees. The data was analysed using thematic analysis and

captured using methods conducive to qualitative research such as purposive sampling and semi-structured interviews. The chapter concluded with an exploration of the importance of reflexivity in ensuring research rigour and a discussion on the ethics which need to be considered with community-based participatory research.

Chapter 4: Findings

4.1 Theme 1 - Community Health Organisations

4.1.1 Health Inequalities

All of the interview participants mentioned health inequalities faced by those living in the community served by NICHE. It was clear from the participants that access to health services was vital to address the health needs of the community. Goran Dahlgren and Margaret Whitehead developed the rainbow model in 1991 to map the relationship between the individual, their environment, and their health. The Dahlgren-Whitehead model clearly illustrates the impacts and influences that social factors can have in determining the health of an individual (Dahlgren and Whitehead, 2006). Community and social networks can determine the health of populations and in disadvantaged communities in particular, health inequalities are evident. The community served by NICHE is one that could certainly be described as disadvantaged; the percentage of people from Knocknaheeny with a third level qualification is 6.7%, the national average is 28.5% (Knocknaheeny Electoral Division Profile, 2017). The Census of Population 2016 Summary Results – Part 2 published on 15 June 2017, recorded Knocknaheeny as an unemployment blackspot. The unemployment rate for knocknaheeny was recorded at 33.5% the national average is 12.9% (Census 2016 Summary Results - Part 2, 2017).

Interview participants were very vocal in describing the environmental and social factors which necessitated the development of a community health organisation for the community of Knocknaheeny and Hollyhill. When NICHE started 20 years ago, the community was very badly planned and laid out, there were alleyways where rubbish was dumped, and a lack of green areas. Peter recalls a community member stating “ No wonder I suffer from depression, I wake up in the morning and I look out my window and that is what I see, rubbish and burnt out cars” (Peter). NICHE facilitated the establishment of an environment group which allowed members of the community to get together and discuss areas of the local community which were considered hot spots for dumping

rubbish. The environment group was a prime example of how participants identified an issue that was contributing to their ill health; the group highlighted areas of concerns and NICHE helped to address them. For example, Hollyhill Lane was heavily littered and rife with anti-social activity, and locals considered it a major concern for their health and safety. NICHE commissioned an environmental study of the lane which was able to determine the level of rubbish per metre, NICHE then used the results of the study to lobby the council and within days - diggers moved in and Hollyhill Lane was cleaned up and the alleyways off the lane were closed. Added to the environmental factors were the low levels of employment and educational attainment which according to Judy, cemented the area as one of extreme poverty and disadvantage “doesn’t it sometimes come down to the fact that you can be at a disadvantage from the moment you were born because you’re born into a certain family in a certain area” (Judy).

According to the interviewees, NICHE began as a health initiative based on the principles of participation and community development. It was tasked with improving the health of participants and the community through identification of health needs and inequities and implementing programmes which aimed to address these disparities in health.

“If you look at social determinants of health, if you look at Marmot and the priorities for addressing health inequalities, that is where NICHE sat, that is where NICHE fits in addressing health inequalities”. (Peter)

Marmot et al. (2010) argue that there is a social gradient in health, the lower a person's social position, the worse his or her health. Marmot et al. (2010) also concluded that reducing health inequalities is a matter of fairness and social justice (Marmot et al., 2010). Your health and wellbeing, quality of life and even your life expectancy can be determined, influenced, and indeed directly affected by the part of a city, county, or country that you are born and live in. The desire for a better health outcome for community members coupled with the desire to reduce health inequalities in the community led to the development of NICHE, as a CBHO based on the social model of health.

4.1.2 Social Model of Health

Empowerment and participation with a focus on strengths and wellness are the principles on which NICHE was founded and developed. According to the interviewees, it was designed as a social model of health. Interviewees were explicit on the fact that NICHE is not a medical centre and that it does not provide a medical service, rather, it plays a role in facilitating access to services for the local community.

“It is a community health project based on the principles of participation, community development, and the role of the community health worker. It was based on the social model of health and the understanding that people living in communities that have faced a certain degree of disadvantage are the people who can best determine what their health needs are and for the most part, these health needs are not necessarily medical. We put in structures that allowed people within communities to identify their own health needs and to participate in addressing those health needs”. (Peter)

The model, according to the interviewees, was influenced by the success of community projects in other countries such as Scotland, Ethiopia, and the United States. From the interviews, I was also able to determine that the previous experience and expertise of some of the workers were instrumental in the development of a model that was workable at community level. One of the CHWs had travelled to Scotland and had witnessed the success of their community programmes. He knew the same model was suited to NICHE as there were many commonalities between the communities particularly around disadvantage and poverty. Similarly, according to Tim, another member of staff had worked on community projects in Ethiopia and could testify to the benefits of broad - based community participation where community members identified their own health needs. This model of health was considered radical and risky 20 years ago and it took a lot of persuasion and determination to gain support. Many people, particularly in the HSE felt that it was a departure from the medical model, when in reality it was a preventative model.

“In Scotland community health was further along than we were, you had a lot of poverty in Scotland but they had a lot of community projects, we worked with them and following the Scottish model we insisted on employing local people,

that it wasn't a professional project parachuted in with doctors, it wasn't health promotion where we were blaming people for their ill health". (Chris)

Peter also highlighted that the model was greatly influenced by programs which had worked in developing countries such as Ethiopia, explaining, "these programs utilised community health workers and had a very high degree of community participation, broad based community participation"(Peter). Tim also highlighted the difference between NICHE and other type of health care services, as he explained, "it is not service delivery, NICHE doesn't gap-fill where services don't exist. The issue is understanding what the gap is and engaging with services to help them understand this from a community perspective to see what can be done to overcome that with the community" (Tim). All of the interviewees were in agreement on in their description of NICHE as a social model of health. Barry emphasised the non-medical nature of the model "we are a preventative model at community level, working with people to meet their needs, we don't promote the idea that we're there instead of a medical option or a medical response" (Barry). Similarly, Peter also described the model as non-medical "it's non clinical, it's non-medical and it's looking at the whole person and so it's a strengths based model and it's not looking at the deficits, it's looking at what access people have and what they can do to and meeting people where they are at" (Peter). Chris also highlighted the non -medical model of the organisation explaining the importance of "seeing it as a well-being centre, it's not a sickness centre, it's a wellbeing centre and that's very important, it's not a medical centre" (Chris).

Interview Participants were also resounding in their description of NICHE as "innovative" when it was first set up. 20 years ago, there was very little attention paid to mindfulness, wellness, and prevention, society was very much still focused on a medical model of health, in other words you sought help when you were sick. Scant if any attention was paid to the factors that may have been causing or adding to a person's ill-health. NICHE was a holistic model which looked at environment and social factors and how improving them could result in a better outcome for participants. The establishment of an Environment Group was a prime example of how participants identified an issue that was contributing to their ill – health. Chris discussed some aspects of the NICHE model which were employed to help improve the health of community members, he explained, "innovative things like stress management, self-

discovery, and personal development, all that kind of stuff was new. NICHE was innovative, the model was in Scotland and there was lots of stuff going on there and in America, there were huge strides especially in mental health and depression and rather than medicating people, they were bringing people together and having art therapy” (Chris). Furthermore, Chris recounted how support from the board and good relationships with people in the community allowed NICHE to develop as an innovative social model of health, explaining “we kept pushing the boundaries because we were able to, we had a lot of agreement as well on the board and we have a good rapport with people, we had lots of experience and help and thinking outside the box” (Chris).

The influence of a social based model of health on NICHE was discussed by all participants and they all agree it was crucial to the success of the organisation.

‘NICHE is based on a social model of health, using a participatory, bottom up approach, whereby community members identify and articulate their own health needs and NICHE through the work of the CHWs facilitate addressing these needs. The NICHE model has been widely recognised as a model for best practice in community health, we had a delegation from China, they said you are the model for best practice”. (Tina)

But it appears that despite this recognition, the model has not been replicated nationally, as highlighted by Tim “Combat poverty agency for e.g. wrote it up as a model, so the model was very much recognised and while NICHE itself wasn’t replicated the CHW role has been” (Tim).

4.1.3 Participation

The literature is emphatic on the pivotal role of CBHOs in encouraging people to engage with health services particularly in areas with low participation rates in health promotion activities and help seeking behaviour. According to Wilson et al. (2012) and Chillag et al. (2002) an understanding of local issues and a knowledge of challenges faced by local people is key to encouraging participation. This was also reflected in some of the interviews. For example, according to Peter, “one of the key things we did was the

community health planning. Community health planning is a form of participatory action research where the community is involved in setting the health priorities and the organisation then brings the relevant statutory agencies together to look at how we can address these priorities” (Peter). Community Consultation, according to the interviewees, was conducted through community meetings, focus groups and outreach where CHWs went door to door to peoples’ homes and to sports clubs, anywhere where they could engage with the community to hear their views. According to Tim, many barriers to seeking help and engaging with services were identified by the community “practical things like transport, low literacy levels, no relationship with service providers, feeling of being judged and being stigmatised, harder to engage and it’s easier not to engage” (Tim). NICHE brought people with similar interests together and helped these people form groups which have both a supportive and participative function. NICHE facilitated these groups in articulating their experiences which offered an opportunity for participants to name the difficulties they encountered when dealing with existing service providers. For example, the young mothers’ group were very vocal in describing the judgement they felt when engaging with the public health nurses. Research was conducted by the school of nursing at UCC which evidenced a negative experience for the mothers just as had been described by the group participants. The research and experience of the group were a catalyst for improving the service and it prompted significant and meaningful change, whereby antenatal care was delivered for the 1st time at St Mary's Orthopaedic Campus bringing it closer to the community and making it accessible for users. The research also resulted in the public health nurses running a clinic from NICHE which had a hugely positive effect on rates of engagement.

A constant theme in the discussion around NICHE’s success was the energy and drive that existed among the group participants and the community health workers.

“Peoples preparedness to get involved, to actually change things, that enthusiasm, that energy that existed there to get involved and get things happening. The energy within the groups was another great strength, the energy from the participants and the willingness to get involved, it was very empowering, I would see empowerment as a model of people being able to sense and value their own power and to use their own power for good”. (Peter)

Participation is fundamental to the success of a CBHO, but it has to be broad based participation in order to have an impact on population health and to address the health inequalities which exist in disadvantaged communities. According to Peter, “participation alone is not enough, it has to be actioned and it needs to be driven” (Peter). NICHE is ideally placed to deliver on all aspects of participation, it has the facilities in the form of a welcoming safe place, it has the energy and drive of both the community health workers and the participants and it also has a belief in the need for connectedness.

4.1.4 Connection

The relationships NICHE developed and nurtured within the community played a pivotal role in its evolution. As highlighted by Peter “the biggest strength was the extent to which it was connected to the community” (Peter). These connections fostered trust and allowed for the participation of community members in community planning and consultation. When people are able to participate and articulate their own health needs it creates a sense of empowerment which is often lacking at community level, particularly in disadvantaged areas. Having a voice and being able to articulate concerns is necessary for a better health outcome and increased health and well-being. According to Berkman & Glass (2000), “The nature of human relationships – the degree to which an individual is interconnected and embedded in a community – is vital to an individual’s health and well-being as well as to the health and vitality of entire populations.” It was agreed and understood that in order to reach the statistically hard to reach members of the community, particularly those with a low record of engagement with health services, NICHE had to nurture and develop relationships of trust and acceptance first and foremost at community level.

“I think that when you have services that allow people to trust them and to come in and engage with them, I think that is the gateway and the pathway to grow the community and it is so important nowadays having something central where people can come and connect and feel safe to connect and it takes them away from that isolation they may have in their lives or from the difficulties they’re experiencing”. (Tina)

Peter also reflected on the importance of good relationships with community members and highlighted that “there was a lot of isolation and I think NICHE because it is a group based activity was able to overcome that and people didn’t feel threatened, they felt welcome” (Peter). Despite the clear consensus among interviewees on the importance of relationships with community members, Tina feels that it can be a challenge to stay connected to the community “it’s a community development approach, you need to listen to what’s going on, on the ground and I think that is the key challenge in that nowadays we have so much social media, we have so much information, but yet are we actually listening to what people are looking for? (Tina).

Interviewees were emphatic on the importance of good relationships with community members, connections between NICHE and other organisations were also key to its evolution. People from NICHE would meet members of other organisations for example UCC, HSE, as well as local GPs and Public Health Nurses, and discuss the work that was happening at local level and this contributed to the organisations growth and fostered a spirit of partnership which still exists today as highlighted by Chris “the connectedness of people meeting people and talking about NICHE lead to the development of many programs and initiatives” (Chris).

4.1.5 Partnerships

The evolution and development of NICHE has been attributed to the connection of the organisation to the community and also to the connections and partnerships between NICHE and other stakeholders and service providers. Some authors have questioned the partnership approach and the challenges it can present for community organisations, specifically with regard to an organisation’s ability to fulfil its core mandates such as advocacy and representation (Maddison et al., 2004; Owen and Kearns, 2006).

Furthermore, others have suggested that partnerships with mainstream services can undermine an organisation's connections with the community (Brown, 1997). NICHE seems to contradict some of these findings and the interviewees highlighted that partnerships have been one of the biggest strengths and a major contributing factor to the role of NICHE in the community.

“Trust and relationships are the biggest things and being where people are at and NICHE provides all of those things, it may not have the solutions itself but it can work in partnership, it’s almost like a bridge between the community and the public services, it is the social model of health”. (Tim)

The interviewees spoke about the value of NICHE working in partnership with other organisations to overcome barriers and find solutions for identified health needs. For example, Peter discussed “identifying what the needs are, what are the barriers to health and working collaboratively in partnership with people from other sectors to have a positive influence on that and overcome those barriers” (Peter). Tim further explained “it is a development role and the HSE would be clear on this as well, we are not there to provide services, it is not service delivery. It is about a shared understanding of the issues and a partnership to look at solutions for the issues” (Tim).

“The issue is understanding what the gap is and engaging with the services that should be providing those services and helping them to understand this from a community perspective and to see what can be done to overcome that with the community. It’s developmental and it’s in partnership for e.g. the primary care work with the public health nurse, you know people not attending clinics and appointments, well it’s about understanding why people aren’t coming and being able to look at a solution together, so the solution was to bring the public health nurse to NICHE”. (Tim)

The interviewees were clear about the significance of partnerships with other organisations, Chris explained how NICHE was “very much supported by the HSE and that was crucial” (Chris). The interviewees also provided concrete examples to illustrate the positive impact of partnerships on the community.

“We had a fantastic program around breast check and cervical screening, we did a massive developmental piece of work with all the CHW who got training and worked with the local community and targeted area where there was low uptake, the uptake was at nearly 70%, so we didn’t screen people, we didn’t fill a gap but we worked with BreastCheck to come up with a solution around screening programs”. (Tim)

Working collaboratively enabled NICHE to bring professionals, services and organisations which were otherwise inaccessible to many into the community. One of the most prolific examples of such a partnership was the one with UCC, for a community where the attainment of third level education was four times below the national average this proved hugely significant. Barry described the significance of the relationship with UCC stating “we were very lucky we had contact with UCC very early on and the department of public health. Ivan Perry who was a professor running that department and he had a very good way of dealing with people committed to public health and he understood the difference between health promotion and public health” (Barry).

Chris also discussed the relationship between NICHE and UCC, explaining “the involvement of Professor Ivan Perry from the Department of epidemiology, who made that strategic link with the community and UCC that was never there before. Professor Perry became part of the management structure and gave his insights into the models of best practice” (Chris).

“ So that was something very unique as well because you know the relationship between UCC and the community, it was non-existent, so now we were able to have UCC come to the community and work with us at community level, that mushroomed into the G.P training unit. Professor Conor Bradley came on board and Dr John Sheehan and they allocated some time to GP’s who are training to come and work in the community and engage with members of the community, so that they would have worked on the ground with local people, that was ground-breaking”. (Barry)

In 2019 a new Primary Care Centre opened on the grounds of Saint Mary’s Health Campus, Gurrabraher, Cork, this new facility will benefit the community served by NICHE and the surrounding areas. The Interviewees discussed the role NICHE played in the development of the Primary Care Centre and highlighted its establishment as a prime example of the positive impact of working in partnership.

“It was mutually beneficial, that was the beginning of the primary care centre that has just been built in St. Mary’s. UCC got onboard, they saw the opportunity to build the primary care centre, so it was NICHE in negotiation with City Hall

with the help of UCC that kicked it off, NICHE had a huge role in developing the Primary Care Centre”. (Chris)

The interviewees also discussed Kidscope as another example of the collaboration and partnership with UCC. The programme was a joint initiative between UCC and NICHE whereby children from the community would have access to a paediatrician locally. Kidscope, was highlighted by interviewees as a another example of the positive impact of working in partnership.

“One of the other very interesting projects that we have is called Kidscope , Dr Louise Gibson who teaches in UCC and works in the CUH asked for an office in NICHE, she would bring 2 paediatricians every Friday to see all the kids here who wouldn’t be able to go to the CUH and it has proved hugely important because the nurses bought into it, there were families for whatever reason couldn’t keep appointments and now the services were accessible to them, over 700 children have been through the clinic. Kidscope has kept a lot of kids out of care”. (Chris)

According to these accounts, NICHE has undoubtedly benefited from working collaboratively and in partnership. There are, however, challenges to be considered, Barry cautions “NICHE cannot be all things to all men” (Barry). It is crucial that while working in partnership, NICHE remains true to its core values and remains clear in its goal as a CBHO, this can pose a challenge when working collaboratively. Chris believes that NICHE can benefit from working collaboratively and in partnership and remain true to its core values as long as you have the right people on the Board.

“It’s going to be one of the big challenges to maintain that connectedness, you need to have people on the board who have confidence, who aren’t afraid to approach people and to do things. There was a huge amount of mutually beneficial relationships, and I suppose NICHE was clear that it was an independent organisation”. (Chris)

At the moment there is no formal structure in place for new members to join the Board of Management at NICHE, typically existing Board members invite people to join the Board of Management.

4.1.6 Sustainability

Core Values

The need to go back to basics and look at the values on which NICHE emerged as a central theme expressed by the majority of interviewees. Some interviewees felt that NICHE had become a victim of its own success and had gotten so busy that it no longer had time to engage with the community in a meaningful way. The community has grown considerably, and many wondered how new families and community members could be reached. NICHE now operates in a community that has experienced marked changes from the community it was established to serve 20 years ago. There has been a major development in the area which has seen the establishment of new estates such as the Meadows and Milestream, which has implications for the capacity of the organisation to reach community members in these new areas. As explained by Derek, “the Meadows is a huge site, we have a huge amount of new families and non-nationals and different races, culture is going to be a big thing for us, we are way behind, it’s going to be a barrier, we need to bring everyone together as a community” (Derek). Judy also mentioned that “the community has changed, and it is changing again, it’s bigger now, you have the Meadows and Milestream” (Judy). Coupled with the development of new estates the community has also undergone a regeneration programme. The regeneration process began in 2014 and is still ongoing. Many of the older houses in the community have been demolished and new, more modern homes have been built in their place. Many families who have lived in the same area for generations have been displaced during the regeneration and so it has brought many challenges. According to Tina “you have people being displaced in many ways that have been part of the community for many, many years and you have new members coming into the community as well, so that is going to bring massive challenges”(Tina). Lucy also voiced concerns around the changing community “it’s coming full circle now again, there is one school, one supermarket and they’re putting houses up on top of each other, it’s going to go back to square one, anti-social behaviour and drugs are an issue” (Lucy).

A concern for many participants was the need to go back to the core values that the organisation was built on and also the need to stay relevant in a changing space, according to Tim “NICHE needs to go back to the principles on which it was founded”

(Tim). Debbie agrees, “I think that is where the challenge is, I think it’s time to go back to the community consultation again (Debbie). Peter also discussed the importance of staying relevant “need to be driven in what the issues are, and the issues are changing all the time because people are changing and getting older” – (Peter).

The interviewees shared their concerns about meeting the needs of the changing community, as a result of the regeneration, the addition of new estates and also due to societal changes. Many of those interviewed expressed concerns that a lack of community consultation could mean that NICHE was no longer reflecting the needs of the community, according to Peter, “you need to be strategic about it, you need to look at what other services within the area are providing and not compete against that and make yourself unique in it, should we be providing something that isn’t being provided?” (Peter).

“Even if you look at Ireland over the past 20 years and the changes that have taken place, if you look at the change in attitudes and the challenges people are faced with they are becoming more and more acute. Mental health is a big thing, social isolation is a huge thing and yet we are so well connected in terms of technology and what has actually broken down is community and I think that is why organisations such as NICHE are so important, we can become a hub for the community to emerge around that”. (Tina)

The interviewees felt that NICHE was equipped to meet the changing needs of a changing society, according to Tim “we have fantastic facilities here and it’s about having the vision of relooking at what we do, that’s the way I would see it” (Tim).

Board of Management Structure

One of the key concerns around sustainability which emerged from the interviews centered on the structure of the Board of Management. 70% of interviewees questioned the makeup of the board of management and why this has not changed since it was first established. It was felt that new members should be included on the board to reflect the changing needs of the community and also to enable the organisation to further develop

and grow. If an organisation is to grow and develop change is both necessary and inevitable, interviewees stressed and highlighted that there has been very little change to the Board of Management over the 20 years of NICHE and there is a concern around a lack of drive according to Derek, “it’s time to get 30 and 40 year olds in, younger people to mix it up. I would like the board of management to have a connection with people, I mean nobody knows who the board of management are” (Derek). Lucy spoke of the great people who have worked on the Board but also questioned why it has not changed, “very good individuals have been involved for a long number of years, but in order for it to be taken forward, maybe a new lease of life needs to come in - a new challenge, it needs to be looked at because society has changed over the last 20 years so the challenges have changed” (Lucy). Peter also has concerns about the lack of change at board level “what has stopped NICHE developing and evolving because every organisation needs to develop and evolve, where are the young people that need to be involved in the organisation, are the same people sitting on the board of management who were sitting on the board of management 20 years ago, if so why?” (Peter).

Peter also stressed the importance of “succession planning, developing young people within the community to have the skills and competencies” and suggested that representatives of the groups run by NICHE, for example, the young mothers group, the women's group, the environment group, the men's group, could be included on the Board for it to be truly reflective of the community. He also felt that the representatives should be supported in that role so that it was empowering as opposed to disempowering.

“Representatives of the groups on the board, where issues are brought from the groups to the board and from the board to the groups and there is a strong connection there. The representative needs to be supported. That could be the role of the CHW, the board should be highly representative of the participants”.
(Peter)

Succession Planning

Many of the interviewees expressed concern about succession planning particularly with two key members of staff due to retire soon. Many asked where the young people

were. It was felt that new people should be encouraged to become involved in the organisation to reflect the changing needs within the community. Succession planning is often a challenge for many organisations and can be particularly difficult for community-based organisations, where trust and relationships are difficult to establish and are often dependent on a local connection. NICHE has two key workers who will retire soon, and it has been highlighted as a cause for concern. Many of the interviewees were concerned about these retirements. Chris explained that; “Mary Bird was key to making it work, I don’t know what we will do when Mary leaves, she was the glue that kept it all together and kept it going” (Chris). Tim also referred to “losing Mary next year” as a “colossal loss, she is the backbone of NICHE.”

As mentioned earlier, the interviewees were unanimous in their description of NICHE as a community health organisation based on a social model of health. The interviews revealed that NICHE is chiefly concerned with helping the community articulate and address inequalities of health and that its biggest strengths in achieving this goal are its partnerships with other organisations such as the HSE and UCC. The interviewees also revealed that the participation of community members and NICHE’s connection to these community members were key to the organisation's success. While interviewees were very positive in discussing the organisation, they had some concerns around sustainability, specifically around, succession planning and the need to return to community consultation to ensure that the organisation was still reflective of the community and its needs.

4.2 Theme 2 - Role of the Community Health Worker

In this section, I provide findings relevant to the role of the community health worker, which have been organized under emerging key themes from the interviews.

4.2.1 Effectiveness of the Role

All of the interviewees concurred with the literature that the Community Health Worker (CHW) role is key to the implementation, provision, and delivery of services at

community level. The role of the CHW is not easy to define as it is diverse and varied in its nature, what is clear is that it is central to the facilitation of health promotion and increased engagement with health services. The activities of the CHW range from preventative, curative and developmental (Lehmann and Sanders, 2007). NICHE is described by interviewees as a developmental model and it is clear that they do not view it as a medical solution, and thus is largely concerned with the preventative and developmental aspects of the role. As Peter highlighted during his interview, “It was a community development model of community health workers, they were accountable to the community” (Peter). Tim also explained that “the workers set the scene in the community for the engagement and connection with the professionals, they are the connector to the people, for e.g. It was at community level where young people in particular would talk to GPs who were training and there was a mutual benefit” (Tim). CHWs act as connectors, they connect people to services and services to people, they were described by the interviewees as facilitators, relationship builders, programme developers and drivers in facilitating the needs of their communities. In addition to all of these tasks, according to Lucy “it’s information, advocacy, support” (Lucy). Peter adds to this stating, “you are facilitating the community; you have to look at the community and see what the needs of the community are” (Peter). For Debbie a key feature of the role is “building relationships” (Debbie).

“I think sometimes when you come from a working class background and you’re dealing with medical or healthcare professionals, there is always that power imbalance, and there is a feeling that people are not in a position to question that, or look for alternatives. I think the CHW can bridge that gap, they acted as a liaison between the service that people may not have wanted to go to make it more accessible for those individuals, so for e.g. the bra project, bringing screening to NICHE all that innovative type of work”. (Tina)

Peter added to the discussion around the difficulties community members had with engaging with professionals “Mary Bird was critical in breaking down that judgemental aspect of the public health nurse going into your home and you feeling judged, the CHW had a position that could go back to the HSE and say, maybe you need to look at your approach and how you deal with people on the ground” (Peter). In disadvantaged areas with low rates of engagement with health services, the CHW is essential to building

community capacity and advocating for community needs to ensure a better health outcome for community members. They make important contributions to social capital and build networks, partnerships, and trust with their clients (El Arifeen et al., 2013). It has been argued that being from the community they serve is fundamental to the success of the CHW role.

4.2.2 Impact of the Community Health Worker at NICHE

The interview participants were clear in their view that the CHW is the reason NICHE has evolved and been so adept in its role of community development and health promotion.

“The success of NICHE is down to the workers on the ground, this is why the project has been so successful over the years, a lot of them give more than they should be giving, when it really means something to you, people go above and beyond what would be expected of them” . (Tina)

The interviewees agree that the community health worker is the paramount to the work and success of NICHE, according to Peter “it is the CHWs who are the model, they are the people who go out and interact with people who are hard to reach, vulnerable people within society” (Peter).

“Absolutely the CHW is the strength of the organisation, we have 1 or 2 key people who are coming up to retirement and I firmly believe that the loss not only to the project but to the community will be immense because you have Mary and Carmel who are seeing people as grandparents who probably came in as young mothers and they still come back. People only engage with a service when they need it and they will only recommend you if they have a good relationship and you can see the stature of the CHWs here and why in a silent way they’re looked up to” . (Tina)

4.2.3 Strengths of the Role

According to the WHO, CHWs need to be equipped with the skills to mobilise and organise communities for the promotion of their own health. Furthermore, the WHO states that the failure of many programmes can be traced to neglect by planners of the potential of communities to support and sustain their health programs through their own active participation (WHO, 1989). NICHE was developed on this principle of participation and it remains the ethos of the CHWs today.

“One of the key things that CHWs can do is because they are part of the community, are embedded in the community, they can create the mechanisms by which the most vulnerable members of the community can participate, they can encourage people to become involved in groups based on identified needs and priorities for instance, the environment group, the young mothers group”.

(Peter)

Peter gives further insight into the importance of the CHW explaining, “the CHW role is to facilitate involvement because for the most vulnerable people in the community it’s actually really hard to become part of a group. It’s hard to have the confidence, sometimes they need that little bit of support to articulate the issues that affect them” (Peter). Reaching the traditionally hard to reach, giving them a voice and encouraging participation are central to the CHW role at NICHE.

“ we have lads from the area, they would have been in prison, they would have a reputation, they are good lads, they just had tough times growing up and that kind of stigma stuck with them, my main thing is that everyone is treated the same. I tell them I am their voice. There is nothing like closing the gate afterwards and seeing 12 happy faces that would have been doing nothing else that night only sitting on their own and because of you, the 12 of them sat around the table and they ate healthy food, had healthy conversation and they are looking forward to something again next week, that’s what makes it worth it”.

(Derek)

Pride in the work of the CHW at NICHE is evident as is the appetite to drive projects and groups forward. Continued consultation with and participation of community

members coupled with collaborative efforts with other organisations will support the CHW efforts to drive the health needs of the area. Some of the key terms that were used by the interviewees to praise the work of the CHWs were terms, such as collaboration, participation, and creativity.

“I think people working here and their creativity and their views on health and their ambition, everything, I think it needs to be driven by them. I think if it’s not driven by them it becomes more health professional, I wouldn’t like to see it absorbed into the medical health model, I think the CHW is essential to keeping it relevant to the social model”. (Judy)

Consultation was deemed very important by interviewees, according to Peter “through consultation, we were able to work towards solving it, a lot of that wouldn’t have happened only for local people working through NICHE identifying the needs (Peter). Derek agrees stating “I try to do everything in a collaboration so that nobody is feeling left out” (Derek).

“Somebody needs to drive it and I would say community workers have to be facilitators and you have to facilitate the voice of the community, you have to put structures in place whereby that is coming from the ground up. When you find your voice it’s massively empowering. NICHE was, is and should be the voice for the people of the area”. (Peter)

4.2.4 Challenges of the CHW Role

All of the CHWs were very forthcoming in discussing the challenges associated with their role. Frustrations ranged from a lack of cooperation/coordination with other organisations in the community, to being limited in their ability to reach people and also feelings of being unappreciated and undervalued.

“I can’t understand why there are 3 or 4 different organisations up here and everyone is going in different directions, we have an opportunity, community centres are closed at 7pm in the evening, a full gym that won’t open on Saturdays. There are 10 of them over there and 5 of us over here, my feeling is

that we should be working together, that is the connection that springboard and NICHE should have". (Derek)

Springboard is a community-based family support service which has an office in Knocknaheeny, there is also a youth centre in the area. In many instances families engage with more than one service, interviewees discussed the benefits of a coordinated approach from the different organisations in the community.

Workload

The interviewees also discussed the challenges around their workload. There were clear issues around the amount of work they had to fit in, Derek explains "we don't have a start and finish time with this job" (Derek). Tina further explains "there are other services that close at 5 and people walk out the door, that doesn't happen here and sometimes you can see it on people it weighs on them" (Tina). The interviewees also voiced their frustrations about not being able to do outreach which they believe is a crucial part of their role.

"Do you know how long it has been since I got to do outreach? I miss it because I know there are lots of older people who are in their homes and they don't have people calling, we have the Meadows and Shanakiel, when have I got a chance to call to them, it's in our area, we're meant to do it but we can't do it". (Judy)

Community Garden

The community garden is a source of great pride for NICHE and the wider community, that view was shared by all interviewees. However, it has significantly added to the workload for CHWs and has split resources between two sites, Lucy explains the impact of the second site "the staff are split between here and the garden, we only have funding for five CHWs, and we already have five but now two of them are at the garden" (Lucy). Judy also details the effect of the second site, "there are five of us but now we have two buildings, there were 5 in one building but now we have five covering two buildings. It's

more work, we have two great premises, but we can't utilise them the way we want to. We are all doing more than what we should, and we could be doing more" (Judy). Tina adds weight to the discussion explaining "when it was seen as very successful you had five workers operating out of one base and now, we have two sites, and although we have five CHWs really we have 2.5 because they are all part time. So, for the work that's being done and the diversity of skill set that's needed it's actually incredible what has been done, we don't have enough staff for what we would like to achieve" (Tina).

Disconnect with Board of Management

As previously highlighted the structure of the Board of Management was a concern highlighted by many of the interviewees, further to this, some interviewees said they felt disconnected from the Board.

"We need more staff and if the board of management acknowledged that we are working above and beyond our hours, I don't feel acknowledged, we have no contact from them. It's the same board of management for years, the same people making the decisions, there is a huge disconnection". (Lucy)

4.2.5 Significance of Being a Local

NICHE was founded on a model where community health workers came from the community they serve, something that was discussed by all of the participants. The majority of interviewees agreed that in order to gain buy-in and the trust of the community it was essential that the CHW were locals. It was felt that you had to understand the needs and issues of your community in a way that only locals could, in order to engage with the community to address these concerns. Having local knowledge, an understanding of the community and an empathy for the people of the community have been highlighted as key attributes of a successful CHW. The linkage of CHWs to community was highlighted by Dr Mahler then Director General of the WHO during a study group in Geneva 1989

“community health workers must be of the community they serve, they must live with them, work with them, rejoice with them, suffer with them, grieve with them and decide with them”.

Dr Mahler's view is shared by the interview participants who repeatedly stressed the advantages and indeed the necessity of the local connection. They felt it was essential to have locals working for and promoting the project. Peter explains, “CHW are from the local community and that is their expertise, they have a specific type of knowledge and a specific type of relationship with the community which really nobody else can have and they have insights from a different perspective” (Peter). Tim agrees stating “it helps for the CHW to be local reflecting local issues” (Tim). Chris highlights the advantages of being a local, “the strengths are that people are local, they have knowledge of the area, they have training, that they are accredited, and they know what they can do and what they can't do” (Chris). Added to these strengths is the CHWs ability to voice the concerns of the community as Peter explains “community voice is very important, that was why we were very clear in having the CHW as being part of the local community because that was the mechanism by which that voice was articulated” (Peter).

There are challenges associated with being a local which need to be considered, from the CHW perspective it can be difficult to maintain boundaries, in that people will often approach workers looking for support or advice outside of normal working hours. CHWs have reported for example, being approached at home and at the local shops. From an organisational perspective there is also the challenge of how to ensure the variety and depth of skills required to meet the project needs are met: do you train a local person which takes time and costs money or do you bring somebody in who may have the skills but not the connection to the locals?

“I suppose it is a strategic decision that we will invest in somebody local to develop the skills for this role rather than bringing in somebody who already has the skill set but not necessarily that local embeddedness”. (Peter)

Training is expensive and of course there is always the risk of people moving on to other jobs after they have upskilled, according to Peter “you are investing a lot in an individual from the perspective of the organisation, developing their skills, developing their capacity and confidence and they are well within their rights to walk off and get a

better job” (Peter). Retention of community health workers features largely in the literature (Gibson et al., 1989; Lehmann and Sanders, 2007; Swider, 2012) and has been identified as an area of concern due to the associated costs of recruitment and training new staff. NICHE is again the exception to this in that its community health workers have all been in their roles for many years and the turnover of staff is low.

4.2.6 Training, Support and Supervision

Many in the literature have highlighted the significance of training, support, and supervision to the success of CHW programmes (Lehmann and Sanders, 2007; O’Donovan et al., 2018). The interviewees also discussed the importance of supervision, training, and support.

“There does need to be a more professional level of supervision, for the CHW, it’s ok talking to your manager but there should be something else like counselling, things crop up in the line of work that trigger you or impact on your family and it’s how you deal with it afterwards, maybe if staff were provided with a number of counselling hours over the year, but it’s cost”. (Lucy)

The majority of the participants emphasised the need for ongoing training, support and supervision for CHWs, for example Judy stressed “it should be mandatory that the CHW is given ongoing training, yes it should be part of your role. I would see ongoing training as a necessity” (Judy). Tina agrees and explains “they need supervision, they need support, it’s the boundary issue, people need to be supported so that those boundaries are maintained” (Tina). The importance of support and supervision was also discussed by Lucy “there is a definite need for more support for the CHW, we don’t get to meet and see each other as a team anymore, we need more supervision” (Lucy).

4.3 Theme 3 - The Impact of a Neoliberal Agenda

4.3.1 Rise of Neoliberalism

The rise of the neoliberal agenda discussed in the literature (Kelleher and O' Neill, 2018; Meade et al., 2016; Harvey, 2015) was also highlighted by interviewees. Specifically, the dismantling of community structures, a feature of a neoliberal agenda was a cause for concern for interviewees.

“Up until the point the country went into recession, we had very good community health structures, groups who are active on the ground tended to have a broader community base and tended to be based more on the principles of community development than they are today. There were networking structures and the existence of things like Combat Poverty which provided us with a mechanism for impacting on policy. We were looking at priorities for us and also national priorities, policy level priorities that needed to be influenced”.
(Peter)

The majority of participants stated that increased bureaucracy, a feature of neoliberalism, has had a detrimental effect on the work of community organisations. Time which should be spent with clients and engaging with community members is now taken up with form filling and report writing. According to the interviewees this has severely hampered their efforts to engage and connect with the community and drastically reduces the time available to actually carry out the work that is necessary on the ground at community level.

“There are a lot of things that can take you away from the core work around governance and policy and legislation which is really challenging, you could spend all day dealing with that stuff rather than the core work”. (Tina)

Many in the literature discussed ways in which governments appeared to exert control over community organisations (McCrea, 2016; Harvey, 2015). The interviewees also revealed their struggles with an increasingly bureaucratic policy agenda, With Chris stating, “Governments cannot do everything for communities, there are always tensions between politicians and community groups, they will always try to take them over” (Chris). Tina elaborates on the impact of increased bureaucracy explaining “it’s the community and these not for profit organisations that do the work that governments

don't want to do and that's fine but you need to be flexible to do that but when they impose excessive restrictions, you become less and less flexible" (Tina).

"the amount of regulations that are coming on stream at the moment, the requirements that are being imposed and the cost of them to community organisations, so for us we get a limited budget and a lot of our expenditure would go on that type of activity so the more regulations that come onboard, the higher the cost and as a direct result, a cut back in your service so that is a challenge" .(Tina)

A further feature of a more bureaucratic sector is the increased challenges around securing funding as Chris explains, "the more professionalised you become, the more restricted you become, you have to become authoritarian because you have to get money" (Chris).

4.3.2 Funding

Since 2002, community organisations have been severely impacted by funding cuts and changes to funding policies, many in the literature argue that funding has been used to exert control over community organisations (McCrea and Finnegan, 2019; Harvey, 2015; McCrea, 2016). Thus, funding is a challenge for many community organisations and NICHE is no exception. Funding was discussed by all 10 interviewees, they identified uncertainty around finance as a difficulty and as a barrier to progress.

"It was successful at a time when there was a lot of money , staff were able to go abroad to be trained, they had strategy meetings, they went away as a board together, they planned together and all of that involved money, time and energy".
(Tim)

According to Peter, "funding is a huge issue, it's becoming more difficult, more problematic and there's so many conditions and so much bureaucracy and so much time and energy goes into it that there is so much less time and energy left for implementing programs" (Peter).

“An ongoing problem is short term funding, there are organisations working on year by year funding, the whole idea that community work should be funded on a year by year basis is absolutely ridiculous, it’s like a wing and a prayer that it will be here again next year and you are employing staff. Groups that have their own funding base are in a stronger position and are less dependent on statutory agencies, so they are stronger, they have backup money. Groups that are dependent on statutory funding if they haven’t got it spent within the year it can be taken off their budgets for next year, so it is a model that needs to be changed really”. (Peter)

Under a neoliberal agenda, competitive tendering has become the preferred policy for funding. Community Work Ireland (2015) warn that competitive tendering is a threat to the independence of community organisations and interviewees also expressed concerns about this funding policy, for example, Tina explained “you have commissioning in place where organisations compete against each other for funding. It’s getting harder and harder to bring in money” (Tina). Chris also has concerns about the impact of a more bureaucratic funding policy agenda and questions, “is it about being accountable for money and grants or is it about enabling people to do things and supporting people and helping people” (Chris).

4.3.3 Bottom Up Versus Top Down

Many in the literature argue that community organisations should be given the scope to impact and influence policy (Forde et al., 2015; Healy et al., 2019). The interviewees also shared this view, that the voice of the community is essential to implementing policies that are appropriate, workable, and equitable. It cannot be a case of “one size fits all”. There was consensus that community health organisations can and should be a mechanism for influencing policy decisions.

“If it’s community health it has to be from the bottom up and the voice of the community has to be evident, it is about changing structures, changing processes and changing policies that negatively impact on the health of the community. I think in terms of community health that’s not happening to the same extent

today because those mechanisms don't exist, they haven't been invested in and there's a model of community development in vogue today that is very much top down rather than bottom up". (Peter)

Community organisations like NICHE have the ability to address health issues at local level, according to Barry "public health policy needs to be very supportive of what projects like NICHE are doing at community level, if we can invest more in prevention at local level, because public health policy doesn't start at the door of A and E" (Barry). Policy decisions need to be workable at local level to be effective and community development has a role to play in influencing policy to ensure that policies address the needs of community members. According to Chris "statutory agencies have their own agendas about how money should be spent and where services should be directed, it is not a case of one size fits all, communities are unique in their needs and that should be reflected in policy" (Chris).

"This project has tried to take higher level policy decisions and make them workable on the ground. The community garden is fascinating in that yes there is a sustainable and green element to it that will appeal to higher level policies in terms of our role in healthy cities, Cork as a healthy city but on a very practical level what you have is men and women coming into the garden every day and eating a freshly made lunch with fresh vegetables and produce that they may never have had exposure to in their lives and you see it gradually seeping into their mindset. With the men's cooking course we are hitting mental health, social isolation and the environment and fresh food. So healthy Ireland gave us the policy, and this is how we adapt it to make it work here for us". (Tina)

The interviewees were in agreement that NICHE has a role to play in shaping future health policy, according to Peter "an aspect of public health policy being discussed at the moment is a move from a health service and tertiary care to community based care and I suppose a very strong role that a group like NICHE could have would be in shaping how that will look" (Peter).

" There is a move towards a top down model where priorities are dictated by government and perceived needs are met through things like commissioning and I think that is detrimental to participation because community development isn't

a short term gain, it's a long term gain and there has to be structures that allow ongoing participation. NICHE can play a role in changing that and in articulating and influencing that and in demonstrating successes". (Peter)

The community sector in Ireland pre 2002 was based on a participatory model, where communities had the autonomy to identify and meet its own needs. As the sector grew in strength it became a concern for the government (Kelleher and O'Neill, 2018; Meade et al., 2016; Harvey 2015). The shift in policy from 2002 to a neoliberal agenda has quietened the sector and ensured its compliance for it is now controlled in a managerial fashion by the Government using a top down approach. NICHE can play a role in influencing policy and advocating for a return to a bottom up, participatory model of community development.

Chapter 5: Discussion

5.1 Introduction

In this chapter the key findings from the research are analysed under 3 main emerging themes: the NICHE model; the role of the community health worker; and the impact of a neoliberal agenda.

5.2 Discussion

5.2.1 The NICHE Model

NICHE was designed and developed on a social model of health. The model works on the principles of community participation, where members of a community identify and articulate their own health needs. Community health workers then advocate for and facilitate the community in addressing these needs. The interviewees were unanimous in attributing the success of the organisation to this model, but the majority of them also expressed some concerns. First, some interviewees were concerned about the fact that overtime NICHE may have lost sight of its core values, and they highlighted that it should strive to go back to the principles on which it was founded. The organisation appears to have become so busy that some interviewees questioned whether they are engaging with the community in a meaningful way.

A second major issue highlighted by research participants concerned the structure of the Board of Management, which they perceive to be disconnected from the workers. The majority of interviewees questioned the makeup of the Board and wondered why it has not changed for the last 20 years. It was felt that the Board was lacking in young people and no longer reflected the profile of a changing community.

5.2.2 The role of the Community Health Worker

All of the research participants concurred with the literature that the community health worker is instrumental in the implementation and facilitation of health provision at local level. There was also consensus on the importance of the CHW being locals, something that the literature also highlights. In contrast to the literature, however, the CHWs also revealed some difficulties and challenges associated with being a local. Issues such as boundary management and workers being approached outside of work were discussed by all of the health workers and the managers. This is a potential area for further study which would add to the existing literature on CHWs.

5.2.3 Impact of a Neoliberal Agenda

The literature on community health organisations in Ireland details a shift from participatory democracy to neoliberalism in 2002 which had profound consequences for the community sector (Kelleher and O’Neil, 2018; Meade, 2012; Harvey, 2007;). This study confirms that NICHE is no exception: the interviewees repeatedly complained that the top-down approach to community development, a feature of a neoliberalism that became increasingly pronounced since the early 2000s, has had a huge impact on the organisation and its practices. They consider this new model makes it more difficult for organisations like NICHE to engage in groundwork that shall reflect the needs of a community. The structures that once supported communities’ ability to influence policy have been dismantled. This is a huge concern as it essentially means the voice of community has been silenced. Further research looking at the impact of a neoliberal agenda on the relationship between communities and community organisations would benefit the sector.

5.3 Conclusion

This chapter outlined the key findings of the study under the themes of the NICHE Model, CHW role and the impact of a neoliberal agenda. The findings discussed here, will underpin the conclusions and recommendations in the next chapter.

Chapter 6: Conclusion and Recommendations

6.1 Introduction

This research aimed to reflect on 20 years of NICHE and how the organisation has evolved in that time. Based on a qualitative study of the experiences of 10 people who have worked for NICHE as community health workers, managers and board members, the research sought to explore the role that NICHE, as a community health model, and community health workers have played in the Northside of Cork city. In the process, it also identifies some emerging challenges and opportunities for the organisation. The research also revealed the impact of a neoliberal policy agenda on NICHE as a community-based health organisation. A systematic literature review and analysis of the primary research informs the recommendations outlined here. The chapter concludes with a discussion of some of the limitations of this study and a reflective piece on the research process.

6.2 Findings

The “Evolution of NICHE” charts a community health organisation from its inception at a time when community development in Ireland favoured a bottom up, participatory approach, through to a shift to a neoliberal top down paradigm. In the process, this study highlights the challenges which resulted from this change at policy level. The documented experiences of those who participated in this research may influence further investigation into community development in Ireland and it may encourage organisations to lobby at policy level in order to develop structures that would allow them to return to a participatory approach.

6.2.1 NICHE Model

NICHE was developed as a community health organisation based on a social model which favoured broad-based community participation with community health workers

facilitating community members in identifying and articulating health needs. The community served by NICHE has changed and grown considerably in recent years and the research suggests there may be a need to re-engage with the needs of the community at ground level.

6.2.2 Role of the Community Health Worker

The Community Health worker is key to implementing the programmes at NICHE. Health workers advocate for community members and help bridge the gap between professional services and services users. Central to the role is the trust which community members have in their health workers, which is often based on the fact that they are local. Being from the locality is not without its challenges and health workers often struggle to maintain boundaries outside of work hours. Furthermore, more support and supervision has been highlighted as essential for community health workers.

6.2.3 Impact of a neoliberal agenda

NICHE was founded in a time when community development came from the ground up when policy was influenced by communities and favoured a bottom up approach. The shift to a neoliberal paradigm documented in both the literature and in the research interviews has disabled the organisation's ability to affect and influence change at policy level.

6.3 Recommendations

In this section, recommendations are presented under the 3 key themes of community health organisations, the role of the community health worker and finally the policy context.

6.3.1 Community Health Organisations

- Community Consultation needs to be re-prioritised. This study points at a need to pause and ask: what are the needs of the community now?
- A new strategy is crucial to ensure that NICHE continues to evolve: a process of planning and broad-based consultation may benefit the organisation.
- The governance structure needs to be re-evaluated: this may entail a renewal of the board to represent the many voices of the community and its changing profile.
- There is a need to emphasize the relevance of a bottom - up approach: NICHE needs to continue to advocate for the community, influence policy and remain true to community development ethos by implementing participatory structures and being a voice for the community.
- NICHE will benefit from continuing to work collaboratively: partnerships with UCC, HSE and other organisations need to be nurtured and maintained.

6.3.2 Community Health Worker

- Community Health Workers need a forum to express their views, so that they feel acknowledged, heard, and empowered.
- Support and supervision for CHWs needs to be addressed as a priority: building on the established links with UCC may offer an opportunity to develop a program whereby CHWs are offered a certain amount of training, counselling or whatever they deem necessary. It could be a mutually beneficial relationship similar to the G.P programme.
- The Community Garden has been a huge success in reaching people who are traditionally hard to reach. It appears, however, to have resulted in many extra demands on CHWs and this may need to be addressed at organisational level.

- Funding opportunities may also need to be explored and a strategy for moving forward as one organisation with two sites may need to be further developed.
- Succession planning may also need to be addressed: new CHWs need to be trained and mentored by current workers for a period of time before they leave, so that existing relationships with clients and other organisations can be maintained and continue to grow and develop.

6.3.3 Policy Context

- NICHE needs to continue to advocate for the community, influence policy and remain true to community development by implementing participatory structures and being a voice for the community.

6.4 Limitations

This research was limited to documenting the experiences of 10 interviewees who have worked for NICHE due to the nature of the study and the time frame allowed. Further study involving those who have participated in the health programmes at NICHE would be very valuable. Assessing the success of these programmes was beyond the scope of this study.

6.5 Final reflection on the research process

I was instantly drawn to this CARL project because it represented all of the things I value most: people, community, participation. I was very excited to work with NICHE because I grew up in the community it serves, and I believed in the research project. I have worked with many community organisations over the years and felt my experience would be an advantage. I was quite unprepared for how difficult the research process. I knew what I needed to do and how to do it and yet I stumbled and struggled a lot throughout the process. The literature review proved very challenging

for me, and I spent hours searching and reading and still come away feeling that I still had not found what I needed. I knew the value of reviewing existing research and literature, and with the support of my supervisor, I managed to navigate my way through the process. It was certainly a lesson in perseverance. The interview process was my favourite part of the research process. I was fascinated by the experiences that participants shared with me and I could not wait to tell their stories in the context of the study findings. The collaborative aspect of this project was very important to me. I loved working with NICHE and I particularly liked the participation aspect of the study. I did, however, develop many concerns. For example, what if NICHE did not like what my study found? This thought stayed with me a lot in the early stages of the research process, finally I realised that it would be the results that would be speaking, and not me. I was mostly trying to facilitate the stories of the people I interviewed and locating the overall story of NICHE within a wider policy context. Furthermore, this is something that was discussed with NICHE, and I have to thank them for their continuous support.

This research process has been one of the most valuable experiences of my life, it has contributed so much to both my professional and personal skills and I am grateful for all I have learned.

Bibliography

Adshead, M., Millar, M. (2003) *Ireland as Catholic corporate state: a historical institutional analysis of healthcare in Ireland*, Limerick: University of Limerick.

Ajuebor, O., Cometto, G., Boniol, M. and Akl, E. (2019). Stakeholders' perceptions of policy options to support the integration of community health workers in health systems. *Human Resources for Health*, 17(1).

Bach-Mortensen, A., Lange, B. and Montgomery, P. (2018). Barriers and facilitators to implementing evidence-based interventions among third sector organisations: a systematic review. *Implementation Science*, 13(1).

Barrington, R. (1987). *Health, medicine & politics in Ireland, 1900-1970*. Dublin, Ireland: Institute of Public Administration.

Berger, R. (2015) 'Now I see it, now I don't: researcher's position and reflexivity in qualitative research', *Qualitative Research*, 15(2), pp. 219–234.

Berkman, L.F. and Glass, T., 2000. Social integration, social networks, social support, and health. *Social epidemiology*, 1, pp.137-173.

Bhan, A., Singh, J., Upshur, R., Singer, P. and Daar, A. (2007). Grand Challenges in Global Health: Engaging Civil Society Organisations in Biomedical Research in Developing Countries. *PLoS Medicine*, 4(9), p.e272.

Bondi, L. and Laurie, N. (2005). Introduction. Special Issue: Working in the Spaces of Neoliberalism: Activism, Professionalisation and Incorporation. *Antipode*, 37(3), 393 - 401.

Brown, M.P. (1997). *Replacing citizenship: Aids activism and radical democracy*. London: Guildford Press.

Bryman, A., 2012. *Social Research Methods*. 4th ed. New York: Oxford.

Buetow, S. (2019). Apophenia, unconscious bias and reflexivity in nursing qualitative research. *International Journal of Nursing Studies*, 89, 8–13.

Carey, G., Braunack-Mayer, A. and Barraket, J. (2009). Spaces of care in the third sector: understanding the effects of professionalization. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 13(6), pp.629-646.

Central Statistics Office (2017). *Census 2016, Summary Results*. Cork, Ireland: CSO.

Chavis, D.M. and Florin, P., 1990. Nurturing grassroots initiatives for health and housing. *Bulletin of the New York Academy of Medicine*, 66(5), p.558.

Chillag, K., Bartholow, K., Cordeiro, J., Swanson, S., Patterson, J., Stebbins, S., Woodside, C. and Sy, F., 2002. Factors affecting the delivery of HIV/AIDS prevention programs by

community-based organisations. *AIDS Education and Prevention*, 14(3 Supplement), pp.27-37.

Cometto, G., Ford, N., Pfaffman-Zambruni, J., Akl, E., Lehmann, U., McPake, B., Ballard, M., Kok, M., Najafizada, M., Olaniran, A., Ajuebor, O., Perry, H., Scott, K., Albers, B., Shlonsky, A. and Taylor, D. (2018). Health policy and system support to optimise community health worker programmes: an abridged WHO guideline. *The Lancet Global Health*, 6(12).

Community Work Ireland, 2015. *In Whose Interests? Exploring the Impact of Competitive Tendering and Procurement on Social Inclusion and Community Development in Ireland*. Community Work Ireland.

Cousins, M., 2007. *Welfare Policy and Poverty*. Dublin: Institute of Public Administration.

Dahlgren, G. and Whitehead, M., 2006. Concepts and principles for tackling social inequities in health: Levelling up Part 1. World Health Organisation: *Studies on social and economic determinants of population health*, 2.

deMarrais, K.B. and Lapan, S.D. eds., 2003. *Foundations for research: Methods of inquiry in education and the social sciences*. Routledge.

Department of Health (2013). *Healthy Ireland: A framework for improved health and wellbeing 2013 -2025*. Dublin, pp.6-39.

Dupre, M., Moody, J., Nelson, A., Willis, J., Fuller, L., Smart, A., Easterling, D. and Silberberg, M. (2016). Place-Based Initiatives to Improve Health in Disadvantaged

Communities: Cross-Sector Characteristics and Networks of Local Actors in North Carolina. *American Journal of Public Health*, 106(9), pp.1548-1555.

Durham Community Research Team, 2011. Connected Communities: Community-based Participatory Research: Ethical Challenges. *Centre for Social Justice and Community Action, Durham: Durham University.*

Edwards, C. and Fernández, E. (2017). *Reframing health and health policy in Ireland*. Manchester: Manchester University Press.

El Arifeen, S., Christou, A., Reichenbach, L., Osman, F., Azad, K., Islam, K., Ahmed, F., Perry, H. and Peters, D. (2013). Community-based approaches and partnerships: innovations in health-service delivery in Bangladesh. *The Lancet*, 382(9909), pp.2012-2026.

Eversole, R. (2010). Remaking participation: challenges for community development practice. *Community Development Journal*, 47(1), pp.29-41.

Fitzpatrick, P., Molloy, B. and Johnson, Z. (1997). Community mothers' programme: extension to the travelling community in Ireland. *Journal of Epidemiology & Community Health*, 51(3), pp.299-303.

Forde, C., O' Byrne, D. and O' hAdhmaill, F. (2015). Community Development in Ireland under Austerity and Local Government Change: Policy and Practice. Cork: *Institute for Social Sciences in the 21st century (ISS21)*, University College Cork.

Fyfe, N. and Milligan, C. (2003a). Out of the shadows: Exploring contemporary geographies of the welfare voluntary sector. *Progress in Human Geography*, 27(4), 397-413.

Fyfe, N. and Milligan, C. (2003b). Space, citizenship and voluntarism: Critical reflections on the voluntary welfare sector in Glasgow. *Environment and Planning A*, 35 (11), 2069-86.

Geoghegan, M. and Powell, F. (2006) Community Development, Partnership Governance and Dilemmas of Professionalization: Profiling and Assessing the Case of Ireland, *British Journal of Social Work*, 36(5), pp. 845–861.

Gilson, L., Walt, G., Heggenhougen, K., Owuor-Omondi, L., Perera, M., Ross, D. and Salazar, L., 1989. National community health worker programs: how can they be strengthened? *Journal of public health policy*, 10(4), pp.518-532.

Government of Ireland (2000). White Paper on a Framework for Supporting Voluntary Activity and for Developing the Relationship between the State and the Community and Voluntary sector. Dublin: Government of Ireland.

Government of Ireland (2013). Healthy Ireland Policy Framework. Dublin: Government of Ireland.

Government of Ireland (2015). Our Communities: A Framework Policy for Local and Community Development in Ireland. Dublin: Department of Rural and Community Development.

Government of Ireland (2017). Project Ireland 2040: Building Ireland's Future. Dublin: Government of Ireland.

Government of Ireland (2018). Project Ireland 2040. The First Year: Annual Report 2018. Dublin: Government of Ireland.

Government of Ireland (2019). Sustainable, Inclusive and Empowered Communities. Dublin: Department of Rural and Community Development.

Gray, D.E., 2014. Theoretical perspectives and research methodologies. *Doing research in the real world*, 752.

Harris, P., Sainsbury, P. and Kemp, L. (2014). The fit between health impact assessment and public policy: practice meets theory. *Social Science and Medicine*.

Harvey, B. (2007). Evolution of health services and health policy in Ireland. Dublin: *Combat Poverty Agency*.

Harvey, B. (2015). Local and Community Development in Ireland - An Overview. Cork: *Institute for Social Sciences in the 21st Century (ISS21)*, University College Cork.

Healy, S., Bennett, C., Leahy, A., Murphy, E., Murphy, M. and Reynolds, B. (2019). *Social Justice Matters*. Dublin: Social Justice Ireland, pp.156 - 178.

Jenkins, K. (2005). No way out? Incorporating and restructuring the voluntary sector within spaces of neoliberalism. *Antipode*, 37(3), 613-18.

Kelleher, P. and O'Neill, C. (2018). *The Systematic Destruction of the Community Development, Anti-Poverty and Equality Movement (2002-2015)*.

Kelly, J. (2007). Reforming Public Services in the UK: Bringing in the Third Sector. *Public Administration*, 85, pp1003-1022.

Koch, E., Thompson, A. and Keegan, P., 1998. Community health workers: a leadership brief on preventive health programs. Washington, DC: *The Civic Health Institute at Codman Square Health Center and the Harrison Institute for Public Law at Georgetown University Law Center and the Center for Policy Alternatives*.

Lee, A. (2003) Community development in Ireland, *Community Development Journal*, 38(1), pp. 48-58.

Lehmann, U. and Sanders, D. (2007). Community health workers: What do we know about them? World Health Organisation. Geneva.

Lyons, M. (2001). Third sector: The contribution of non-profit and cooperative enterprises in Australia. Sydney: Allen & Unwin.

Maddison, S., Denniss, R. and Hamilton, C. (2004) Silencing dissent: Non- government organisations and Australian democracy. *The Australia Institute Discussion Paper 65 (June)*. Canberra: The Australia Institute.

Marmot, M. 2011, Global action on social determinants of health, World Health Organisation. *Bulletin of the World Health Organisation*, vol. 89, no. 10, pp. 702.

Marmot, M., Allen, J., Goldblatt, P., Boyce, T., McNeish, D., Grady, M. and Geddes, I., 2010. *The Marmot review: Fair society, healthy lives*. London: UCL.

McCrea, N., 2016. Community development, venture philanthropy and neoliberal governmentality: a case from Ireland. *Politics, Power and Community Development*, pp.103-120.

McCrea, N. and Finnegan, F. (2019). *Funding, power, and community development*. Bristol: Policy Press, pp.1-15.

McGinnis, J., Williams-Russo, P. and Knickman, J. (2002). The Case for More Active Policy Attention to Health Promotion. *Health Affairs*, 21(2), pp.78-93.

McKee, E. (1986). Church-state relations and the development of Irish health policy: the mother-and-child scheme, 1944–53, *Irish Historical Studies*. Cambridge University Press, 25(98), pp. 159–194.

Meade, R. (2011). Government and Community Development in Ireland: The Contested Subjects of Professionalism and Expertise. *Antipode*, 44(3), pp.889-910.

Meade, R., Shaw, M. and Banks, S. (2016). *Politics, power, and community development*. Bristol: Policy Press.

Meade, R. (2017). The re-signification of state-funded community development in Ireland: A problem of austerity and neoliberal government. *Critical Social Policy*, 38(2), pp.222-243.

Milligan, C. and Conradson, D. (2006) Contemporary landscapes of welfare: the voluntary turn? *In Landscapes of voluntarism: New spaces of health, welfare, and governance*. Bristol. Policy Press.

Molloy, B. (1996) *The Community Mothers Programme*. Dublin. Eastern Health Board.

O'Donovan, J., O'Donovan, C., Kuhn, I., Sachs, S. and Winters, N. (2018). Ongoing training of community health workers in low-income and middle-income countries: a systematic scoping review of the literature. *BMJ Open*, 8(4), p.e021467.

O'Mullane, M. (2015). *Health impact assessment and policy development*. Manchester: Manchester University Press

Oancea, A. (2016) *Including Ethics in Social Science Research*

Owen, S. and Kearns, R. (2006) Competition, adaptation, and resistance: (Re)forming health organisations in New Zealand's third sector. In C. Milligan and D. Conradson (Eds), *Landscapes of voluntarism: New spaces of health, welfare and governance*, pp 115-34, Bristol: The Policy Press.

Popay, J. (2008). Social Exclusion Meaning, measurement and experience and links to health inequalities A review of literature. World Health Organisation.

Rosenthal, E. (1998). *Summary of the National Community Health Advisor Study*. The University of Arizona, The Annie E. Casey Foundation.

Salamon, L. (1997). *Holding the center: America's nonprofit sector at a crossroads*. New York: Nathan Cummings Foundation.

Swider, S. (2002). Outcome Effectiveness of Community Health Workers: An Integrative Literature Review. *Public Health Nursing*, 19(1), pp.11-20.

Wilson, J. and Lindsay, P. (2017). Neoliberal governmentality and public health policy in Ireland. In: C. Edwards and E. Fernandez, ed., *Reframing Health and Health Policy in Ireland*. Manchester: Manchester University Press.

Wilson, M. (2010). Supporting the use of research evidence by community-based organisations in the health sector. *McMaster University, Ontario*.

Wilson, M., Lavis, J. and Guta, A. (2012). Community-based organisations in the health sector: A scoping review. *Health Research Policy and Systems*, 10(1).

Wistow, G. and Callaghan, G. (2011). Empowering local communities to commission for health and wellbeing: the connected care initiative in England. *Journal of Management & Marketing in Healthcare*, 4(1), pp.63-71.

Wolch, J.R. (1989). The shadow state: Government and voluntary sector in transition. In J.R. Wolch and M. Dear (Eds.), *The power of geography: how territory affects social life*, pp. 197-221. Boston, MA: Unwin Hyman.

Wolch, J. (1999). Decentering America's nonprofit sector: Reflections on Salomons crises analysis. *Voluntas: International Journal of Voluntary and Nonprofit Organisations*, 10(1), 25-35. Philips, R. (2005). Australian NGOs: Current experiences of corporate citizenship. *Journal of corporate Citizenship*, 17(Spring), 21-6.

World Health Organisation (1987). Community health workers: *Working document for the WHO study group*. Geneva. WHO.

World Health Organisation (1989). Strengthening the performance of community health workers in primary health care. *World Health Organisation Technical Report Series*. Geneva. WHO.

World Health Organisation (2018). *Guideline on Health Policy and System Support to Optimize Community Health Worker Programmes - Selected Highlights*. WHO.

Appendices

Appendix 1: Information Sheet

Information Sheet

University College Cork, Ireland

Purpose of Research: The purpose of the study is to reflect on the NICHE model 20 years on and identify the challenges and opportunities going forward.

What will research involve? The research is a collaboration between UCC and NICHE through the CARL Initiative (Community-Academic Research Links). The participatory study will involve interviewing participants about their experiences while working at NICHE.

Why have you been asked to participate? You have been asked to take part in the study because of your direct involvement/experience with the organisation.

Do you have to take part? No. Participation is voluntary, and you can withdraw at any stage.

Will your participation in the study be kept confidential? Yes. There will be no link to your identity in the dissertation and any extracts from what you say that are quoted in this project will be anonymous.

What will happen to the information you give? The data will be kept confidential for the duration of the study and discussed only between me and my research supervisor. It will be stored on a password protected device. The data will be stored (without names) for a minimum of a further ten years and then destroyed.

What will happen to the results? The results will be presented in my dissertation. They will be seen by my supervisor, a second marker and the external examiner. The thesis will be presented to NICHE as part of the collaboration between NICHE and UCC to undergo the community-based research project. The results may be published in a research journal and will be published on the CARL website.

Appendix 2: Consent Form

Participant Consent Form

University College Cork, Ireland

Iagree to participate in Catherine, Majella Canty’s research study. The purpose and nature of the study has been explained to me in writing.

I am participating voluntarily.

I give permission for my interview with Majella Canty to be audio- recorded.

I understand that I can withdraw from the study at any time.

I understand that I can withdraw permission to use the data within two weeks of the interview, in which case the material will be deleted.

I understand that anonymity will be ensured in the write-up by disguising my identity.

I understand that disguised extracts from my interview may be quoted in the thesis and any subsequent publications if I give permission below:

(Please Tick One)

I agree to quotation/publication of extracts from my interview.

I do not agree to quotation/publication of extracts from my interview.

Signed: Date:

Print Name:

Appendix 3: Interview Questions

1. Can you tell me about your role at NICHE? Describe the role.
2. When did you start/finish working here?
3. How would you describe the NICHE model and how does it work?
4. How has the organisation evolved over the past 20 years?
5. Can you tell me more about the development of NICHE?
6. What are the NICHE's strengths?
7. What are the challenges facing the organisation?
8. What is the role of the CHW at NICHE?
9. What are the strengths of the role?
10. Tell me about the difficulties/challenges faced by the CHW.
11. There have been discussions around whether or not the role should be considered a profession, what are your thoughts on this?
12. Does the fact that CHWs are often local help or hinder their work?
13. How does NICHE fit into current policy on health?
14. What are your views on current health policy?
15. Does funding impact/influence decisions/activities?
16. Can you give me 3 words to describe NICHE?
17. What do you think is next for NICHE?
18. Further thoughts.