PAY PENNIES, REBUILD LIVES

An evaluation to determine health care and economic savings as a result of client engagement in Action Mental Health's New Horizons Services and a qualitative exploration of the perceptions of carers of clients of the New Horizons programme

October 2012

A commissioned report by
Dr Derek McLaughlin & Dr Karen Casson
University of Ulster

Contents

List of Tables

List of Figures

List of Appendices

Acknowledgements

The work described in this report was commissioned by Action Mental Health (AMH). We are most grateful to them for their support.

Firstly, a special acknowledgement goes to all the clients in the AMH New Horizons programme who participated in our survey and provided valuable information on their own personal circumstances. Secondly, we would like to thank the carers of clients who willingly gave up their time to come to our focus groups and share their experiences of caring for someone with a mental health problem. The input of both clients and carers was generous and insightful.

Throughout our work we benefited from the advice and guidance of the Steering Group, Bernie Best, Ingrid Gallen and Peter Shields, who oversaw the study. They gave generously of their time to help us with all aspects of the evaluation.

We are also grateful to the managers of the Action Mental Health services who run the AMH New Horizons programme Amanda Barrett, Caroline Ferguson, Mickie Harkin, Brian Hughes, Selwyn Johnston, Colin Loughran, Gavin McConvey, Nadya MacLynn, and Andrew Sutherland/Joanne Stroud. Without their facilitation of data collection with clients and carers the study would not have been possible. We appreciate the time and effort involved in this.

Thank you all for being generous with your time and support.

1.0 Executive Summary

1.1 Economic evaluation is not about saving money but about producing the best outcomes within available resources and budgets. In these times of economic downturn it is even more important to focus resources on programmes that can produce benefits in the long-term to health and wellbeing and to the economy as a whole. This study has provided compelling empirical evidence that investment in AMH New Horizons programme is a better use of public money and could help address as much as £50 million of costs of mental health problems in Northern Ireland annually. Please refer to the Annexe for a breakdown of the savings. This equates to £27,443 per client per year and £528 per client per week. Such savings are particularly welcome in light of the 2010 spending review plan with cuts in departmental spending of around 11% in real terms (in addition to cuts in welfare benefits) by 2014/15 (Appleby, 2011).

1.2 The magnitude of savings presents a very strong case for changing the way services are funded; there should be recurrent, mainstream Government investment in the AMH New Horizons programme. This is particularly relevant in light of *Transforming Your Care A Review of Health and Social Care in Northern Ireland* (DHSSPS 2011b) with the move towards providing services in the community and the greater level of involvement of the third sector. Additionally, social values generated include improved family relationships. In effect, AMH New Horizons is a ‘cost-saving’ service i.e. it improves mental health while reducing costs.

1.3 One in five adults in Northern Ireland will show signs of a possible mental health problem (DHSSPS 2011a). Actual spending per capita on mental health services in NI is 10-30% lower than in England, despite requiring nearly 44% higher per capita funding (Appleby 2011). In 2010/11 only 8% of the health and social care budget (£228 million) was spent on mental health services (NI Assembly 2012).

1.4 There is a strong evidenced association between unemployment and mental health (Mclean et al. 2005) and appropriate work has been shown to improve health outcomes for people with mental health problems (Waddell and Burton 2006; RCPsych 2002 cited in Perkins et al. 2009). If work is not possible it is important to focus on helping individuals to move towards open employment as their skills and competencies develop (Perkins et al. 2009). The National Mental Health Development Unit (2012) reported that costs to mental health services can be reduced by half when people with severe mental health problems are supported into mainstream services and subsequent hospital stays are fewer and shorter.

1.5 Poor mental health has been associated with an increased risk of suicide and it is estimated that 90% of the 162 suicides in Northern Ireland were associated with mental health problems (Sainsbury Centre for Mental Health and NIAMH 2004).

1.6 The overall purpose of Action Mental Health's programme is to help people to overcome the effects of mental ill health and in many cases return to work. A range of recognised qualifications are offered and training, personal development programmes and social and recreational activities are provided (Action Mental Health 2012). Action Mental Health (AMH) uses both person-centred and strengths-based approaches, working closely with clients to not only improve their employability prospects but also to build and develop their self-esteem and social interaction skills.

1.7 The aim of this commissioned independent economic evaluation was to assess and quantify, in financial terms, any savings to Health and Personal Social Services and the Exchequer generated as a result of clients with mental health problems engaging in Action Mental Health's New Horizons programme over time. The perceptions of carers of clients in the New Horizons programme were also explored through focus groups. Ethical approval for the study was obtained from the University of Ulster's Research Ethics Committee.

1.8 A Steering Group, comprised of members of Action Mental Health's Senior Managers and the Researchers, provided guidance on all aspects of the study and facilitated access for data collection at the eight Units delivering the AMH New Horizons programme.

1.9 The inclusion criterion for the client survey was all clients who had enrolled in AMH New Horizons since 1st May 2010 (n=469). The response rate was 25% (n=116) which fulfilled the requirement of a power calculation (n=107). Respondents were representative of the client group in the AMH New Horizons programme. Data were collected relating to three time Points; 3 months prior to engagement in AMH New Horizons (Point 1) and at two further 3-month intervals (Point 2 & Point 3). There was some attrition at Point 2 and Point 3, mainly due to clients having left the programme or not being in attendance at the time of data collection. The validated Client Service Receipt Inventory (CSRI) and EQ-5D instruments were self-completed by clients at each of the three time Points, with the researchers or a member of AMH staff present to assist if required. Written consent was obtained prior to data collection. The CSRI collected data on the frequency and intensity of use of health and personal social services, inpatient admissions, medication, life experiences and receipt of state benefits. The EQ-5D collected data on the health status and psychological wellbeing of clients.

1.10 The inclusion criteria for the carer survey were being a carer for a client who had been engaged in the AMH New Horizons programme for 6-12 months. Four semi-structured focus groups were undertaken with 19 carers. Both researchers were present at all focus groups and written consent was obtained prior to the start of the focus group. Information on the individual they cared for was collected using a short questionnaire. Information on the health status and psychological wellbeing prior to their relative engaging in AMH New Horizons and on the day of the focus group was collected using the EQ-5D.

1.11 Our study has conclusively shown that helping people move towards employment through the AMH New Horizons programme results in significant societal savings and improved health-related quality of life. The direct impact on community-based HPSS services and inpatient admissions was a reduction in costs of 39% and 70% respectively, giving an average 58% reduction in HPSS costs. The associated annual saving for direct HPSS services is £14,835,722.

1.12 It is likely that if clients were not engaged in AMH New Horizons that they would be attending statutory day care centres. Based on attendance of 2 days per week for 52 weeks, the estimated annual saving to day care services are £9,328,494.

1.13 Just over half (56%) of inpatient admissions were for self-harm/attempted suicide, with the majority being in the 3 months prior to engagement in AMH New Horizons. The estimated annual saving due to avoided premature mortality from suicide, based on a 7% fatal repetition of self-harm and a cost of £1.68 million per suicide is £17,310,202.

1.14 Furthermore, it has been evidenced that engagement in the programme also contributes £460,550 to the economy through employment and tax revenue. It is assumed that economic output will increase through time as individuals move from part- to full-time employment, gain promotion or career advancement and more clients obtain employment. Due to the complexity of rules for entitlement to state benefits we have only costed savings to the Exchequer emanating from employment-related reductions in Incapacity Benefit – a modest £1,645. However, it is known that the proportion of respondents on Disability Living Allowance (both care and mobility components) also reduced during the period of the study and it is assumed other benefits will most likely be reduced once an individual obtains work.

1.15 AMH New Horizons has also had a beneficial impact on the physical and psychological health of clients, as evidenced by a statistically significant reduction in reported problems in the dimensions of usual activities ($p=.027$), pain/discomfort ($p=.005$) and anxiety/depression ($p<0.0001$). The 17.2% improvement in health-related quality of life was found to be statistically significant ($p=.001$), as was the 28% increased score in self-reported psychological health ($p<.0001$). The annual monetary savings for the mean gain in health status equivalent to 0.172 of a Quality Adjusted Life Year (QALY)was £10,303,036 across all AMH New Horizons clients.

1.16 As evidenced by the focus groups with carers, the person-centred and strengths-based approaches used in the AMH New Horizons programme help clients to build on their strengths and competencies. Support is also provided with the wider aspects of clients' lives, including when they experience setbacks in their mental health. This approach was perceived by carers as being invaluable in improving the mental health of their relatives.

1.17 The majority of carers lived with the person they cared for full-time. Almost half were the sole carer, with a further third being the main carer. Respite, where available, was provided mainly by family and friends. It is of concern that more than half of carers were unable to take a break from caring; only one-third reported the use of supported activities outside the home.

1.18 Carers reported they often felt their needs were not met by the statutory services. An unanticipated benefit highlighted by carers was the respite they received knowing their relative was safe and being looked after by 'experts' who cared about them and their wellbeing. Indirect benefits of the programme were confirmed by the improvement in carers' health status and wellbeing since their relative joined AMH New Horizons. The annual savings resulting from the mean gain in carer health status equivalent to 0.035 of a QALY was £230,620 (based on 11% of clients having a carer).

1.19 Carers held both AMH New Horizons and the caring from Action Mental Health staff in the highest esteem. The poignant language used in focus groups clearly showed the reliance carers placed on AMH New Horizons and they are now very concerned about the impact of financial cuts on the mental health of their relatives, and on their own health and wellbeing. In light of the increasing financial constraints posed on Health and Personal Social Services it is likely that the gap between need for and provision of services will widen. Thus, the burden placed on informal carers is likely to increase. Informal care in the UK has a value of £21,000 per carer (Buckner & Yeandle 2011). The provision by carers of clients in AMH New Horizons has an estimated value of £4,208,820.

1.20 A number of impacts from the AMH New Horizons programme could not be measured:

- enacting Mental Health Order
- savings in welfare and housing benefits, other than Incapacity Benefit
- savings to third sector organisations such as homeless hostels
- savings to the criminal justice system
- social impact on individual, families and wider society
- reduction in medications due to poor completion of this section of the questionnaire and the time-bound nature of study
- potential reduced use of services by carers
- change in use of services associated with client co-morbidities
- savings from carers' retention of employment

Furthermore, the increase in HPSS costs between 2008/09 and 2010/11 has not been accounted for.

1.21 Although the purpose of this economic evaluation was to assess the financial impact of the AMH New Horizons programme, other benefits of the programme were evidenced. There is a need for further research to determine the full extent of outcomes from engagement in AMH New Horizons:

- research to provide insight into the intangible benefits to clients and carers through engagement with Action Mental Health services
- economic impact on carers through lost opportunities for employment and effect on physical and psychological health

- temporal sequence of mental health problems and unemployment
- tangible gains to the Exchequer from AMH New Horizons programme
- quantitative and qualitative research that explores the outcomes and quality of life benefits enjoyed by 'Leavers' from the AMH New Horizons programme.

Recommendations

1. The statutory sector should invest in targeted interventions and services that make a difference to people with mental health problems. Mainstream, recurrent funding should be available for the AMH New Horizons programme.

2. Enhanced investment in the AMH New Horizons programme should be considered to ensure that individual clients remain in the programme based on assessed need and not based on available funding.

3. Services should be developed to deliver approaches that offer support to people who are no longer entitled to remain in the service but may still need support.

4. The exit strategy from the AMH New Horizons programme should be planned sensitively in conjunction with the client and, on the request of the client, relatives.

5. The 'added value' of purpose, structure, socialisation and inclusion in a community should be developed through the inception of social activities, including evenings and weekends. This would help in the recovery process and also benefit the carer. Resource implications would be associated with this development.

6. Services should be promoted to the general public and other public agencies by Action Mental Health and mental health professionals. The capacity to deal with increased demand for services would obviously be dependent on levels of funding.

7. Action Mental Health should consider establishing a forum for carers of clients where they will benefit from the support of peers in a caring role. Resource implications would be associated with this development.

Annexe

Annual gains through provision of AMH New Horizons programme

Component	Cost without New Horizons £	Cost with New Horizons £	Difference In costs	Annual gain per client	Weekly gain per client
Health and social care					
HPSS community-based services	10,307,458	6,249,645	4,057,813		
HPSS inpatient services	15,300,512	4,522,553	10,777,959		
Substitute for day care services	9,328,494	0	9,328,494		
Value of carers' support	4,208,820	0	4,208,820		
Human costs					
Premature mortality from suicide	20,775,230	3,465,028	17,310,202		
Quality of life (QALY) clients	27,315,025	17,011,989	10,303,036		
Quality of life (QALY) carers	4,803,491	4,572,871	230,620		
Annual gain to HPSS	92,039,030	35,822,085	56,216,944		
Annual payment by Trusts			6,678,279		
Net annual gain to HPSS			**49,538,665**	**27,189**	**523**
Other public sector costs					
Social security costs	72,124	70,479	1,645		
Gains to society from employment					
Income from tax revenue	0	7,528	7,528		
Income from employment	0	453,022	453,022		
Annual gain to society			**50,000,860**	27,443	528

2.0 Introduction and Background

Action Mental Health (AMH) aims to enhance the quality of life and employability of people with mental health needs or a learning disability. It promotes the positive links between health and work to help move people with mental health issues to find and stay in employment. It provides those who lack work experience the opportunity to develop confidence and skills in a work environment through employment programmes, volunteering and supported work environments.

AMH New Horizons provides a range of training and development options:

Training for Employment programmes are designed for clients who wish to undertake vocational qualifications. The duration of these programmes is normally 24 to 30 months following which clients may progress onto the employment programme.

Employment Programmes are for those individuals who wish to participate in employment preparation training and progress on to an employment option or further education or training. The normal duration of these programmes is 12 to 18 months.

Day Support Services are available for clients with enduring mental health conditions who require on-going support. The programme is available to individuals for a period of up to 36 months (AMH 2012).

A “person centred” approach is adopted in assisting and supporting clients to return to work or further education. Action Mental Health recognises that many of their clients may not be ready to pursue employment and, consequently, have a broad range of programmes which develop “Employability Skills”. Unlike occupational or technical skills, employability skills are generic in nature, rather than job specific. They are often the types of things that can be developed or learnt in one situation and then used in other contexts and situations. Critical aspects of personal development including self-confidence and self-esteem are also explored. Recreational and social activities also encourage clients to access opportunities in their community and to develop and maintain friends, interests and social networks.

Aim and objectives

The aim of the evaluation was to assess and quantify, in financial terms, any health and social care and economic savings generated as a result of clients with mental health problems engaging in AMH New Horizons services over time.

Objectives

- To identify the range of health care professionals and/or agencies clients utilise at the point of entry to AMH New Horizons and at intervals thereafter
- To identify the number of contacts and frequency of sessions clients make with each health care professional/agency at entry and at intervals thereafter
- To determine the sessional costs of health care professionals and calculate variance in contacts and costs over time with a view to identifying an overall average saving per week per client over time
- To provide examples of key life events and/or experiences impacting upon the client's symptomatology as reported by clients e.g. reduction in hospitalisation or reduced suicide attempts or self harm
- To identify variances in client dependency on social security benefits through engagement in AMH services and any net savings to the Exchequer
- To explore with the carers of people who attend the AMH New Horizons programme the effects on their self and family and to ascertain an estimate of gained/lost health related quality of life

Thus, for this study the term 'costs' includes both monetary costs to the Health and Personal Social Services (HPSS) and to the wider economy and also the non-monetary costs in terms of psychological wellbeing of individuals with mental health problems and to carers of these individuals.

The terminology in mental health is not used consistently. In this report we use the term 'mental health problem'. In the results section this term refers to clinically diagnosed conditions including depression and anxiety disorders, schizophrenia and bipolar disorders and alcohol misuse.

3.0 Literature Review

3.1 Introduction

The World Health Organisation has stated that “there is no health without mental health” and this mission statement has led to an increasing recognition of the importance of mental health and the need to address it as an integral part of improving overall health and wellbeing (WHO 2004; 2005). This literature review describes the search strategy to obtain the literature, examines mental health and mental health problems, the prevalence and financial cost of mental health problems and the policy context. The final sections look at the association between unemployment and poor mental health and the psychological and financial impact of caring for someone with a mental health problem.

3.2 Search strategy

A rigorous search strategy was employed to obtain the relevant literature to inform the study. The following databases were targeted: PsychINFO, CINAHL and Medline. The databases were searched from January 2007- April 2012, selecting only English language papers using the following terms (all preceded by mental health): problems, disorders, illnesses, recovery, rehabilitation, training, vocational. This, together with a hand trawl, produced the papers and policy documents used for most of the literature review. In relation to carers, the same databases were targeted using the same timeframes and English language papers, using the search terms: carer, relative, mental health problems. This specific search identified no published English literature. We, therefore, believe this study helps to fill an important gap in our understanding of this issue and an important gap in the literature.

3.3 Mental health and mental health problems

The WHO (2010a) defined mental health as not just merely the absence of mental health problems but stated:

> *Mental health is a state of well-being in which an individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community* (WHO 2010a)*.*

In this positive sense, mental health is the foundation for individual wellbeing and the effective functioning of a community. The positive definition of mental health is evident in Northern Ireland (NI) policy with the report *Mental Health Improvement and Well-Being – a Personal, Public & Political Issue* from the Bamford Review highlighting that mental wellbeing underpins all health and wellbeing and that mental health, like physical health, is a resource that must be protected and promoted (DHSSPS 2006a).

Fontaine (2009) explains that mental health problems may begin with a sense of disharmony with aspects of living which are distressing to the individual, family, friends or the community …. the person may feel miserable .. suffering multiple fears .. .. withdrawal from relationships. MIND (2012) articulates that mental health problems can be influenced by a number of elements. These factors include our genes, relationship issues, use of substances, brain chemistry and other social aspects such as poverty, being made redundant or having significant periods out of work.

Barry and Jenkins (2007) categorise the social determinants of mental health into three areas: **Individual** including: an ability to manage feelings, thoughts and life in general, emotional resilience, and an ability to deal with stressful circumstances; **Community** including social supports, having a good sense of belonging, and an experience of citizenship and participation in own community and **Structural** including economic and cultural factors such as adequate housing, employment and education opportunities, access to good transport and a political system that enhances health.

3.4 Prevalence

WHO (2010a) estimated that globally at least 450 million people suffer significant mental health problems which are or could be diagnosed as such, with many more experiencing poor mental health which would fall below clinical diagnosis but which would still present distress and disturbance for the person and their family. It is estimated that 151 million people (33.6%) suffer from depression, 26 million people from schizophrenia and 125 million people are affected by alcohol use disorders. As many as 40 million people suffer from epilepsy and 24 million from Alzheimers and other dementias. Depression is the single leading cause of disability worldwide with just over one-third of those with a mental health problem suffering from depression (WHO 2012). Mathers and Loncar (2006) reported that the WHO has stated that by 2030 the three leading global causes of burden of disease are projected to include HIV/AIDS, unipolar depressive disorders and ischaemic heart disease.

Mental health problems accounted for almost 20% of the burden of disease in the WHO European Region and mental health problems affect one in four people at some time in life in this region (WHO Europe 2012). According to a systematic review of data and statistics from community studies in the European Union (EU) countries Iceland, Norway and Switzerland, 27% of the adult population (aged 18-65 years) had experienced at least one of a series of mental disorders in the past year. This included problems arising from substance use, psychoses, depression, anxiety, and eating disorders. These figures do not capture the complexity of the problems many people face; 32% of those affected had one additional mental disorder, while 18% had two and 14% had three or more additional disorders. These figures represent an enormous human toll of ill health, with an estimated 83 million people being affected. The figures are likely to underestimate the scale of the problem as only a limited number of disorders were included and the review did not include data on those aged over 65 years, a group that is at particular risk of mental health problems (WHO Europe 2012). The rate of mental health problems for women (33.2 per 100,000) was significantly higher than for men (21.7 per 100,000), except for substance use disorders (men 5.6%, women 1.3%), and psychotic disorders (almost identical estimates) (WHO Europe 2012). In the UK mental illness accounts for nearly 40% of morbidity, compared with, for example, 2% due to diabetes. For all ages up to 65 years, mental illness accounts for nearly as much morbidity as all physical illnesses put together and has the same effect on life-expectancy as smoking, and more than obesity (London School of Economics and Political Science 2012).

In 2005 across all reporting OECD countries, the average hospital length of stay for depression and other mood disorders was 21 days, for dementia 33 days and for schizophrenia and other delusional disorders 38 days (OECD 2008).

NI has come through significant civil conflict and has experienced high levels of socioeconomic deprivation which may help, in part at least, to explain the estimated 25% higher prevalence of mental health problems compared to England (McWhirter 2002 cited in Centre for Social Justice 2010). In 2007 in England 17.6% of the population had one common mental disorder with 9% of these presenting with mixed anxiety and depressive disorder (NHS Confederation 2009). In NI it was estimated that one in five adults will experience mental health problems such as anxiety or depression (CMO 2010; DHSSPS 2011a) giving a 14% higher prevalence than in England. Thus, it would appear the differential in prevalence between Northern Ireland and England is decreasing. Findings from the *Health Survey Northern Ireland* (DHSSPS 2011a) showed proportions were higher for females (23%) than for males (17%). A study examining mental health associated service use in Ireland (Doherty and Moran 2009) found that respondents in Northern Ireland were 1.7 times more likely to report less than good mental health than those in the Republic of Ireland and were 1.5 times more likely to report mental health problems in the previous year. It was estimated that at least 45,000 children and young people aged 5-15 years had a moderate to severe mental health problem requiring mental health services (DHSSPS 2008a).

Around 844,000 people die by suicide every year (WHO 2010b). Nine of the ten countries with the highest rates of suicide in the world are in the European Region (WHO Europe 2012). In 2010, there were 313 deaths registered in NI as suicide, equating to a suicide rate of 17.4 per 100,000 (NISRA 2012a) which is considerably higher than the rate of 9 per 100,000 in the UK (ONS 2011). Over the last ten years the rate for males has been 3-5 fold higher than that for females. Suicide was most prevalent among 15-34 year olds (25.5 per 100,000) and 35-54 year olds (26.8 per 100,000) (NISRA 2012a). Poor mental health has been associated with an increased risk of suicide with studies from both developed and developing countries revealing an overall prevalence of mental health problems of 80-100% in cases of completed suicide (WHO 2000) and 90% of the 162 suicides in Northern Ireland in 2002 were assumed to have been associated with mental health problems, particularly depression (Sainsbury Centre for Mental Health and NIAMH 2004). Recurrent self-harm is a predictor for suicide (Gunnell et al. 2004; Yates et al. 2008). It is estimated that, on average, 7% of people who have attempted suicide will go on to die by suicide at a later date (Owens et al. 2002).

3.5 The economic burden of mental health problems

In 2002/03 spending per head on health and social care services in NI was 6.5% higher than in England. However, spending on mental health was 15.6% lower, despite the 25% higher prevalence of mental health problems in Northern Ireland (Sainsbury Centre for Mental Health and NIAMH 2004). This differential is still apparent as reported in *Rapid Review of Northern Ireland Health and Social Care Funding Needs and the Productivity Challenge: 2011/2012-2014/15* by Professor Appleby (2011) on behalf of the DHSSPS. Appleby reported that while mental health needs in NI are estimated to require nearly 44% higher per capita funding than in England, actual spending (for a programme that consumes just 7% of total spend) is possibly between 10% - 30% lower than per capita spending on mental health in England. This underfunding has also been recognised in *Transforming Your Care A Review of Health and Social Care in Northern Ireland* which notes that there is up to 30% less investment in Mental Health, Learning Disability and Children and Family Services in NI compared with other parts of the UK because the NI model over consumes resources in hospital provision (DHSSPS 2011b).

Friedli and Parsonage (2007) reported that in Northern Ireland spending on mental health problems during 2002/03 was estimated at £2,852 million; equivalent to 11.7% of Northern Ireland's GDP in that financial year and equating to £1,680 per head of population (Sainsbury Centre for Mental Health and NIAMH 2004 cited in DHSSPS 2008a). Thirteen per cent (£372 million) of the estimated £2.85 million was related to health and social care in the form of statutory services and informal care, a further 27.7% (£789 million) was related to output losses due to the inability to work, with the largest percentage of 59.3% (£1,691 million) being related to the human costs, particularly the impact on the quality of life of those individuals suffering from mental health problems (Sainsbury Centre for Mental Health and NIAMH, 2004).

During 2006/07 the spending on mental health services in the UK was calculated to be over £110 billion with the NI portion of this figure estimated to be around £3.5 billion, reflecting a prevalence rate for mental health problems which is 20-25% higher than in the rest of the UK (Friedli and Parsonage 2007). Edwin Poots, Health Minister for NI, reported in the Northern Ireland Assembly that in 2010/11 8% of the total health and social care budget (£228 million) was spent on mental health services (Northern Ireland Assembly 2012). This is a decrease from the spend during 2006/07 but is most likely related to the overall budget cuts within the HPSS.

In NI the total annual estimated cost of suicide is £262 million, or £1.68 million per suicide (DHSSPS 2010). These costs include: direct costs such as the post mortem and funeral costs; the indirect costs such as the value of the potential earnings lost; and the intangible costs which estimate the human costs such as suffering, grief and loss of non-market outputs such as voluntary work, housework etc. Self-harm has a significant economic impact and contributed to 1.46% of all hospital admissions and £6.6 million in hospital costs, lost earnings and other lost output (DHSSPS 2006b).

3.6 Employment and unemployment

Globally the issue and importance of employment for people with or without mental health problems has been highlighted. One of the most recognised and arguably important documents ever written is the United Nations (UN) Universal Declaration of Human Rights (UN 1948). This document does not view employment as a privilege but as a basic human right. The right to work is enshrined in Article 23 of the Declaration and states:

> *Everyone has the right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment* (UN 1948).

Employment has been shown to generally have positive benefits on a person’s mental health. Employment provides people with meaning and purpose in life, a means of structuring and occupying time, status and identity in society, social inclusion, income and resources to stay out of poverty and social contacts, social networks and social support (RCPsych 2002).

There is a strong relationship between unemployment and mental health (Mclean et al. 2005) and it has been shown that unemployment and economic inactivity increase the risk of mental health problems developing in previously healthy individuals (DHSSPS 2003a; RCPsych 2008). Unemployed people are almost twice as likely to show signs of a possible mental health problem (30%) as those in employment (16%) (NISRA 2002 cited in DHSSPS 2004).

People with mental health problems do want to work, given the appropriate opportunity; unfortunately they often find gaining employment very difficult. The

Social Care Institute for Excellence (SCIE) highlighted that people with mental health problems are more likely to be unemployed than any other group with disability in the UK (SCIE 2011). In Great Britain in 2004 overall rates of employment for people considered disabled by a long-term mental health illness were 21%, compared to 47% for all people declaring a disability and 74% for the overall working age population (Social Exclusion Task Force 2006 cited in RCPsych 2008). Burns et al. (2007) reported that in the UK up to 95% of people with a diagnosis of severe mental health problems can be unemployed. In NI nearly 50,000 people were not working on the grounds of mental and behavioural disorders (Centre for Social Justice 2010). This is such a waste of talent, an unacceptable cost to the Exchequer and a loss of valuable tax income to the country.

Waddell and Burton (2006) reported that up to 43% of days lost from work were due to mental health problems such as depression and anxiety. In 2006 in NI 2.9% of the total adult population were in receipt of Disability Living Allowance (DLA) for mental health reasons; this was three times the comparable figure for Great Britain (0.9%) (ARK 2007). In NI mental health problems were the most common reason for claiming illness-related out-of-work benefits, including Disability Living Allowance (42,000 people in 2009) and Incapacity Benefit (45,000 people in 2009) (Centre for Social Justice 2010). Eighty-six per cent remained on the benefits for more than three months compared to 76% for all other claimants. The longer a person remains out of the labour market the more difficult it is for him or her to return to employment (DWP and DoH 2009).

A recent review of the health of Britain's working-age population carried out by Dame Carol Black estimated that over £100 billion is lost to the economy through ill-health associated sickness absence and unemployment. It is estimated that one-third (£30-40 billion) of these costs can be attributed to mental ill-health, in lost production and NHS costs (DWP and DoH 2009). On a number of indicators Northern Ireland is relatively more deprived compared with the UK. The Labour Force Survey data for October to December 2011 reported that, while unemployment rates in NI (7.2%) were lower than in the UK (8.4%), a higher proportion of economically inactive persons aged 16-64 years in NI identified sickness or disability (32.1%) as their main reason for not wanting work compared to the UK (21.5%) (NISRA 2012b). Given the evidenced relationship between unemployment and poor mental health, as more people find themselves out of work there is likely to be an associated correlation with more demand for mental health services (NHS Confederation 2009).

In Northern Ireland socioeconomic inequalities in mental health problems were identified, with people who were unemployed being almost twice as likely to show signs of a possible mental health problem as those in employment. Women in the lowest socioeconomic group (unskilled) were 60% more likely to experience some form of mental health problem than those in the highest socioeconomic group (professional) (DHSSPS 2002a).

The effects of unemployment can be fatal. In the UK it was found that unemployment caused by redundancy can double mortality rates for men (Dorling, 2009). A number of epidemiological studies have reported that unemployment is associated with higher rates of suicide, and gaining employment is protective of suicide (Blakely et al. 2003; Platt and Hawton 2000; Mclean et al. 2005). Bartley (1994) has suggested that the link between unemployment and suicide mortality is related to financial strain, stress related to job loss and an accumulation of unemployed experience among certain groups. The report *Safety First National Confidential Inquiry into Suicide and Homicide by People with Mental Illness* reported that, in relation to suicide by people in NI with a mental illness, 60% were either unemployed or long-term sick (DHSSPS 2003b). The National Suicide Research Foundation (NSRF) (2010) has indicated that the increased rate of self-harm among young people may be attributable to the current recession in the Republic of Ireland.

In his Annual Report, Northern Ireland's Chief Medical Officer (CMO 2010) clearly identified unemployment as a risk factor for poor mental health and employment as a protective factor for good mental health. This was further reinforced within the document, *Investing for Health Strategic Review* (DHSSPS 2010) which highlighted the mental health problems people experience due to being unemployed.

3.7 Policy context

Mental Health and Development: Targeting People with Mental Health Conditions as a Vulnerable Group highlights the global issue that mental health problems present and calls on governments to develop policy that addresses factors that contribute to mental health problems to prevent and intervene earlier. The aim is to stamp out stigma and discrimination and to integrate people with mental health problems, thus preventing exclusion (WHO 2010b).

In 2011 the UK strategy; *No Health Without Mental Health: A Cross-Governmental Mental Health Outcomes Strategy For People of All Ages* (DoH 2011) set out six objectives for improving and maintaining the mental health and wellbeing of the UK population; included in it are objectives related to economic and social inclusion. The second objective is:

> *More people who develop mental health problems will have a good quality of life - greater ability to manage their lives, stronger social relationships, a greater sense of purpose, the skills they require for living and working, improved chances in education, better employment rates and a suitable stable place to live (*DoH 2011).

The issue of employment for people with mental health problems has drawn special attention in government policy. One such joint initiative between the Department of Work and Pensions and the Department of Health (2009) is *Working Our Way to*

Better Mental Health: a Framework for Action. This Great Britain-wide strategy clearly shows the pressing need to assist people with mental health problems to maintain or regain work as central to effective recovery from their mental health problems. One of the dual approaches advocated for action is to:

> *Deliver significantly better employment results for people with mental heath conditions, supporting them into work, helping them to stay in work and assisting them to return to work more quickly after sickness absence* (DWP and DoH 2009).

Investing for Health (DHSSPS 2002a) identified mental health as a priority with a target to “reduce the proportion of people with a potential psychiatric disorder (as measured by the GHQ12 score) by a tenth by 2010”. The integrated approach, addressing the wider determinants of mental health, was outlined in the subsequent strategy *Promoting Mental Health - Strategy and Action Plan 2003-2008 (*DHSSPS 2003a). This recognised that mental health problems are a major public health issue, particularly depression which, while not the most severe form of mental health problem, is a chronic disease and the most prevalent. While this policy is now spent it set policy in NI that directed local mental health services in relation to promoting mental health, protecting and assisting individuals with mental health problems, as well as addressing some of the issues influencing mental health problems, such as poverty and unemployment. One of the levels the Action Plan recommended working on was reducing structural barriers to mental health through initiatives which, among others, included meaningful employment for those who are vulnerable.

The subsequent *Bamford Review of Mental Health & Learning Disability (NI)* comprised of a series of reports covering issues from legislation to care, treatment and carers. *A Strategic Framework for Adult Mental Health Services* (DHSSPS 2005) included a principle “promotion of independence, self-esteem, social interaction and social inclusion through choice of services, facilitation of self management, opportunities for employment and social activities”, with the issues of Education, Training and Occupation being viewed as important both for vocational outcomes and personal development. A key section *of Promoting the Social Inclusion of People with A Mental Health or Learning Disability* relates to employment and assisting people with mental health issues to keep employment or assist them back into employment (DHSSPS 2007). A new *Mental Health and Wellbeing Promotion Strategy* is due to be published in 2012. This will focus on interventions to promote positive mental health at various stages of the life course and in various settings such as schools and workplaces. *Transforming Your Care A Review of Health and Social Care in Northern Ireland* (DHSSPS 2011b) highlights a continued focus on promoting mental health and wellbeing with a particular emphasis on reducing the rates of suicide among young men.

A diverse range of mental health services is necessary to provide a comprehensive service for the population. The Sainsbury Centre for Mental Health, cited in Donaldson and Scally (2009) has categorised these into: community support; 24-hour, residential provision and housing; day-care and daytime activities and; financial support. For day-care and daytime activities they note day centres, day hospitals and drop-in centres and employment, supported employment and employment rehabilitation places.

The recent *Transforming Your Care A Review of Health and Social Care in Northern Ireland* (DHSSPS 2011b) recommends that the voluntary and community sectors play a crucial role in providing the diverse range of support that may be needed for people with mental health problems. The Review recommends greater involvement of these organisations in planning provision for local populations.

3.8 Addressing the problem of unemployment for people with a mental health problem

The National Mental Health Development Unit (2012) document *The Costs of Mental Ill Health* clearly showed that helping people to return to work after a period of sick leave for mental health reasons results in reduced welfare claims and reduced use of health and social services, including mental health services. Receiving employment support, alongside treatment for common mental health problems such as depression and anxiety disorders, can help people to stay in or return to work. Mental health service costs can be reduced by half when people with severe mental health problems are supported into mainstream employment. People with severe and long-term mental health problems who are given intensive support to return to the workplace reported fewer and shorter subsequent hospital stays than people receiving usual mental health services.

For people with a mental health problem, appropriate work has been shown to improve health outcomes and decrease the chances of relapse (Waddell & Burton 2006; RCPsych 2002 cited in Perkins et al. 2009). Knapp et al. (2007 cited in Vieth 2009) proposed that mental health policy makers now face a number of key questions and challenges promoting quality of life, for example, through emphasising and encouraging access to employment and other valued social roles. Perkins et al. (2009) proposed that if a person wants to work, the initial focus should be on real work. If this is not possible alternatives such as sheltered settings, training or volunteering may be appropriate. Where alternatives are pursued, the focus should continue to be on helping the individual move towards open employment as their skills and confidence develop.

Burns et al. (2007) carried out a Europe-wide study (n=312) looking into the benefits of an Individual Placement and Support Programme (IPS) for people who experienced severe mental health problems, compared to standard vocational training. They found the IPS to be very effective in assisting people back into work and a reduced re-admission rate to mental health hospitals, hence the programme also improved their mental health. Rinaldi et al. (2011) conducted a smaller trial on people with longer-term mental health problems using the IPS approach in the UK and again found significant benefits in relation to employment for those taking part.

3.9 Carers

The DoH (2012) state that a carer provides unpaid support to family or friends who could not manage without this help, whether they are caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems. The concept of wellbeing depends on absolute things such as health, relationships, employment and income. Caring for a relative with mental health problems has a huge impact on the quality of life of carers and family members (WHO, 2003). Hence the wellbeing of carers is closely linked to the wellbeing of those individuals they care for.

The *Health Survey Northern Ireland* (DHSSPS 2011a) reported that 14% of respondents indicated that they cared for someone else on an informal basis. Carers UK reported there are approximately 207,000 carers in Northern Ireland, with approximately 30,000 of these caring for more than one person. By 2037 the number of carers in NI could have increased to 400,000 (Carers UK 2012a).

The true value of the care and support provided by carers cannot be quantified, as caring is also an expression of love, respect, duty and affection for another person. Some carers have no choice to care because of the paucity of care services (Buckner and Yeandle 2007). It is important to recognise the unpaid contribution of carers for those with a mental health problem. Conventionally in economic evaluations, resources are valued at their opportunity cost i.e. their next best alternative use (Drummond et al. 2005 cited in Francis and McDaid 2009). Drummond et al. (2005 cited in Francis and McDaid 2009) also reported that informal care is far from being a costless resource. In addition to the emotional and physical impacts it can have, coupled with any out-of-pocket costs for additional fuel, food or cleaning for example, there are the opportunity costs of time spent caring that could otherwise have been spent engaged in other activities. These include paid employment, voluntary work, education and training, household production, leisure activities or even sleeping. A study by The Equal Opportunities Commission (2005) found that one in five carers give up work to care. This has a significant economic impact in terms of taxes lost, increased uptake of benefits and potential health costs for the carer.

Data from the 2001 census (NISRA 2003) indicated there were an estimated 185,000 carers in Northern Ireland. Based on data collected in 1997, *The Informal Carers Report* (DHSSPS 2001) reported that 11% of carers were looking after someone with a mental health difficulty. Frequently the Compton Review

Transforming Your Care A Review of Health and Social Care in Northern Ireland (DHSSPS 2011b) heard from carers about the centrality of their role and their sense of being taken for granted. These dependants were more likely to be living in the same household as the carer than in another household (16% and 7% respectively). A further 6% of carers were looking after someone with a learning difficulty/mental disability and again the dependant was more likely to be living in the same household (10% v 2%). Carers looking after someone who lived with them were more likely to show signs of the possible presence of psychiatric morbidity (34%) than those caring for someone who lived elsewhere (26%). Those carers looking after someone for more than 20 hours per week were also more likely to show signs of the possible presence of psychiatric morbidity (37%) than those looking after someone for less than 20 hours per week (25%). Singleton et al. (2002) reported that caring had an effect on relationships with friends, social life or leisure activities (33%) and on relationships with spouse/partner or other relatives (34%). Conversely, one-quarter of respondents (25%) felt that their relationships with their spouse/partner or children had been strengthened by their experience of providing care. WHO (2003) reported that family members of people with a mental health problem were also exposed to the stigma and discrimination associated with mental health problems. Often friends, relatives, neighbours and the community may reject the person and family and this can increase the family's sense of isolation, resulting in restricted social activities, and the denial of equal participation in normal social networks.

A very recent report by Carers Northern Ireland and seven other Carer Week charities reported that 81% of carers have seen a negative impact on their physical health as a result of caring. Nine out of ten said caring was taking a toll on their mental health and over one-third had suffered a physical injury as a result of caring. Three-quarters of carers in Northern Ireland blamed their poor health on a lack of practical support (Carers UK 2012b). The effects of caring on physical and emotional health, either directly because of the strains of their caring role or because their caring role restricts their ability to access health care, are also reported in *Transforming Your Care A Review of Health and Social Care in Northern Ireland* (DHSSPS 2011b). The Review cites statistics from Carers UK that carers are twice as likely to be permanently sick or disabled than the average person and research by the Princess Royal Trust for Carers (2011) that 69% of carers reported a negative impact on their physical health from their caring role, and the same percentage reported that caring had a detrimental effect on their mental or emotional health.

Based on the 2001 Census figures (185,000 carers) and the replacement cost of providing home care to an adult, it was estimated that a modest economic value of the contribution made by carers in NI in 2002 was £2.17 billion. The updated 2011 estimated monetary value attached to the informal care provided by carers in NI is £4,389.9 million, an increase of 41% since 2007. The distribution, and the percentage change since 2007, across the five Health and Social Care Trusts were Belfast £913.5 million (27%), Northern £1,033.9 million (43%), South Eastern £848.2 million (42%), Southern £856.1 million (51%) and Western £738.2 million (45%) (Buckner and Yeandle 2011). If 11% of carers in NI are looking after someone with a mental health problem (DHSSPS 2001) this equates to an estimated £4.83 million for informal care for people with mental health problems.

Buckner and Yeandle (2011) estimated that if all caring responsibilities had to be met by the state the additional costs to the public purse would be, on average, £21,000 per carer. In the UK it is estimated that by 2037 the number of carers is set to increase by around 65% or an extra 3.4m carers (Carers UK 2001). It is estimated that the number of carers in NI will increase by 93% from 207,000 to 400,000 by 2037 (Carers UK 2012b). This would be an additional cost to the Exchequer of £4,053 million.

Given the huge savings informal carers contribute to the HPSS in NI it is vital that they are properly supported so the burden of caring does not adversely affect their own health and wellbeing. The NI economy simply could not afford to replace the care they provide for people with mental health problems. Furthermore, the potential resultant increased costs to HPSS services for the carers themselves would place an extra burden on the already stretched HPSS staff and budgets.

Research has shown that even quite a small investment in support of carers – providing them with good quality information, offering breaks and sitting services, providing practical support and training to enable them to care safely – can make a huge difference to their everyday lives (Buckner and Yeandle 2007). In NI the Department for Social Development has acknowledged carers' needs in the study, jointly undertaken with DHSSPS, *Review of the Support Provision for Carers* (DSD and DHSSPS 2009). DHSSPS has provided a strategic direction for the provision of support services for carers through its strategy documents *Valuing Carers* (2002b), and *Caring for Carers* (2006c). Following a number of recommendations made by the *Bamford Review of Mental Health & Learning Disability*, a draft *Strategy for the Development of Psychological Therapy Services* was issued for consultation (DHSSPS 2008b). The strategy acknowledges that carers need psychological support, to maintain and improve their mental health and to assist them to look after their loved ones with long-term physical, mental health and learning disabilities. The valuable role of informal carers and their needs is also recognised in *Delivering the Bamford Vision* (DHSSPS 2008a).

3.10 Conclusions

Upon reviewing the literature it is evident that mental health is a complex phenomena made up of many aspects including biological, psychological, spiritual and social issues, including employment (WHO 2010a; Barry and Jenkins 2007). Globally, nationally and regionally mental health problems significantly affect large numbers of individuals (WHO 2010a; NHS Confederation 2009; DHSSPS 2011a). The resultant financial costs and poor health and psychological wellbeing are of concern for Governments, communities, families and individuals (WHO 2010b; DoH

2011; DHSSPS 2005; 2007). The need to change the shift in care provision from the hospital to community setting with an objective being to shift expenditure to a ratio of 60% community and 40% hospital has not yet been achieved but is necessary to provide greater productivity and value for money (DHSSPS 2011b).

There is an evidenced association between unemployment and mental health problems, with those with mental health problems being much less likely to gain employment and all too often to lose employment and find it difficult to get back into the workplace because of their mental health problem (Mclean et al. 2005). However, the literature shows that, with appropriate support, people with mental health problems can return successfully to the workplace. Furthermore, support to move towards employment reduces the use of health and social care services and costs to the Exchequer as well as, importantly, improving the mental health of individuals (National Mental Health Development Unit 2012). The effects of mental health problems are felt acutely by carers of the person directly affected; often it causes their health and wellbeing to suffer (Singleton et al. 2002; DHSSPS 2011a; Carers UK 2012b). These carers provide an invaluable service to society and need to be supported to protect their own health and wellbeing (DHSSPS 2008b).

4.0 Methods

Data from clients were collected using questionnaires and data from carers were collected through focus groups. The data from clients and carers were totally independent and it was not the intention to link the information in any way.

4.1 Client survey

4.1.1 Design of client survey

A repeated cross-sectional study design was employed with data collected longitudinally from the same cohort of clients at three Points in time; baseline data at 3 months prior to entry to the AMH New Horizons programme (Point 1) and two further points (Points 2 and 3).

4.1.2 Sample for client survey

In choosing the sample it was important to achieve an adequate sample size but also to balance this requirement with the collection of robust data and the need to allow sufficient time to assess service use subsequent to engagement in the AMH New Horizons programme. There is always the potential for retrospective self-reported data to suffer from recall bias i.e. memory recall. This potential bias may be increased with those with a mental health problem due to the effects of the condition itself and/or the effects of medication. The inclusion criteria were thus set as clients who had been in the AMH New Horizons programme for up to 12 months i.e. 'New Starts'. At each time Point a 3-month retrospective period was used, thus reducing potential for poor recall. All clients who had enrolled at one of the eight Action Mental Health services providing the AMH New Horizons programme since 1st May 2010 were invited to participate in the study (n=469).

A power calculation based on a population of 469, an estimated 10% reduction in contacts with services and a margin of error of 5.22% elicited a required sample size of 107 (at a CI of 95%).

4.1.3 Consent procedures for client survey

Clients meeting the inclusion criteria were identified by staff in the Units providing the AMH New Horizons programme. Letters of Invitation, Participant Information Sheets and Consent Forms (Appendix 1) were given, by AMH staff, to this cohort of clients prior to the date set for data collection by the researchers. At the time of the first data collection (Point 1) potential participants had the purpose of the study and what it involved verbally explained to them by the researchers before giving written consent. Clients were provided with a copy of the signed consent form. While ongoing written consent was not obtained all clients who participated at Point 1 were advised that participation in the study at Points 2 and 3 was entirely voluntary.

4.1.4 Data collection for client survey

The Client Service Receipt Inventory (CSRI) and EQ-5D instruments (Appendix 2) were self-completed by the clients. The CSRI (Beecham and Knapp 1999), a validated instrument developed by staff in the Centre for the Economics of Mental Health and the Personal Social Services Research Unit for people with mental health problems, was used to collect retrospective information on the frequency and intensity of use of a range of services. Non-service implications of mental health problems were also captured through information on the receipt of state benefits. The CSRI has been shown to have a strong correlation with medical records (r=0.93). On contacting the authors of the instrument it was agreed that, of the numerous adaptations of the instrument, *The Client Service Receipt Inventory: Endeavour Study* version was most suitable for this study. The researchers adapted this to the local Northern Ireland setting. The adapted version also incorporated relevant key life experiences from the Life Experiences Survey (Sarason et al. 1978) that could potentially impact upon the person's mental health and/or affect contact with services. The instrument was self-completed by the clients, with the researchers or a member of AMH staff being available to offer assistance if required. This method of completion had been confirmed as suitable by the authors of the instrument. The CSRI was completed for the three time Points during the study.

The impact of mental health problems on health and social wellbeing was measured at the same three time Points during the study using the EQ-5D from the EuroQol Group (2009). Approval was received from the copyright holders to use the instrument. The EQ-5D is a standardised, non-disease-specific instrument for describing and valuing health and the most commonly used questionnaire in health economic studies. It measures health status across five dimensions – mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each dimension has three levels 'no problems', 'some problems' and 'extreme problems'. This results in a possible 243 health states, with the addition of 'unconscious' and 'dead' bringing the total to 245. The EQ-5D was coded to provide an index ranging from 0-1 which provided an estimate of gained/lost health-related quality of life (QALY).

The EQ-5D also reports a measurement of health status on the day of completion using a Visual Analogue Scale (VAS) where a score of 100 indicates 'the best imaginable state' and a score of 0 indicates 'the worst imaginable state'. As the EQ VAS is anchored on 100 (best health) and 0 (worst health) it cannot be used in QALY calculations. The EQ-5D was self-completed by the clients for the three time Points with the researchers or a member of AMH staff being available to offer assistance if required.

4.1.5 Pilot study for client survey

To test the instruments and the administrative process a small pilot study (n=6) was undertaken with clients attending one of the AMH New Horizons Units. Following the pilot study, minor amendments were made to the Letter of Invitation, Participant Information Sheet and Consent Form.

4.1.6 Statistical analysis for client survey

All statistical analyses were undertaken using SPSS Version 17.0. Descriptive statistics in the form of frequency counts and central tendency are presented. Inferential statistical tests were used to determine differences between service use and receipt of benefits between the three time Points.

As we were looking at variables measured on three occasions and preferred not to make any assumptions on the distribution of the data repeated-measures design non-parametric tests were used. The Wilcoxon Signed Rank Test was the statistical test employed to examine differences between Point 1 & Point 2, Point 2 & Point 3 and Point 1 & Point 3. This is the non-parametric alternative to the paired t-test. Differences between pairs of 'scores' at different time Points are calculated and then ranked with the sign of the difference (negative or positive) being assigned to the rank. The test statistic is given by z and the significance level was set at $p \leq 0.05$ (Asymp. 2-tailed). It should be noted that smaller sample sizes are less likely to pick up statistically significant differences and clinical differences are important.

The Freidman ANOVA for repeated measures test was used to examine differences across Points 1, 2 & 3. This is the non-parametric alternative to the one-way repeated measures ANOVA and is an extension of the Wilcoxon test for two conditions. For each of the clients with data at all 3 time Points, the variables are ranked and the sum of ranks over the respondents are calculated. The test statistic is chi-square and the significance level was set at $p \leq 0.05$. It should be noted that smaller sample sizes are less likely to pick up statistically significant differences and clinical differences are important.

4.2 Economic appraisal

4.2.1 Cost measurement

Service use and receipt of benefits and all associated costs were calculated based on data collected using the CSRI.

A requirement of economic evaluation is that all outcomes can be quantified in some way. Service utilisation was costed using NI Annual Trust Financial Returns 2008/09 for mental health services and, where these were not available, Personal Social Services Research Unit (PSSRU) 2008/09 costs for England were used. General Medical Services 2009/10 costs were used for GP consultations. All are full costs i.e. fixed and variable costs.

The costs of services were estimated by multiplying the number of contacts by standard unit costs. To ensure reported service utilisation was in the same unit of measurement as service costs, intensity of contacts i.e. average duration of visits was used for services where unit costs were provided per hour of client contact time.

The costs of the AMH New Horizons programme were also based on full costs i.e. fixed and variable costs. The AMH New Horizons costs are for 2011/12, however, there was very little change between 2008/09 and 2011/12 and the effect of non-adjustment is an underestimation in the estimated savings.

Costs of informal care provided by relatives were based on the valuation of £21,000 for UK carers (Buckner and Yeandle 2011).

Savings to the Exchequer in the form of reduced illness-related benefits were based on the weekly rate of the relevant state benefits.

The monetary valuation for client and carer QALYs is based on the change in mean health-related quality of life scores elicited from the EQ-5D and the figure of £38,000 for a QALY (Friedli and Parsonage 2009).

4.3 Survey of carers

4.3.1 Sample for carers survey

To assess the indirect benefits of the AMH New Horizons programme four focus groups were conducted with carers (n=19) of clients who had been in the AMH New Horizons programme 6-12 months. The sample was originally chosen to be representative of carers across Northern Ireland i.e. urban and rural areas. However, communication with the managers of the Units based in urban areas revealed two aspects of their client group that precluded using these Units (a) confidentiality was perceived to be an issue as clients may not have told family they were attending the programme (b) some clients were resident in other forms of accommodation such as homeless hostels. The final sample for the focus groups remained representative of urban and rural areas.

4.3.2 Recruitment and consent procedures for carers

AMH staff in the four Units distributed a Letter of Invitation, Carer Participant Information Sheet and Carer Consent form (Appendix 3) to carers of all clients who had been in the AMH New Horizons programme for 6-12 months. Documents were given to clients at their normal training session. AMH staff arranged for those who had agreed to participate in focus groups to be available on AMH premises at a time prearranged with the researchers. On the day of the focus groups the researchers explained the purpose of the study to the carers and informed written consent was obtained prior to the start of the focus group. Carers were given a copy of the signed consent form.

4.3.3 Data collection with carers

A focus group has been defined as a carefully planned discussion designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment (Krueger 1998). King and Horrocks (2010) inform that focus groups can be very formal to informal depending on the project. As talking to carers of people who have experienced significant mental health problems may be a sensitive topic it was decided to have well conducted focus groups but run in an informal relaxed manner. It was hoped by putting people at ease they would open up and discuss the area under investigation freely and without any perceived concerns. Based on a literature review, a semi-structured interview schedule was developed by the researchers in consultation with the Steering Group. This comprised of six questions with enough flexibility to allow a free flow of ideas and experiences, with additional probes to be used as appropriate (Appendix 4). Focus groups took place on AMH premises and lasted approximately one hour. Refreshments were provided. All focus groups were facilitated by both researchers; (DMcL) led the discussion while (KC) recorded a written note of the discussion and non-verbal observations. The researchers had a debriefing session after each focus group and the administrative process and/or interview schedule were adapted as appropriate following each group.

At the end of the focus group participants were invited to complete a short questionnaire about the person they care for (Appendix 4). This has been adapted from the Carers' Well-Being and Support Measure (RETHINK 2009). Two copies of the EQ-5D instrument were also completed – the first related to the 3-month period prior to their relative joining the AMH New Horizons programme and the second to the day of the focus group.

4.3.4 Pilot study for carer survey

To test the instruments and the administrative process a small pilot study (n=2) was undertaken with carers of clients attending one of the AMH New Horizons Units. Following the pilot study minor amendments were made to the Carer Letter of Invitation, Carer Participant Information Sheet and Carer Consent Form.

4.3.5 Data analysis for carer survey

The focus groups were audio recorded, with the consent of the participants. The tapes from the focus groups were listened to and listened to again; any new issues were identified and incorporated into the next focus group. The tapes were then transcribed verbatim, with the transcripts being read and reread to gain understanding from the raw data. Newell and Burnard's (2006) framework for qualitative data analysis was used to guide the thematic content analyses. This approach has six stages:

1. Take memos after each interview (focus group)
2. Read transcripts and make notes of general themes
3. Repeat reading and generating open coding headings to describe all aspects of data
4. Reduce the codes under higher order headings
5. Return to the data with higher order codes
6. Collate the organised data for reporting

Polit and Beck (2012) report the minimum standard in qualitative data analysis is the inclusion of another person to independently analyse the material. This standard was adhered to with both researchers independently undertaking the six stages and then meeting and comparing and contrasting their findings. There was considerable agreement; the very few issues of divergence were resolved via discussion.

Credibility of the findings was ensured through: the researchers emphasising their independent status from Action Mental Health; debriefing after each focus group and; undertaking a small pilot study (n=2) in one of the AMH Units to test the interview schedule and the recruitment process for the main study.

4.4 Ethical considerations

The study received ethical approval from the University of Ulster's School of Nursing Research Governance Filter Committee and from the University of Ulster's Research Ethics Committee. Action Mental Health will make a copy of the Executive Summary available to staff and clients in the Units and on their website. A summary of the findings from focus groups with carers will be provided to those carers who expressed an interest in receiving these and provided contact details.

5.0 Survey of clients

This section reports on the survey undertaken with clients with mental health problems who were 'New Starts' in the AMH New Horizons programme. Data were collected in respect of the 3-month period prior to engagement in the AMH New Horizons programme (Point 1) and at two subsequent 3-month intervals (Points 2 & 3). The primary aim of the survey was to ascertain any changes in use of services and receipt of benefits since joining the programme. Changes in clients' wellbeing were also examined as were key life experiences which may have had an effect on wellbeing and/or use of services. All findings are reported as the percentage of respondents who answered the question.

Response rates were 25% (116/469) at Point 1, 22% (104/469) at Point 2 and 16% (74/469) at Point 3. The 35% attrition between Points 1 and 3 is partly explained by 'Leavers' (13/116, 11%) and absence from the Unit (10/116, 9%). Of the 116 clients who participated in the survey at Point 1, 68 also participated at Points 2 & 3 (Table 1).

Table 1 Participation at Points 1, 2 & 3

Time point	No.	%
Points 1, 2 & 3	68	58.6
Points 1 & 2	33	28.4
Points 1 & 3	3	2.6
Point 1 only	10	8.6
Point 2 only	1	0.9
Point 3 only	1	0.9
Total	116	100

Data were, on average, across a 14-month period, with a range of 7–16 months, median value 11 months.

5.1 Respondent characteristics

Table 2 shows that respondents were relatively evenly split by gender at all three time Points with the gender split being representative of the total number of 'New Starts' in the AMH New Horizons programme 1st May 2010 to 31st July 2011. Respondents were aged 21 to 74 years with a mean age of 45 years. The age group of respondents was generally representative of all New Starts in the AMH New Horizons programme, with the largest proportion being 25-49 years (60.2%). Older clients were slightly overrepresented in the study (3.5% v 1.1%) and younger clients were underrepresented with 3.5% of respondents aged16-24 years compared with 8.1% of all New Starts.

On entry to AMH New Horizons, just over half of the respondents had been diagnosed with depression/anxiety/mood disorders (54.3%) with a further one-quarter diagnosed with psychotic disorders (24.8%). Eight respondents had two and one respondent had three diagnosed mental health problems. The gender split was relatively equal for depression/anxiety/mood disorders but 81% (21/26) of respondents diagnosed with psychotic disorders were male.

Table 2 Baseline characteristics of respondents

Characteristic	**Point 1**		**Point 2**		**Point 3**	
	No.	**%**	**No.**	**%**	**No.**	**%**
Gender						
Male	63	54.3 (54.5)[1]	54	55.1	35	49.3
Female	48	41.4 (45.5)	43	43.9	35	49.3
Age group						
16-19 years	0	0 (1.2)				
20-24 years	4	3.5 (6.9)				
25-49 years	68	60.2 (62.8)				
50-54 years	12	10.6 (14.8)				
55-64 years	22	19.5 (13.2)				
65+ years	4	3.5 (1.1)				
Diagnosis on entry						
Psychotic disorder	26	24.8				
Other severe and enduring condition	7	6.7				
Depression/anxiety/ mood disorders	57	54.3				
Alcohol problems	5	4.8				
Adjustment disorder	4	3.8				
Personality disorder	4	3.8				
Other[2]	2	1.9				
New Horizons Unit						
Antrim	19	16.4	15	12.9	13	17.6
Ards	15	12.9	14	13.6	10	13.5
Bangor	4	3.4	4	3.9	2	2.7
Belfast	10	8.6	9	8.7	7	9.5
Craigavon & Banbridge	10	8.6	7	6.8	2	2.7
Derriaghy	3	2.6	3	2.6	1	1.4
Downpatrick	14	12.1	14	12.1	11	14.9
Fermanagh	11	9.5	11	10.7	7	9.5
Foyle	14	12.1	12	11.7	10	13.5
Newry	16	13.8	15	1.46	11	14.9
Total	116	100	104	100	74	100

[1] percentages in brackets are proportion of all New Starts in New Horizons programme 1/5/10-31/7/11

[2] self -esteem and confidence issues, Aspergers

5.2 Use of health and personal social services

This section examines the pattern of service utilisation across statutory, community, and hospital-based services.

5.2.1 Community-based health and personal social services

Table 3 shows the number and proportion of clients who had contact with each professional group in the 3-month period prior to entry to the AMH New Horizons programme and at two further 3-month intervals.

Table 3 Use of health and social care services

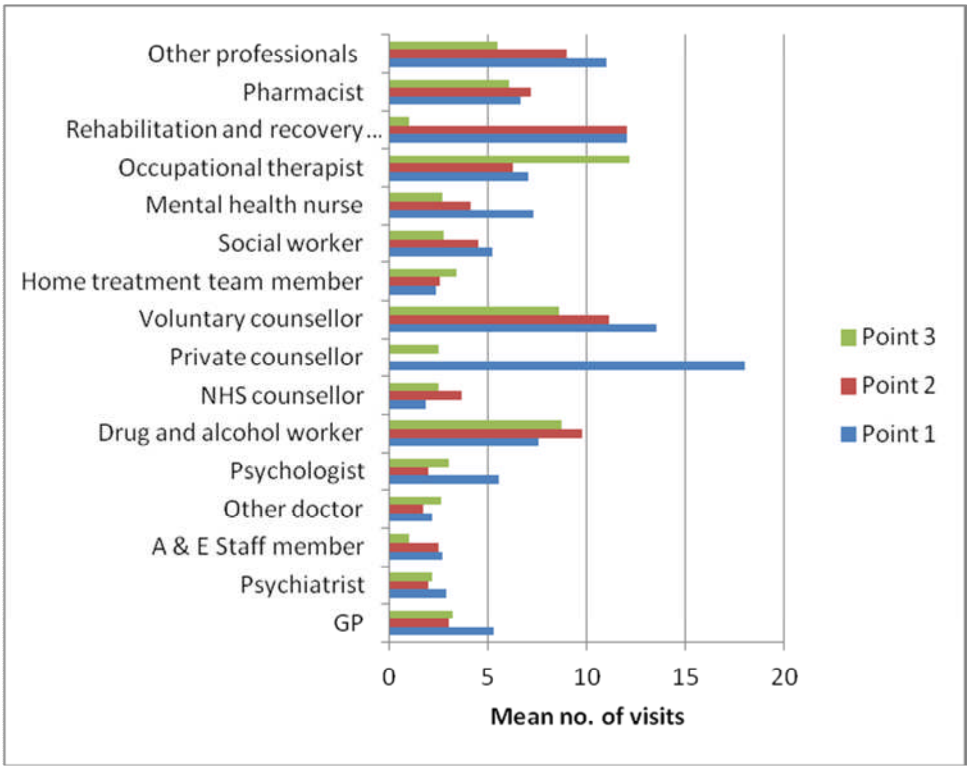
Professional group	Point 1		Point 2		Point 3	
	No.	%	No.	%	No.	%
GP	97	85.1	77	76.2	59	83.1
Psychiatrist	79	69.3	49	48.5	33	46.5
A & E	29	25.4	18	17.8	6	8.5
Other doctor	27	24.1	23	23.0	19	26.8
Psychologist	28	24.6	13	12.9	6	8.5
Drug & Alcohol worker	17	14.9	7	6.9	7	9.9
NHS Counsellor	18	15.8	10	9.9	11	15.5
Private Counsellor	4	3.5	0	0	4	5.6
Voluntary Counsellor	5	4.4	8	7.9	4	5.6
Home treatment/crisis team/assessment team member	23	20.2	8	7.9	10	14.1
Social worker	32	28.1	20	19.8	17	23.9
Mental health nurse/CPN	71	62.3	49	48.5	27	38.0
Occupational Therapist	17	14.9	11	10.9	8	11.3
Rehabilitation and Recovery Team member	6	5.3	8	7.9	2	2.8
Pharmacist	57	50.0	51	50.5	36	50.7
Other professional*	11	9.7	5	5	6	8.5

*Key worker, pain specialist, physiotherapist, condition management programme, blood clinic, acupuncturist

Not surprisingly, the most commonly used service was the GP (76-85%), followed by Psychiatrist (47-69%), Mental Health Nurse (38-62%) and Social Worker (20-28%). It should be noted that, based on the time spent at each GP contact, these contacts were face-to-face. In respect of contacts with the pharmacist, reporting appears to be for collection of medications only.

The overall trend was a reduction in the mean number of contacts for each of the noted services provided by health and social care professionals (Figure 1). The greatest reductions were for contacts with Mental Health Nurse (7.29 to 2.71), Social Worker (5.2 to 2.73), GP (5.26 to 3.22), Psychologist (5.52 to 3.00) and Psychiatrist (2.89 to 2.14).

Figure1 Trend in mean number of contacts with Health and Personal Social Services



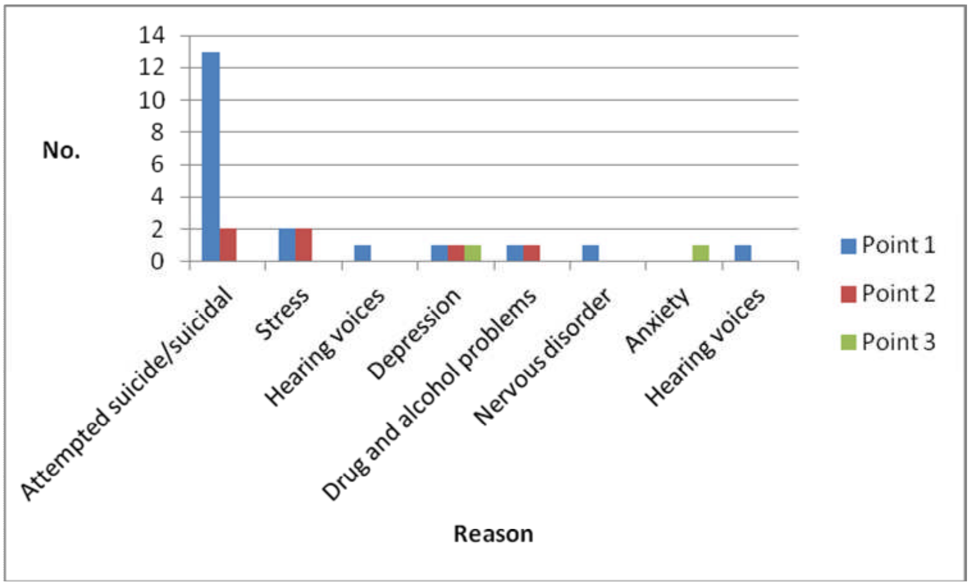
A series of Wilcoxon Signed Rank Tests and Freidman ANOVA tests showed that changes in the median number of contacts across the three time Points were statistically significant for contacts with GP (p <.001), Psychiatrist (p=.002, p=.011), Social Worker (p=.043, p=.042, p=.008) and Mental Health Nurse (p=<.001, p=.003, p=.010). The median number of contacts with services at each time Point is presented in Appendix 5. It should be noted that small sample sizes are less likely to detect a statistically significant difference and clinical differences are important.

5.2.2 Inpatient admissions for mental health reasons

A total of 22 (19%) respondents had at least one admission as an inpatient to mental health services with the majority of these (19/27) being prior to engagement with the AMH New Horizons programme. The mean number of months across which inpatient admissions were recorded was 11.45 (range 3-27 months).

Of the 27 inpatient admissions for mental health problems across the three time Points just over half (56%,15/27) were for self harm/attempted suicide, with the majority of these (13/15) being in the 3 months prior to joining the AMH New Horizons programme (Figure 2). Admissions for self harm/attempted suicide were evenly split between males (53.8%) and females (46.2%).

Figure 2 Reasons for inpatient admissions (mental health problems only)



Hospital admissions for mental health problems were reduced by 91% following engagement in the AMH New Horizons programme. Only two respondents who had an admission prior to engagement in the AMH New Horizons programme had a subsequent readmission during the study period. Based on the respondents who provided information on their length of stay in hospital at Point 1 (n=18) the mean length of stay was 32.14 days. The proportion of admissions under the Mental Health Order (1986) remained relatively constant at around one-third. One respondent was admitted twice under the Mental Health Order (1986).

5.2.3 Day care services

Within day care services the largest proportion of respondents used mental health resource centres (18-26%) followed by self help/support groups (11-14%). Day hospitals and drug/alcohol services were used by 8-13% of clients (Table 4). In relation to adult education classes it is likely that some clients included the education classes provided on-site at AMH New Horizons.

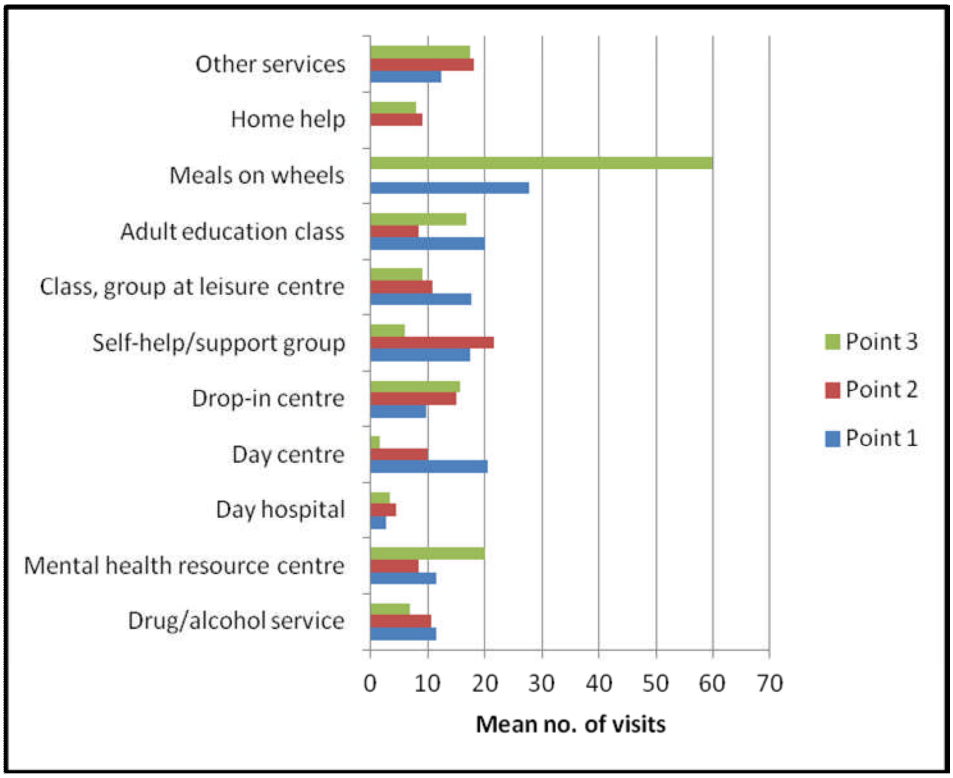
Table 4 Use of day care services

Service	Point 1		Point 2		Point 3	
	No.	%	No.	%	No.	%
Drug/alcohol service	13	11.3	9	8.8	9	12.0
Mental health resource centre	30	26.1	18	17.6	19	25.3
Day hospital	12	10.4	10	9.8	10	13.3
Day centre	9	7.8	8	7.8	8	10.7
Drop-in centre	4	3.5	2	2.0	7	9.3
Self-help/support group	16	13.9	14	13.7	8	10.7
Class/group at a leisure centre	9	7.8	10	9.8	10	13.3
Adult education classes	8	7.0	13	12.7	20	26.7
Meals on wheels	3	2.6	1	1.0	2	2.7
Home Help	4	3.5	6	5.9	2	1.7
Other services*	7	6.1	8	7.8	4	5.3

* Praxis, Mindwise, Starus, Simon Community homeless hostel, Mother helps

There was no clear trend in the mean number of attendances at day care services across the study period with an increase in some and a decrease in others (Figure 3). This is not unexpected given the small numbers using services.

Figure 3 Trend in mean number of visits to day care services



Due to the small numbers of respondents using day care services limited conclusions can be drawn about the change in use of day care services across the study period. The change in the median number of contacts with mental health resource centres between Point 1 & Point 2 was of borderline statistical significance ($p=.063$) (Appendix 6). It should be noted that small sample sizes are less likely to detect a statistically significant difference and clinical differences are important.

5.3 Savings to Health and Personal Social Services

This section estimates the savings to Health and Personal Social Services based on the unit cost per service. Full cost Annual Trust Financial Returns 2008/09 for mental health services costs were used for Psychiatrist, Accident & Emergency, Drug and Alcohol Worker, Mental Health Nurse and Recovery and Rehabilitation Team services. Unit costs of Health and Social Care 2009 English costs (Personal Social Services Research Unit 2009) were used for Psychologist, NHS Counsellor, Home Treatment/Crisis/Assessment Team, Social Worker (mental health) and Occupational Therapy services. Northern Ireland General Medical Services 2009/10 costs for GP consultations were used for GP services.

5.3.1 Savings to community-based health and personal social services

The reduction in service use was reflected in decreased costs across time to the Health and Personal Social Services in NI. Taking the most commonly used services the mean savings per client between Point 1 & Point 3 were £47 for GP (£120 to £73; $p=0.000$); £161 for Psychiatrist (£619 to £458; $p=0.13$) and £515 for Mental Health nurses (£819 to £304; $p=0.042$).

Table 5 presents (a) mean cost per client at each time Point (b) savings per client (difference in mean costs across time) and (c) extrapolated savings for all clients in the AMH New Horizons programme 1st May 2010 to 31st July 2011 (difference in mean cost x 1822). Engagement in the AMH New Horizons programme reduced the costs to Health and Personal Social Services by 39% per client from £6,538 at baseline to £3,964 at Point 3. Across the 15-month study period this equates to an estimated saving to the HPSS of £2,574 per client and estimated extrapolated savings of £4.7 million across all AMH New Horizons clients (Table 5). The increased costs for drug and alcohol worker services and the home treatment/crisis care team across the study period are most likely due to Action Mental Health staff identifying unmet needs and thus enhancing client access to appropriate support services.

Conversion of these savings to an annual basis shows an annual saving of £2,227 per client, £4,057,813 across all AMH New Horizons clients (Table 6).

Table 5 Savings to Health and Personal Social Services across the study period

Service (unit of cost)	Mean cost/client P1	Mean cost/client P2	Mean cost/client P3	Saving per client P1-P2	Saving across all NH clients P1-P2[1]	Saving per client P1-P3	Saving across all NH clients P1-P3[1]
GP (consultation)[2]	119.64	68.22	73.37	51.42	93,693	46.27	84,313
Psychiatrist (consultation)[3]	618.86	423.02	457.52	195.84	356,823	161.35	293,975
A & E visit (consultation)[3]	280.00	262.50	105.00	17.50	31,885	175.00	318,850
Psychologist (hour)[4]	425.17	154.00	231.00	271.17	494,079	194.17	353,785
Drug and alcohol worker (consultation)[3]	919.07	1189.50	1063.14	-270.43	-492,730	-144.08	-262,507
NHS counsellor (consultation) [4]	603.00	217.50	150.00	385.50	702,381	453.00	825,366
Home treatment/crisis team (hour) [4]	462.00	504.00	666.40	-42.00	-76,524	-204.40	-372,417
Social worker (contact) [4]	483.60	415.76	253.64	67.84	123,596	229.96	418,994
Mental health nurse (visit)[3]	819.46	464.99	304.23	354.46	645,831	515.23	938,748
Occupational therapist (hour) [4]	308.00	276.00	535.33	32.00	58,304	-227.33	-414,201
Recovery and rehabilitation team (visit)[3]	1500.00	1500.00	125.00	0.00	0.00	1375.00	2,505,250
Total savings	**6,538**	**5,475**	**3,964**	**1,063**	**1,937,339**	**2,574**	**4,690,156**

Footnotes: Costs are mean costs

[1] based on mean cost x 1822 New Horizons clients

[2] GMC 2009/10 costs

[3] NI Annual Trust Financial Returns 2008/09

[4] PSSRU 2008/09 costs

Table 6 Annual savings to Health and Personal Social Services

Service (unit of cost)	Saving per client £	Saving across all New Horizons clients[1] £
GP (consultation)[2]	40.04	72,945
Psychiatrist (consultation)[3]	139.59	254,341
A & E visit (consultation)[3]	151.41	275,862
Psychologist (hour)[4]	167.99	306,086
Drug and alcohol worker (consultation)[3]	-124.65	-227,115
NHS counsellor (consultation) [4]	391.93	714,087
Home treatment/crisis /assessment team (hour) [4]	-176.84	-322,206
Social worker (contact) [4]	198.96	362,503
Mental health nurse (visit)[3]	445.76	812,183
Occupational therapist (hour) [4]	-196.68	-358,357
Recovery and rehabilitation team (visit)[3]	1189.62	2,167,484
Total savings	**2,227**	**4,057,813**

Footnotes: Costs are mean costs

[1] based on mean cost x 1822 New Horizons clients

[2] GMC 2009/10 costs

[3] NI Annual Trust Financial Returns 2008/09

[4] PSSRU 2008/09 costs

5.3.2 Savings to inpatient services

The estimated savings to the HPSS from hospital non-readmissions were £6,837 per client (cost per day x difference in mean LOS Point 1 and Point 3) equating to £12,457,524 across all AMH New Horizons clients (mean difference in cost per client x 1822). Patients admitted under the Mental Health Order were more likely to have had a severe event and the associated costs with admissions would be higher.

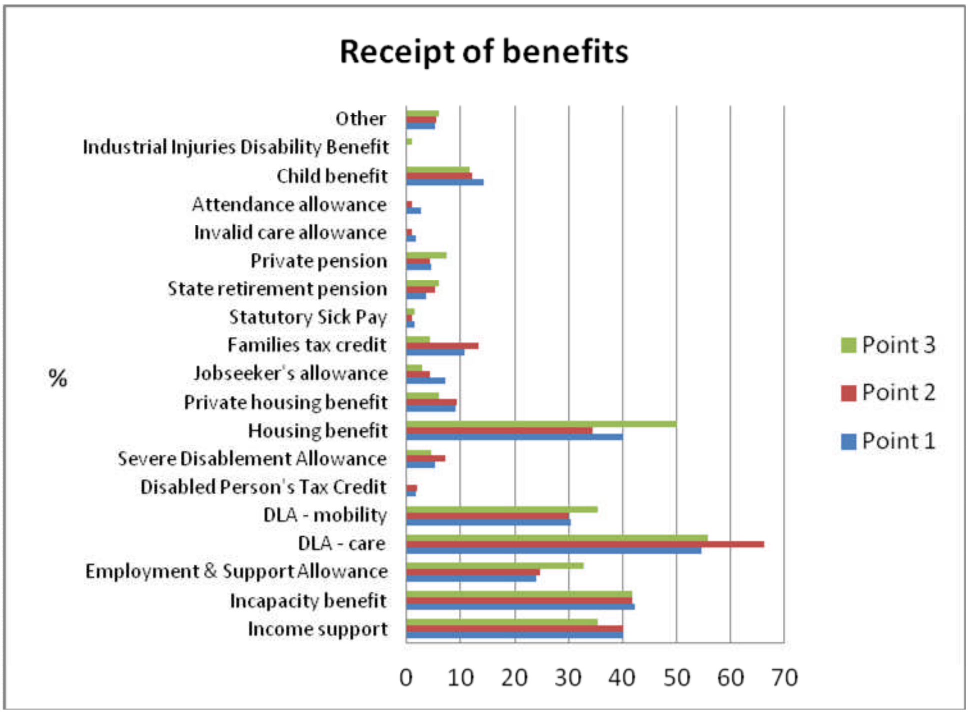
5.3.3 Savings to day care services

Unit costs for day services were not available locally or regionally except for day centres. As the number of respondents using day centres was very small the resultant savings were not costed. However, based on the premise that attendance at the AMH New Horizons programme 2 days per week for 52 weeks in the year is a substitute for attendance at adult day centres the estimated savings to the HPSS are £5,120 per client and £9,328,494 million across all New Horizon clients.

5.4 Receipt of state benefits

From Figure 4 it can be seen that the most common benefits received by respondents were Disability Living Allowance (care component) (55-66%), Income Support (35-40%), Incapacity Benefit (stable at 42%) and Housing Benefit (35-50%). Just over half (54.5%) of respondents were in receipt of at least one component (care or mobility) of DLA. The majority of respondents on Incapacity Benefit (80%) and Disability Living Allowance (92%) had been in receipt of these benefits for at least three months.

Figure 4 Receipt of state benefits



Wilcoxon Signed Rank Tests and Friedman ANOVA tests, which only use data from clients who provided information at two/three time Points respectively, showed that benefit receipt did not change significantly across time, with the exception of DLA (care component) which showed a statistically significant reduction between Points 1 & 2 (n=97; p=0.003) and across all three time Points (n=62; p=0.035). The reduction in DLA (mobility component) between Points 2 & 3 was of borderline statistical significance (n=61; p=.058).

5.5 Savings to Exchequer

Information was not collected on employment since joining AMH New Horizons. We were, however, able to provide a crude estimate of the input to the economy based on information for 35 clients who had been on the programme between 1st May 2010 and 31st July 2011 and who had entered, mainly part-time, employment. The average annual salary for these 35 clients was £7,551 and the employment rate across all AMH New Horizons clients was 3.84% (70/1822) resulting in a contribution to the economy of

£453,022 (personal allowance x no. New Horizon clients x employment rate). At the time of the study the personal tax allowance was £6,475 with a basic rate of income tax of 10%. A very conservative estimate of revenue from tax income is £7,528 (mean salary – personal allowance x no. AMH New Horizons clients x employment rate x tax rate).

As information on rate of benefits or change in benefits was not collected a crude estimate of savings to the Exchequer has been calculated as below. The long-term basic rate for Incapacity Benefit was £94.25/week. At the time of the study claimants could earn up to £95/week before their Incapacity Benefit was affected. Assuming those earning over £4940/year (57%; 20/35) lost their Incapacity Benefit, this equates to savings of £1,645 (weekly rate x % AMH New Horizons clients on IB x employment rate x % earning >£4940/year) to the Exchequer. A conservative estimate of the total contribution to the economy from employment following engagement in the AMH New Horizons programme is £462,195 annually. It should be noted that we know there was a statistically significant reduction in the number of respondents in receipt of DLA care component across the study period, however, these savings could not be costed due to the complex rules for receipt of DLA. Employment will most likely also affect a number of other benefits so the estimated savings of £462,195 are an underestimation.

The annual estimated savings for premature mortality from suicide were £17,310,202 for all AMH New Horizons clients. These estimates are based on an average of 7% fatal repetition of self-harm (Owens et al. 2002) and an estimated cost associated with one suicide death being £1.68 million per person (DHSSPS 2010).

5.6 Savings from informal care provided by carers

Based on the replacement cost of providing home care to an adult, it is estimated that the economic value of the contribution made by carers in the UK is £21,000 per year per carer (Buckner and Yeandle 2011). Assuming 11% of AMH New Horizons clients have carers (DHSSPS 2001) this equates to an annual saving of £4,208,820,

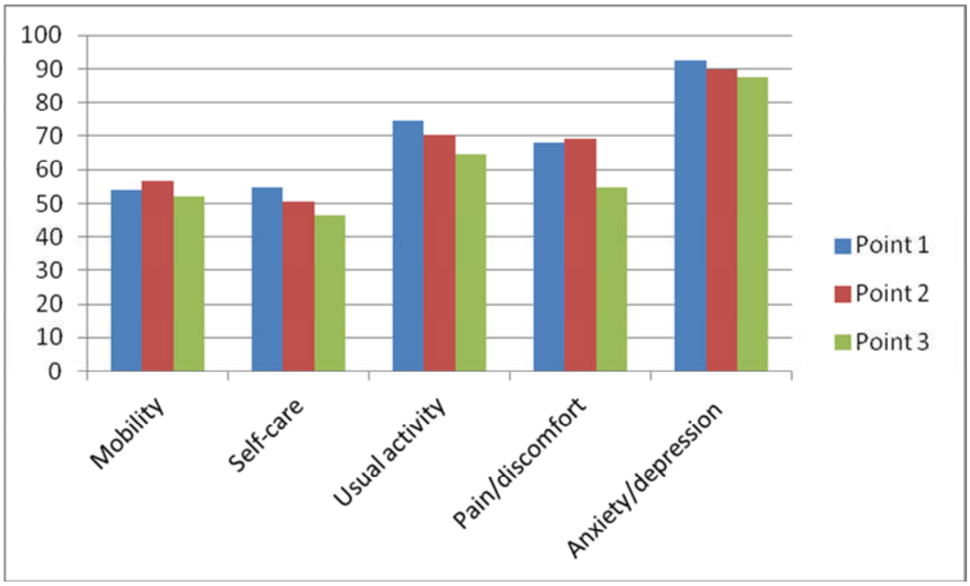
5.7 Health status and wellbeing of clients

This section reports on the findings from the client EQ-5D questionnaire.

5.7.1 Change in client health status

Data collected using the five EQ-5D dimensions are not continuous but ordinal, hence the information is presented as the proportions of the population reporting level 1 (no problems), level 2 (some problems) and level 3 (extreme problems) per dimension. As the number of people reporting severe problems was very small, the sum of the proportions of reported level 2 and level 3 problems was used in Figure 5. This essentially changes the 3-level EQ-5D dimensions into 2-level dimensions, with categories ‘no problems’ and ‘problems’.

Figure 5 Change in reported problems in five dimensions of health – client EQ-5D



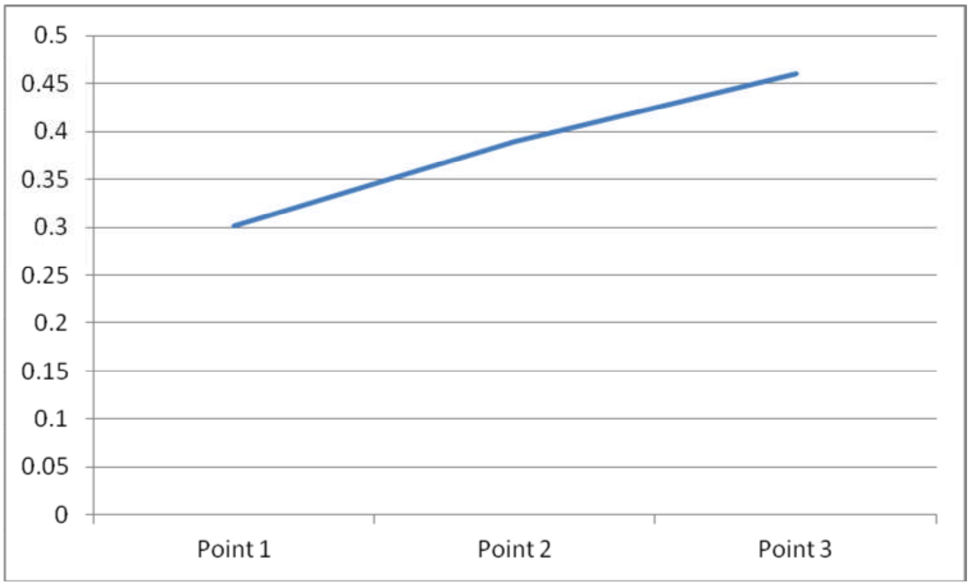
Footnote: % are those reporting ‘moderate’ or ‘extreme’ levels of each dimension

The general trend is that the reported frequency of problems has decreased over time. A series of Friedman ANOVA Tests on each of the five dimensions showed that the change in mean ranks across the three time Points was statistically significant for usual activities (p=.027), pain/discomfort (p=.005) and anxiety/depression (p<0.0001) showing that the improvement in these problems did not occur by chance.

5.7.2 Change in client health-related quality of life

The scores from the five dimensions of the EQ-5D (mobility, self-care, usual activities, pain/discomfort, anxiety/depression) were converted to a single summary index value by applying a formula that essentially attaches weights to each of the levels in each dimension e.g. state 11111 indicates no problems on any of the five dimensions, while state 12345 indicates no problems with mobility, slight problems with washing or dressing, moderate problems with doing usual activities, severe pain or discomfort and extreme anxiety or depression. The resultant index values range from 0 (worst imaginable health) to 1 (best imaginable health). The increasing trend in the mean index values from .284 to .456 was statistically significant (p=.001; X^2 14.058), demonstrating a gain of health status equivalent to 0.172 of a QALY. In other words health-related quality of life is improved by 17.2% (Figure 6). The annual monetary valuation of the total number of QALYs gained across all New Horizon clients is £10,303,036 (increase in mean index value x value of QALY x no. of AMH New Horizons clients).

Figure 6 Change in respondent health-related quality of life



The EQ VAS records the respondents' self-rated health on a vertical, visual analogue scale 0-100 where 100 is 'best imaginable health state' and 0 is 'worst imaginable health state'. This information is used as a quantitative measure of health outcome as judged by the individual respondents. The mean score increased by 28% from 39.59 to 50.55 ($p=<.0001$; X^2 17.595). This increasing score is consistent with reported increases in measured dimensions of health.

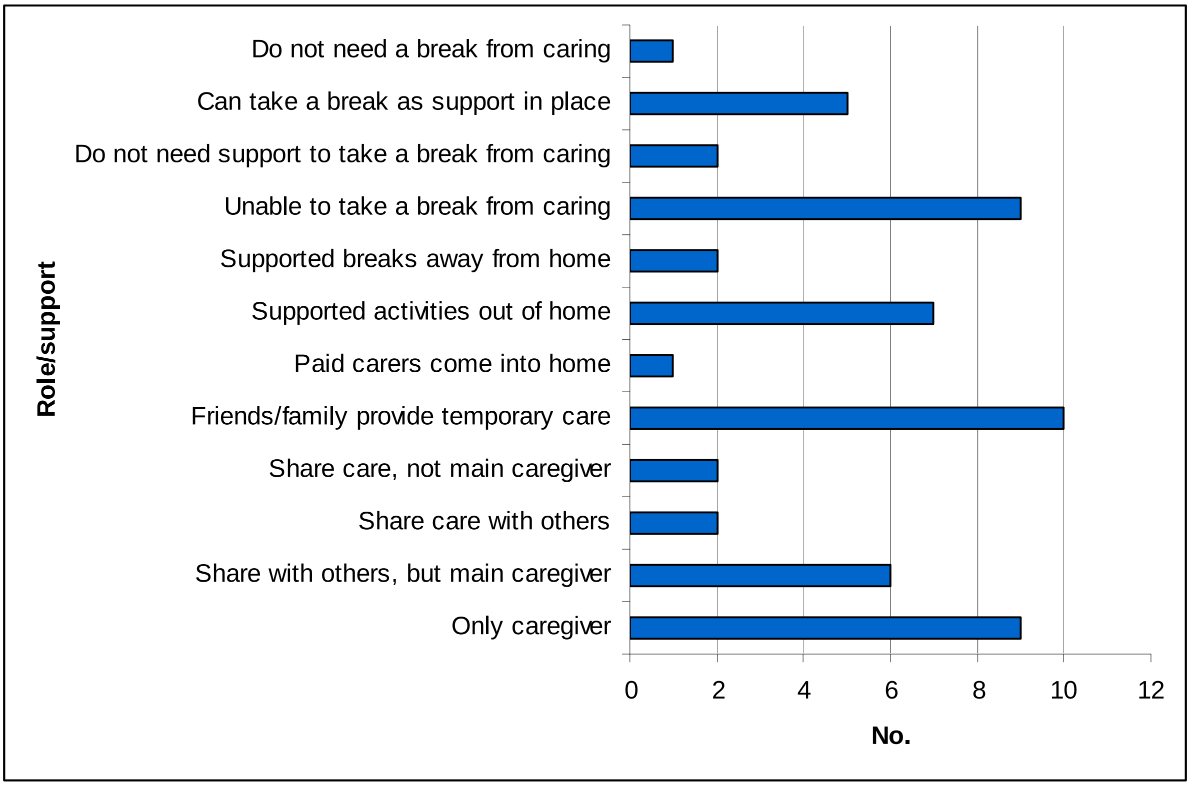
5.8 Personal circumstances, health status and wellbeing of carers

This section reports on the findings from the questionnaires 'About the Person You Care For' and the EQ-5D (Appendix 4) completed by carers (n=19).

Just over two-thirds of carers (13/19) were caring for a son or daughter, four were caring for a spouse or partner and two were caring for a brother or sister. The conditions of the person being cared for were psychosis/schizophrenia (8), bi-polar disorder/manic depression (4), depression (4), personality disorder (1) and aspergers/autism (2). Almost two-thirds (12/19) of those being cared for lived with their carer full-time, with a further three living with their carer most of the time. Of the seven individuals who did not live full-time with their carer five lived in their own or rented accommodation, one lived in supported accommodation and one lived with another family member or friend.

Almost half of the carers were the sole caregiver, with a further third being the main caregiver. Respite care was mainly provided by family and friends (10/19). It is of concern that more than half of carers (9/15) were unable to take a break from caring. Only one-third (7/19) of carers reported the use of supported activities outside of the home (Figure 7).

Figure 7 Role as carer and support for respite

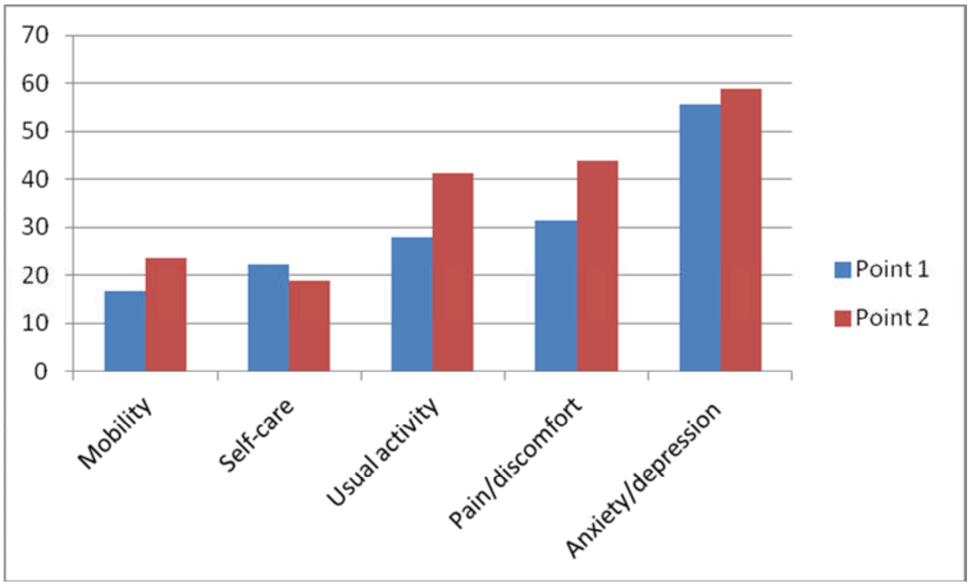


The main issues highlighted by carers were the invaluable service provided by, and support from, Action Mental Health (7/19), the lack of support and information available from professionals (4/19) and concern for the future of their relative (2/19).

The self-rated health of carers on the vertical, visual analogue scale (0-100) showed a 24.4% increase in the mean score from 54.72 to 68.06 (p=.055) indicating an improvement in their psychological wellbeing since their relative engaged with the AMH New Horizons programme.

Carers also reported an improvement in all five measured dimensions of their health since their relative engaged in the AMH New Horizons programme (Figure 8).

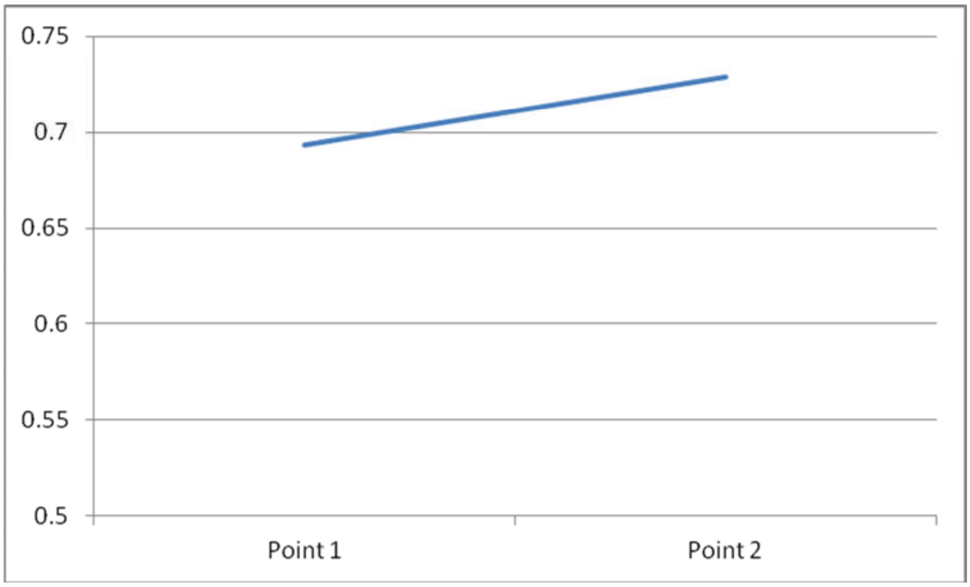
Figure 8 Change in reported problems in five dimensions of health – carer EQ-5D



Footnote: % are those reporting ‘moderate’ or ‘extreme’ levels of each dimension

The improvement in health-related quality of life since their relative engaged in the AMH New Horizons programme from .694 to .729, failed to achieve statistical significance. However, this is most likely due to the small sample size (Figure 9). The annual estimated monetary valuation for the increase in health status equivalent to 0.035 of a QALY is £230,620 (increase in mean index value x value of QALY x estimated % of AMH New Horizons clients with a carer).

Figure 9 Change in carer health-related quality of life



5.9 Savings to the HPSS and the Exchequer from engagement in AMH New Horizons

The total estimated savings across the study period, based on the difference in mean costs between Point 1 and Point 3 of the study period, to the Health and Personal Social Services and the Exchequer from engagement in the AMH New Horizons programme are £57.8 million equating to £31,719 per client per year and £610 per client per week.

The annual savings resulting from the AMH New Horizons programme are £50 million equating to £27,443 per client or £528 per client per week.

Table 7 Annual gains through provision of AMH New Horizons programme

Component	Cost without New Horizons £	Cost with New Horizons £	Difference In costs	Annual gain per client	Weekly gain per client
Health and social care					
HPSS community-based services	10,307,458	6,249,645	4,057,813		
HPSS inpatient services	15,300,512	4,522,553	10,777,959		
Substitute for day care services	9,328,494	0	9,328,494		
Value of carers’ support	4,208,820	0	4,208,820		
Human costs					
Premature mortality from suicide	20,775,230	3,465,028	17,310,202		
Quality of life (QALY) clients	27,315,025	17,011,989	10,303,036		
Quality of life (QALY) carers	4,803,491	4,572,871	230,620		
Annual gain to HPSS	92,039,030	35,822,085	56,216,944		
Annual payment by Trusts			6,678,279		
Net annual gain to HPSS			**49,538,665**	**27,189**	**523**
Other public sector costs					
Social security costs	72,124	70,479	1,645		
Gains to society from employment					
Income from tax revenue	0	7,528	7,528		
Income from employment	0	453,022	453,022		
Annual gain to society			**50,000,860**	27,443	528

It should be noted the above savings are a conservative estimate. The increase in HPSS costs between 2008/09 and 2010/11 have not been accounted for. Furthermore, a number of sources of savings could not be measured in this study, namely:-

- enacting Mental Health Order
- savings in welfare and housing benefits, other than Incapacity Benefit
- savings to third sector organisations such as homeless hostels
- savings to criminal justice system
- social impact on individual, families and wider society

- reduction in medications due to poor completion of this section of the questionnaire and the time-bound nature of study
- potential reduced use of services by carers
- change in use of services associated with client co-morbidities
- savings from carers’ retention of employment

6.0 Focus groups with carers

When John Donne (1624) stated that “no man is an island, entire of itself” he eloquently identified that we need other people. Not only do we need other people, we are deeply connected to them and to our loved ones; there are strong bonds of a physical, psychological, social and spiritual nature. When a person becomes emotionally distressed to the point he or she needs active help from mental health services their relatives will tangibly feel this disturbance and will be affected by it. It was apparent to the authors of this study that, not only is the person who is in distress using Health and Personal Social Services, but their relatives could also be availing of these services. As the individual journeys back to health the wellbeing of his or her relatives may also follow this path.

This section reports on the findings from the four focus groups with carers of clients (n=19) in the AMH New Horizons programme.

Following the process outlined by Newell and Burnard (2006) four final themes were identified as below:

1. Graceful care
2. Consequences for family
3. Benefits, challenges and developments of New Horizon services
4. Challenged by the system

To illustrate these themes a number of direct quotes will be used from participants in each of the focus groups. Participants will be identified as P1 or P2 and the Focus Group will be identified as FG1 or FG 2 so, for example, a quote from Participant 5 in Focus Group 3 will be identified as P5 FG3.

6.1 Theme 1 - Graceful care

This was a very strong theme to emerge from the focus groups; graceful care often related to the AMH New Horizons services but also to parts of the Health and Personal Social Services. This graceful care would help the person attending AMH New Horizons by providing structure and aiding self-esteem. Often benefits for carers and families were also identified.

A mother in Focus Group 2 identified that the structure that AMH New Horizons provided was particularly beneficial to her son’s recovery, stating:

“Yeah he loves to come and he is learning about computers and stuff that he didn’t have time to learn about before, but it gives his day a sort of structure. It feels like he has found himself”. (P1 FG2)

A husband in Focus Group 2 spoke very highly of AMH New Horizons and the staff's ability to care for all his wife's needs. A concentration on other issues, not just health, actually helped improved his wife's health, he stated:

"…I couldn't speak highly enough and I have no criticisms at all. Having said that my wife has not been here that long. She was in a kind of a tangle between a crisis team and the CPNs and it was all about her health and their angles on her health and she couldn't get focus on anything but her health and how low she was…She ran her own business, which she had to give up…and she became extremely low, got into debt, everything was wrong in her life. It was only when New Horizons was suggested by the crisis team that things began to lift and they have been going straight up ever since. I have no criticisms, I couldn't agree more whenever there is a hitch of any sort the face goes, but that to me shows that there is good in here. Again following on from what was said I think that (names wife) *likes to not be thinking about the fact that she is mentally ill. That escape to just be in a class as opposed to being analysed all the time, seems to help her. She comes home a different person, she doesn't take to her bed anymore, she is not stuck in the house. I am at work I have to be at work. I had thought about giving it up but that would make things worse because the whole family would probably collapse then. I couldn't praise the place highly enough. She has fitted in beautifully. She has had a couple of seizures down here and they have coped superbly and that is about it".* (P4 FG2)

One female participant in Focus Group 1 felt she and her daughter got excellent help from the HPSS and a Psychiatrist in particular, she said:

"Although from my point of view once (names daughter) *got down to the* (names hospital) *that was the turning point for me and for her as well. That was the first time I was included; it was a totally different way of working with me, and different way of working with* (names daughter) *and that was the start of her, he, he you know the consultant that worked with her was very firm he was a* (names country he was from) *doctor he was just I wanted to bring him home with me* (all laugh) *but was very firm and told her upfront what the condition was, what she was going to have and how she was going to do. He nearly told her she would be back in a fortnight and he was quite right and had fantastic insight. But not only that, but gave me fantastic insight - you know he was just brilliant".* (P2 FG1)

A father reported to witness a huge improvement in his daughter's wellbeing following her attendance at AMH New Horizons:

"*I have a daughter* (names her) *now and it's bad, but she comes up here two or three days a week, and it's a big help. When she is about the other house there she just … lying in her bed depressed until this place, found out she is up here now different person all together … I can't really say enough about the place, it is that great a place, I would recommend it to anyone who is feeling down".* (P1 FG1)

A father in Focus Group 4 felt AMH New Horizons saved his son and aided his recovery from very serious problems, he stated:

"…and this has saved him, absolutely saved him from more serious problems. Brought him back from his anorexia, brought him back to speaking to other people in his own way but he is still integrating". (P3 FG4)

A sister taking part in Focus Group 1 felt her brother's Community Psychiatric Nurse (CPN) gave graceful care to her saying:

"You have somebody to build a rapport with. (names brother) *at the moment has a very good CPN and I know I can pick up the phone that means a lot, you know I got somebody else".* (P3 FG1)

A mother attending the third Focus Group found the level of experience and understanding expressed to her son by the staff was very helpful to his mental health, she said:

"You know if they come in here and they are feeling unwell they can talk to these people because they know they understand, they have seen it all before they will not be shocked. You know that relieves a lot of pressure in their minds". (P5 FG3)

A participant in Focus Group 3 reported her brother never felt judged in AMH New Horizons and was treated as an equal, she said:

"You know my brother has said 'you know they don't judge me in New Horizons or Action Mental Health, you know nobody judges me, nobody cares we are just the same ". (P2 FG3)

It is very clear that this experience of graceful care experienced by clients has been visible to the participants who took part in these focus groups. In each focus group this theme emerged strongly, with some positive examples given in respect of the HPSS also.

6.2 Theme 2 - Consequences for family

The rationale for undertaking this aspect of the commissioned study was the belief that carers of people with mental health problems feel their distress and also benefit when their relative's mental health improves. These two aspects were borne out in the focus groups, with the additional benefit of respite for the carer coming to the fore also. Two sub-themes of Effects and Respite emerged from the analysis.

6.2.1 Effects on family

A major issue for some participants was the lack of knowledge about mental ill health and indeed mental health and this experience will have profound effects for many years.

One sister during Focus Group 1 expressed her views about this unknown issue of mental ill health and the very real impact it has on the wider family, stating:

"I think nobody really tells you what to really expect, so as a carer or you know, my brother's got psychosis and I suppose you know from the very onset of diagnosis. You are

always hoping, particularly for the first years, that this will be something that will go away and I think it takes a long time to actually as a family accept that this is how the person is going to be and this is now part and parcel of who they are and their life and it also means a huge impact on everybody around them. I think that you know it is traumatic, it is emotional, it is sometimes like a rollercoaster…" (P3 FG1)

This issue of true ignorance was also raised by a mother in Focus Group 4 stating:

"..The stress and pressure that is put on you just cannot be described, especially in the early days when you have absolutely no idea what this is all about, what is going on, how do I cope with it..." ?(P2 FG4)

A husband in Focus Group 2 could also identify his lack of understanding:

"There is a big gap between us trying to cope and understand what they are actually going through. The lack of understanding about what they are actually going through is my biggest problem". (P2 FG2)

A husband spoke in Focus Group 2 of his profound difficulty in understanding what his wife was going through, he stated:

"Yes it is far different - someone who is physically ill and someone who is mentally ill it is far different, cause if it is a physical illness it is a lot easier. If it is a mental illness it is way you know if it is something within a person and you come across that person you don't have a clue. I have found there is not much support you are more or less left out there to make your way all on your own, and it is very frustrating for you because no matter how hard you try to understand and cope it is very difficult. It is very frustrating because you can think you are doing well here and you are back to square one..." (P2 FG2)

Another husband spoke in the same Focus Group about the delicate balancing act he had to cultivate when his wife developed mental health problems, he said:

"I was given a very good bit of advice by a family friend that went through something similar and he just warned me to stay close because you can wake up one day and discover that you have drifted apart by not staying involved and not knowing what is going on. So stay close and try not to hurt and say the wrong thing. You have still got to know the person because you will find out that you don't know what is going on and you have almost drifted apart. Still love one and another dearly but you have lost touch with what is going on in her head or in her life. So stay close but not too close, it is a very difficult balance to strike". (P4 FG2)

A mother in Focus Group 1 expressed the real strain she was living with worrying about her son and the impact it had on her own mental health, saying:

"…it does get you down like, you know health wise. When you're laying in bed at night worrying you know what if you know if the phone rings, or something like that. But asides of him getting in trouble like he would be very good like that anyway, but there's just always a fear like you know he would self harm himself. Quite a while before the doctor actually sat up like, you know I would kinda go down and tell the doctor I thought his

behaviour wasn't right. He thought he was attention seeking which he wasn't really, you know. So it's like tough going most of the time like you know, and it does get you down yourself, like you know at the end of the day like…" (P4 FG1)

A mother in Focus Group 5 spoke very clearly about the damage that can occur in a family when a mental health issue develops in one of its members, she said:

"I found that it caused a lot of division within the family because my son would have been physically and verbally abusive. Physically abusive towards myself at times and it was extremely hard to be with him. My youngest son blamed (names son) *for what he did to me, he would just turn into a monster when he would take a wobbly and my oldest son could talk to* (names son). *My oldest son is now living in* (names country) *and I think that part of the reason was to get away and* (names son) *caused division, it certainly caused division. My own family, and I do have family, my husband has brothers and sisters but because my son is so difficult people did try to help at the beginning but they backed off because really nobody could take on that responsibility and certainly I wouldn't have let them because he was outside of what any ordinary person could cope with".* (P5 FG4)

The effects on children were also identified by a husband in Focus Group 2 who feared for the relationship between his wife and their children, he said:

"I suppose the biggest effect would be on the relationship with the children, cause she really can't deal with the children for any great length of time and it is affecting her relationship with the children. If the children are with her for too long she starts to go downhill, it has a very negative effect. I go to work or whatever and she is left with the children for a period of time, it is difficult for them as well. Personally as far as I feel it can be very discouraging, you know you are sitting in a room with someone and what it used to be and what it has turned into can be strange". (P2 FG2)

6.2.2 Respite for family

The theme of respite emerged strongly during the focus groups with a sub-theme being that often the carer felt their relative was in safe hands while attending AMH New Horizons.

A mother spoke about the respite and how it helped to reduce the pressure she experienced, she said:

"..and places like New Horizons are a direction where you are actually happy to release the person you care for into the hands of people who are experts and know what they are doing and it really is uplifting and it definitely, definitely takes away the pressure, not all of the pressure but the peak of the pressure. For a period of time you are not actually worrying about them, because you know they are in the hands of other people who are actually experts in their field". (P2 FG4)

One mother who took part in the third Focus Group spoke very eloquently about the benefits that AMH New Horizons had on her life, and the fact she felt he was in safe hands meant a lot, she said:

"It is true respite, when your loved one is here safe you have that time free and it is just enough usually for those of us who are full time carers to, it is just enough to keep you in a normal life. You can go and do things and in actual fact it has helped me to do other things. My son was very dependent on me for a while and coming here he was separated from me so he was used to that. So now I can go out an odd evening or something like this where I couldn't before, for three or four years I couldn't. I was almost tied. It is like a flower opening when you get part of your life back, just enough of it back to maintain your own wellbeing and somewhere like this does that". (P4 FG3)

One participant spoke about her brother and the benefits she experienced and indeed her whole family by his attending AMH New Horizons, and again the fact she knows he is in safe hands meant a lot to this participant in Focus Group 1, she said:

"…then coming out of hospital and New Horizons is a structure to (names brother) *life and I know when he's going here he's looked after and he's supported you know outside of the family, with people who do have his welfare at the forefront of their mind and I suppose that is a real kind of big burden off the rest of us. When I know he is going to New Horizons I can switch off for the day and concentrate on my own work and concentrate on my own family you know…"* (P3 FG1)

A wife spoke of the benefits she could experience by her husband attending AMH New Horizons she said:

"It is like when he comes here it is a bit of respite for me and I can do other things and I don't have to look after him the whole time. We can take a dander into the park or something, things like that, that I am interested in". (P1 FG2)

This theme clearly showed the effects mental health issues can have on the carers of the person directly affected.

6.3 Theme 3 Benefits, challenges and development of AMH New Horizons services

There were a number of issues that arose about benefits, challenges and areas for future developments for New Horizon services.

6.3.1 Benefits to carers from engagement of relative in AMH New Horizons

The benefits to a range of people clearly emerged in the focus groups.

A mother in Focus Group 3 clearly articulated that her son's attendance at AMH New Horizons allowed her to continue to work. This was a benefit to her health and wellbeing but also to wider society as when she was working she would be contributing to the tax revenue of the Government and not taking from it in the form of benefits, she said:

"It actually enabled me to keep on my own job my son coming here because I could go to my work with a clear mind you know. In the worst times my work was my release". (P6 FG3)

A mother in Focus Group 3 felt attendance at AMH New Horizons for her son benefited the HPSS financially by making fewer demands on services and it should, therefore, be funded, she stated:

"The government should be putting more funding into something like this. The European Social Fund provides the most money for Action Mental Health as far as I am aware but you know the government need to be putting more into this place and then hospitals there wouldn't be as much need for beds in the hospital you know for people, that is the whole point. Plus GPs - my son hardly ever needs to see his GP he just gets a repeat prescription. He is seen by a CPN once a month and that is it. You know he could be running to the doctors every week, into hospital for weeks at a time". (P4 FG3)

Another mother taking part in the fourth Focus Group had a similar view of the benefits of her relative attending AMH New Horizons. She summed up very clearly these benefits to her and her family and indeed the HPSS locally by her son attending AMH New Horizons, she stated:

"This place has been a lifeline to our whole family, my son used to see his psychiatrists, with meetings with the social worker in between. Now he is on less drugs, sees his psychiatrist a lot less and has no appointments with the social worker. Now I think they are savings to the health service". (P5 FG4)

6.3.2 Challenges to carers and clients from engagement in AMH New Horizons

As well as many positive aspects of AMH New Horizons participants at the focus groups also found some challenging issues that raised concerns for them and their relatives.

A wife who was attending the second Focus Group felt that due to cutbacks people were not getting their needs and aspirations met and, in fact, were being asked to leave AMH New Horizons before they were ready, she said:

"..But at the same time I know it is opened from Monday to Friday New Horizons. I have no idea how many people come to the classes or what classes they go to but I feel that my husband, he comes here twice a week, but if it were to prevail you know I think of their own saying yes I would like to come another day or do another project but if they wanted to finish off what they were doing and wanted to go on to another project there is not enough funds for that, for their interest and they have no teacher. Especially if say, for example, if someone was on a computer course and their computer course is finished they want to go on one to do digital photography or art or something like that but they can't do that because there is no funds in the pot for them to do that and for them ones to give

them another opportunity to learn something else to go on to, to sort of help them to come on better within New Horizons itself and then maybe go on to apply for jobs and things like that. But you know sometimes I feel that our people are getting turfed out when they are not ready". (P3 FG2)

A participant in Focus Group 3 expressed very clearly the impact of the 'threat' of an exit strategy on her family, she stated:

"I would not like to be without New Horizons for my brother or my mummy. At one stage they had talked about an exit strategy. He ended up in hospital three months later. Looking back he was told that he would have to leave Action Mental Health that was his life, his routine and there was no talking to him in that meeting. He had to be present and we had asked at further meetings we asked if he could not be involved, but unfortunately he is the patient and that being told that exit strategy to leave and that is one client out of it all, just like disastrous". (P2 FG3)

A mother attending the third Focus Group had grave concerns about the cuts to services, she said:

"From we came here at the beginning it has gradually been cut and cut. Used to be five days a week, he was encouraged to come five days a week. At first he was reluctant, then eventually it was cut to four, then to three and then to two; the very building has been downsized. There used to be a bus went out around the country collecting people to come to New Horizons and they had to pay off a whole lot of the instructors, so the thing is it is not funded the way it used to be". (P3 FG3)

6.3.3 Developments for AMH New Horizons

A number of discussions took place about areas where AMH New Horizons could develop services for the benefit of the person attending or for their relatives.

One participant expressed the lack of help for carers during the second Focus Group. It would appear these participants benefited from just coming along to discuss their issues; this is a development AMH New Horizons could consider. This is the dialogue that followed:

"There does seem to be stuff in place for the person who is suffering but for the carers, there doesn't seem to be help". (P1 FG2)

"I wouldn't really even sit down with the kids like this, it has been really good. I wouldn't mind coming here every say six weeks or so and getting it all off your chest". (P4 FG2)

"Yes me too". (P1 FG2)

Later the following discussion took place in the same Focus Group:

"We don't really know each other we have never met but this was good". (P2 FG2)

"You don't want to analyse in front of the kids, you want that kept away". (P4 FG2)

Another area for development related to the social aspect for a person recovering from serious mental health problems. One mother attending Focus Group 1 stated the following:

"I thought there could be more of a social aspect to New Horizons, like not just 9-5 sessions but maybe there should be something in the evenings…Maybe less structure more of a therapeutic or a recreational type. There's not a lot to do in (names county)*. It is a very rural county and a lot of these people find it hard you know to get transport in and maybe meet and mix and feel sort of out of it or whatever. So if there was something, maybe not in this building, but something that was organised and it was more integrated into the community".* (P2 FG1)

One mother in Focus Group 1 felt that AMH New Horizons was a well kept secret and that people were not accessing its services due to lack of knowledge about its existence and what it did, she said:

"…if a mum comes to me or dad or a whatever you know why don't you suggest to the person who is working with them, the CPN or social worker, you know what about New Horizons. But the information it depends on who you are working with and I always have said New Horizons has been the best kept secret here in (names county). *A lot of clients in here would tell you the same they didn't realise that the place existed and you sometimes can't understand why they weren't referred in you know. So for whatever reason maybe they thought that they weren't well enough or that they just wouldn't you know. You can take a hunch about a person and get it quite wrong but I think you should always give out the menu anyway and just let them pick you know".* (P2 FG1)

This same issue was raised in another Focus Group one father said:

"I found out about New Horizons completely by accident. I was on the internet one day and I found out about it and I spoke to the employment officer in the employment centre and she said oh you don't want to be going there it is just old people who go there you know it would be no good for (names son)*. I came down and I met the staff. He is able to do things, he is doing lower level computer courses but he is able to keep his skills going. He has been doing this for two years and he is doing his maths and he is working in the* (names organisation) *as, believe it or not,* (names job role) a*s a volunteer. He has done this for eight years, it is a high level job and he is supported here and all that. It is very hard to explain as a carer, the problem with this is that I can't bear to see him sitting doing nothing at home after all that time spent on education and all the time I have put in wasted. So at least here he is doing something useful. He is keeping his skills up, he is not socially isolated, he meets other people here, he goes out on outings, and being an autistic person you are not a very sociable person. He finds it very, very hard to mix with other people. This is the only chance that he gets in his life because of our family circumstances to meet anybody else. Other than that he would be leading a monastic existence. So somewhere like this has proved the employment officer wrong in the sense that he is meeting other*

people, he gets on well with the staff and the most important thing is, he is happy, he has more confidence because he had lost his confidence". (P3 FG4)

Finally, this same father in Focus Group 4 felt AMH New Horizons should be funded directly from Government as it met a massive need for some people, he said:

"The New Horizons programme should be jointly funded by Department of Health, Department of Education, and Department for Education and Learning budgets, not lottery funding. They should recognise AMH fulfils a huge need that they are failing to fill, it is providing a lifeline for some of the most vulnerable people; mental health is always at the bottom of the heap". (P3 FG4)

This theme clearly shows AMH New Horizons has a lot to offer both the people attending and also the wider family. It also highlights that AMH New Horizons has some areas to address and should consider developments to enhance its services.

6.4 Theme 4 – Challenged by the health and personal social services system

An issue that came up again and again in the different focus groups related to having difficulties with the health and personal social services system in Northern Ireland. This system is meant to assist families and carers in need of help but the participants in this study reported all too often that the system became an obstacle to overcome or even fight to get the care their relative needed.

A sister taking part in Focus Group 1 felt she had really battled to get information about her brother or get professionals to take her seriously, she stated:

"…sometimes you're going from health professionals to you know hospitals and you are not getting the information. It's one of those things that you know, it's something I would find, it's just hit and miss. It's going yourself to try and find the answers, trying to find the right people to talk to and that sometimes is very infuriating because you really don't know what to expect and you don't always feel like you're getting the right information. There is a lot of you know, we had a situation where my brother would have been released from hospital, and we knew he was very very ill, like very ill and in fact I would have nearly put a danger to the public, a danger to himself and yet they did release him from hospital and within what two days 48 hours, he's back in hospital thankfully. But it was up to us to get him back in if you know what I mean, and that makes you very kind of that's a very hard thing to live with, the fact that your brother could be out there and could do something to somebody else and the health professions are not listening to what you're telling them. Because you've had the years of experience, you have had 9 years of living this or 10 years of living with this and you can see the patterns, you know this person better than anybody else and that sometimes is a real difficulty I would find". (P3 FG1)

This same woman later in this Focus Group went on to describe a very disturbing incident about her brother and explain she got more help from the PSNI than the local Health and Social Care Trust, she said:

"We had a situation a few years, a good few years, back with my dad at 70 years of age went into the local mental health you know place and just literally begged them to come and talk to my brother. Because he knew he was getting really unwell and they had actually already spoken to him and believed that myself and my father had dug a shallow grave the back of our house and you know had actually accepted (laughed) that my brother that this was the truth until 24 hours later my brother broke all the windows in the house and then they arrived up and that is something that you know really galls me. I have to say the situation and I had actually gone to the police at that stage you know to say look there is something …… in fact I got more support from the PSNI than I felt I got from, you know. They were actually very sympathetic and said look ring and we will do something because they knew they would kinda would know the family and myself and knew this was ridiculous. But the actual health the mental health professionals they actually took his word and said well actually you are bullying him …… it took so much for my father at 70 years of age to walk into (hospital) *and literally and that was one of the things that was really I would say probably the lowest point where I just thought there is no hope. There was you know at that point over those few days as a family we were just sitting with broken windows and just the whole thing and eventually as I said he was sectioned and brought into hospital and he was safe. But it was an awful thing to have to go through and to believe that someone would believe that of you, you know I have four children and I have you know".* (P3 FG1)

A mother in this same Focus Group also found great difficulty in getting her concerns taken seriously, she said:

"For a year and a half prior to getting help for (names daughter) *I knew there was something wrong and for a year and a half solid I was up every week up to A&E out of hours. The receptionist knew my life knew who it was and everything before I could get you know they would take it seriously there was something badly wrong here".* (P2 FG1)

A father spoke of his frustration at the wider Government system and how it can spend so much time and energy on people to a point but that assistance can come to a shuddering halt, he stated:

"…there is a whole array of people and I am focusing on people who are sixteen to mid-twenties, who come through an education system and then have left the system and there is nothing, absolutely nothing and all that money that has been spent in educating them, classroom assistance and so on and support has all been wasted and unless you have somewhere like this place, where they can retain their skills and go and keep their skills alive and do courses and social activities they become totally isolated". (P3 FG4)

This father later spoke of his frustration with the system and the lack of practical help his son and family get, stating:

"Well from the carer point of view we are not really getting anything of any use from social services. Anything we have got we have paid for ourselves. I have done a lot of work with (names son) *myself because I was a psychology graduate, I am not an expert but I probably know* (names son) *better than the psychologist and the psychiatrists in the*

hospital and I know the intervention strategies and still on occasions he throws wobblers and it is very difficult to bring him round. But if you rang the doctor or rang social services to come round and see a psychologist and you may wait three months and they don't understand that he is up there in his room now and he won't come out and he won't eat anything and three months is no good". (P3 FG4)

A mother found getting help for her daughter was almost impossible and had to pay privately for care that should be available locally, she said:

"She has been in England being tube fed and now they say she probably has border line personality disorder for which there isn't a service available. The monies have been allocated but it has not been set up here yet, if you want help you have to go to (names city). *We paid to go and see* (names psychiatrist in city), *we got a few appointments privately but at one stage they would have taken them from here, you paid £100 and they took them but not anymore the government doesn't allow them to take them from here so at the minute she is waiting to hopefully get psychotherapy up at what was* (names hospital) *and that is through* (names psychiatrist) *but she won't get the self-harm team even though she needs it. Her left arm is just cut off her…"* (P4 FG4)

It would appear that some health professionals do not easily identify the work carers do and the potential consequences for the HPSS if a carer is not supported when needed. One participant during Focus Group 3 described a worrying incident and the response she received she felt was poor, she stated:

"Mummy had taken a stroke two years ago and I had phoned up (names brother) *CPN looking for what there is for us. She said to me if it is not about* (names brother) *you will need to go and find your own social worker for your mum".* (P2 FG3)

Her mother responded directly saying she felt she had little help when she was so ill herself she went onto say:

"You know my family is all married and away". (P1 FG3)

Her daughter then said:

"I said if we could even get him in here another day, you know to give him a little bit more support and I was totally gob smacked and probably too emotional to deal with it and I would be angry saying you know I am only here for (names brother) *you know you need to go and find your own social worker for your mum and I was saying you know mum is* (names brother) *carer".* (P2 FG3)

A sister in Focus Group 1 reported ringing about her brother who was in crisis; she was shocked by the reaction she received from a health professional, saying:

"But I got somebody else recently during a crisis and their attitude was diabolical and they worked in the same place and they were so really rude to me on the phone and not a bit and I was just you know ringing as a sister concerned and I couldn't believe. I got off the phone and just cried because I couldn't believe I had been spoken to like that. I did think

about you know ringing back and putting in a complaint, didn't do it but I knew it is hit and miss if I had got his CPN it wouldn’t be like that”. (P3 FG1)

During Focus Group 3 a mother felt that the HPSS locally discharged people very quickly and what help was offered was of little practical benefit, she said:

“There are no rehabilitation services apart from agencies like this. They are supposed to be through the health service but the fact is that they are so under pressure that they kind of dismiss people when they come out of hospital. They are signed off very, very, quickly and so you are left with absolutely no help or support really in practice. They will say they are still supervising but in actual fact it doesn’t come to anything practical or helpful”. (P4 FG3)

The other participants in the Focus Group went on to say:

“*Maybe once a fortnight the CPN maybe but all they say is are you taking your tablet and go away again”.* (All FG3)

One participant went on to highlight her individual experience with an Occupational *Therapist, saying:*

“I have an OT lady and I honestly don’t know what she gets paid for. That is the truth, I don’t know what she does. Anything I ever ask her she can’t”. (P3 FG3)

Changes in the health and social care system have not always appeared beneficial this participant stated the following:

“Again another reason for continuing sort of things like this I mean again because of the cuts my son doesn’t have anyone official visiting us, there is someone that I am supposed to phone if there is a problem but when would you ever phone someone that you have never clapped eyes on before”. (P4 FG3)

A father in Focus Group 4 had a similar experience of almost being cut off from services. His concerns were worrying, he said:

“Could I add to that in our own particular circumstance and as I said there is only the two of us and just in the last few year I have been quite ill with a lot of different illnesses and we were completely at a loss as to what could happen to (names son) *in the sense that because he didn’t have a social worker and he had left college no one really knew that he existed any more in other words. God forbid if we had both been killed in a car accident, you know we don’t go out together in the car in case something like that happens. The only people that know officially that* (names son) *exists at the minute are New Horizons. We don’t have a social worker, we have a GP but he doesn’t check up to see how* (names son) *is. You only see your GP when you go to him rather than he checks up on you and we worry. I have actually got to the stage that I have produced a list of emergency numbers for him and it sounds neurotic for some reason and as you say none of us would really trust ourselves to leave him home on his own so we produced these numbers and if for some reason your mummy or daddy doesn’t come home you know give it an hour or two and then ring these numbers and tell them that* (there is something wrong with) *one of*

your parents or both of them. Because as I said when we lost our social worker I put this to them, I said what would happen if both of us were killed in an accident and (names son) *was at home on his own,* (names son) *wouldn't know, he couldn't cook a meal, he wouldn't wash his clothes or anything and he might not even bother phoning. He might be on the internet for days on end. I said how do you know and ah it will not happen, it will not happen and I said could you give me the statistical probability, could you work that out - blank face".* (P3 FG4)

This theme graphically exposes some of the very real barriers and difficulties carers face trying to get help from health and personal social services providers in Northern Ireland.

6.5 Summary of focus group findings

The four focus groups with carers of clients attending AMH New Horizons were very enlightening in respect of their experiences on a daily basis. The participants really engaged with the study and obviously had a lot they wanted to say about their relative and their families' experiences. They really wanted to tell their stories and we feel we have helped to facilitate that to some extent. The carers spoke openly, with real integrity and often with great insights. They were articulate about what they had experienced, the experiences of their relative and their hopes and fears. We thank them all for their participation. The findings of the focus groups are summarised below.

The overwhelming experience of those carers that attended the focus groups was the high esteem they had for AMH New Horizons. They continually highlighted graceful care where the staff of AMH New Horizons really cared for and supported their relative and encouraged them back to health. Also that the programme provided their relative with structure, purpose and social interaction, which, in their opinion, was vital for recovery.

They clearly felt that AMH New Horizons was a real saving to the Health and Personal Social Services in Northern Ireland. They reported that their relative gained better mental health by attending AMH New Horizons and soon used fewer services, needing less contact with professionals and, on occasions, less medication.

They also clearly expressed other indirect savings to the local economy by their relative attending AMH New Horizons. When their relative was at AMH New Horizons they felt assured they were being cared for by professionals who cared for them and had their best interests at heart. This respite allowed them to relax a little, to continue with their life and often to continue to work. By facilitating carers to continue in employment the Exchequer benefited by income from tax revenue and was not paying welfare benefits for more people (the carers) who could easily end up ill themselves and, therefore, possibly claiming benefits.

Participants saw many possible new developments for AMH New Horizons such as support for carers, more social outlets for the clients and advertising the existence of AMH New Horizons and the services provided. A number of participants felt that AMH New

Horizons needed to be centrally funded by Government departments to ensure stability of services.

Areas of concern about AMH New Horizons were the handling of exit strategies and the cuts in the programmes which AMH New Horizons offers. Often it was cited that these cuts were due to funding issues which could be resolved by receiving mainstream funding from Government departments. These recurring issues had caused many anxious periods for clients attending AMH New Horizons and for their relatives. It was said they had precipitated contact with health and personal social services, sometimes leading to admissions to hospital and the subsequent emotional costs to clients and their families as well as the financial costs to the HPSS. Conversely, attendance at AMH New Horizons is very inexpensive, saves a lot of disturbance to the client and their relatives and reduces the burden on mental health services.

A major issue to arise from the focus groups did not directly relate to AMH New Horizons but related to the care provided locally by health and personal social services professionals. The participants gave numerous examples of contacts with the HPSS which were very difficult to say the least. Instead of being an organisation which facilitated people to regain and keep their health, for many of the participants it became an obstacle to work around.

7.0 Discussion and recommendations

This study employed a whole systems economic perspective to assess the financial savings to mental health care through engagement in the AMH New Horizons programme. Change in direct Health and Personal Social Services utilisation was costed as were savings to the Exchequer and society, as measured by the estimated increase in economic output through increased productivity and income tax revenue. Importantly, the change in health-related quality of life for respondents and carers of clients in the AMH New Horizons programme were measured. All savings to services were appropriately based on the full costs. In economic evaluations it is desirable to measure service utilisation and associated costs comprehensively. While an ideal source would be well populated, complete and accurate data from each service provider, it is unlikely these sources would have the breadth or depth of information required. Therefore, the validated Client Service Receipt Inventory (CSRI) (Beecham and Knapp 1999) was used to capture use of services. Data were collected on both frequency and intensity of use of services.

The findings from our study are consistent with those in the literature. It has been confirmed that Action Mental Health's New Horizons programme is effective in: reducing the utilisation of health and personal social services; reducing hospital re-admissions; improving mental health; increasing employment rates and; reducing welfare benefits (Burns et al. 2007; National Mental Health Development Unit 2012). These findings are closely aligned to the recommendations in *Transforming Your Care A Review of Health and Social Care in Northern Ireland* (DHSSPS 2011b) related to the promotion of mental health, a reduction in use of hospital services and the provision of services within the community by third sector organisations. Unanticipated benefits to carers of clients included much needed respite care and security from knowing their relative was well cared for. Carers held the programmes and the caring from Action Mental Health staff in the highest esteem and they are now very concerned about the impact of financial cuts on the mental health of their relatives. These overall findings are discussed in more detail below.

Globally, nationally and regionally mental health problems significantly affect large numbers of individuals (WHO 2010a; NHS Confederation 2009; DHSSPS 2011a). The resultant financial costs and poor health and psychological wellbeing are of concern for governments, communities, families and individuals (WHO 2010b; DoH 2011; DHSSPS 2005; 2007). There is a strong evidenced relationship between unemployment and mental health (Mclean et al. 2005; Perkins et al. 2009) and both the literature (National Mental Health Development Unit 2012) and government policy recognise that inclusion and employment are central to effective recovery from mental health problems (WHO 2010b; DWP and DoH 2009; DHSSPS 2005; 2007).

Action Mental Health aims to enhance the quality of life and employment of people with mental health needs or a learning disability. The AMH New Horizons programme provides training for employment through vocational qualifications, employment preparation training and day support services for ongoing support.

7.1 Demographics

Relative to global proportions (WHO 2012b), a higher proportion of the respondents in our study had been diagnosed as having depression/anxiety or a mood disorder (54.3% v 33.6%) and schizophrenia (13.8% v 5.8%) and a much lower proportion (4.8% v 27.8%) had been diagnosed with alcohol problems. The potential effects of this differential in diagnoses are increased costs for people with schizophrenia as they would usually have longer-term engagement with services and increased prevalence of self-harm by those suffering from depression, although this is dependent on the severity of depression.

7.2 Savings to Health and Personal Social Services and society

The research design enabled examination of change in service utilisation across an average 14-month period. Economic returns accrued on three fronts: HPSS spending, increased economic productivity and improved QALYs for clients and carers.

7.2.1 Savings to Health and Personal Social Services

The majority of services used by respondents were provided by statutory health and personal social services professionals and were mainly community-based. There has been a 39% reduction in the cost of community-based service utilisation, resulting in estimated annual savings of £2,227 per client and £4,057,813 across the AMH New Horizons programme.

It is likely that if clients were not attending the AMH New Horizons programme they would be availing of day care services for the two days a week they currently attend. Thus, engagement in the programme is saving the HPSS £5,120 per client and £9,328,494 across the programme.

The majority of those with an inpatient admission were diagnosed with a psychotic disorder or depression/anxiety/mood disorder (27% and 36% respectively) and had an average length of stay of 32 days which is in line with the literature (OECD 2008). Almost six in ten admissions (56%) were for self harm/attempted suicide. Hospital admissions have reduced by 91% since engagement in the AMH New Horizons programme. This concurs with the literature which reports that people with severe and long-term mental health problems who are given support to return to the workplace report fewer and shorter subsequent hospital stays than people receiving normal mental health services (National Mental Health Development Unit 2012). The estimated saving from the 91% reduction in hospital admissions was £6,837 per client (cost per day x difference in mean LOS) or £12,457,524. This equates to an annual saving of £10,777,959 across all New Horizon clients or £5,915 per client. Qualitative data from carers support the premise that the reduction in hospital admissions is attributed to the care and support of Action Mental Health staff. The estimated annual saving for premature mortality from suicide is £17,310,202.

Informal care is not generally paid for but it clearly has an economic value which has been estimated at £21,000 per carer in the UK (Buckner and Yeandle 2011). The estimated saving to the HPSS for informal care provision by family is £4,208,820. As in the literature (WHO 2003; Singleton et al. 2002; Carers UK 2012b) it was found that the impact of mental health problems was wide reaching within families. Carers shared their experience of siblings leaving home due to the strain of not being able to cope and disruption to family life, even when the person with the mental health problem was living outside the family home. The dependence placed on parents by children reduced the opportunities for a social life for the parents.

A number of ‘added values’ of the AMH New Horizons programme which were not captured in the client survey were evidenced in the focus groups with carers. The programme provided structure, purpose and social interaction, which the carers perceived enhanced their relative’s mental health. The carers also experienced a hidden, but valuable, gain in the form of respite, safe in the knowledge that their relative was being looked after by staff who had the individual’s wellbeing to the forefront of all they did. Conversely, carers worried about cuts in funding for AMH New Horizons and resultant cuts in both the number and range of programmes their relative could attend and the length of time they could remain in the programme. The issue of an exit strategy was a concern for many and this was seen to be destabilising for their relative.

Carers expressed concern about the decreasing support the HPSS could offer and, while a crisis often appeared to be dealt with in a satisfactory manner, there appeared to be little or nothing of any tangible help on offer within HPSS after the crisis had settled. While good examples of care by the health and personal social services professions were reported by carers, on balance more often care was reported as being poor and, at times, unacceptable. On far too many occasions carers reported feeling let down by the HPSS and having to fight the system to try and get help. The only help the carers could identify was AMH New Horizons. If AMH New Horizons were not able to meet this obvious need, not only would the person with mental health problems suffer but also the health and wellbeing of the carer would deteriorate and potentially demand for HPSS services would increase. These concerns are similar to those reported by carers throughout Northern Ireland (DHSSPS 2001; Carers UK 2012b).

7.2.2 Savings to the Exchequer

Government policies recognise the importance of social inclusion for people with mental health problems and specifically the role of employment as being central to effective recovery from their mental health problem (UN 1948; WHO 2010b; DWP and DoH 2009; DHSSPS 2005; 2007). Based on an employment rate of 3.84% the annual contribution to the Exchequer from employment through engagement in the AMH New Horizons programme is £460,550 from economic output and tax revenue. Across Northern Ireland programmes such as AMH New Horizons could potentially help 1,920 people who are not working on the grounds of mental and behavioural disorders back into employment.

These initial returns from employment are low but will increase if clients obtain full-time employment and/or stay in work long-term.

The Centre for Social Justice (2010) reported that in NI in 2009 the majority of people claiming illness-related out-of-work benefits did so on account of mental and behavioural disorders. Eighty-six per cent of these claimants had been receiving benefits for more than three months (DWP and DoH 2009). In our study four in ten respondents (42%) were in receipt of Incapacity Benefit and just over half (54.5%) were in receipt of at least one component (care or mobility) of Disability Living Allowance prior to engagement in the AMH New Horizons programme. Proportions in receipt of benefits for more than three months were similar to those found in the general population with a mental health problem; 80% for Incapacity Benefit and 92% for Disability Living Allowance. The estimated savings in Incapacity Benefit from employment were £1,645. It should be noted these savings from state benefits do not take account of the statistically significant reduction in DLA (care component) as, due to the complex rules for this benefit, savings could not be costed. Nor do they take account of any reduction in client dependency on other welfare and housing benefits.

7.2.3 Improved health-related quality of life for clients and carers

A further measure of the improvement in the mental health of respondents was the statistically significant improvement in their health-related quality of life (usual activities, pain/discomfort and anxiety/depression). The mean improvement was equivalent to 0.172 of a QALY, equating to an annual saving of £10,303,036 across AMH New Horizons clients. There was also a 28% improvement in respondents' mean psychological wellbeing score as measured by the EQ-5D.

The prevalence of mental health problems has a direct impact on the experiences of carers and families. The majority of relatives were living with those they cared for full-time with almost half being the sole carer and a further third being the main carer. Respite care was provided mainly by family and friends and it is of concern that more than half of carers were unable to take a break from caring. Only one-third reported use of supported activities outside the home. Carers of relatives engaged in the AMH New Horizons programme also reported an improvement in their health status and health-related quality of life scores since their relative joined AMH New Horizons. The mean improvement was equivalent to 0.0.35 of a QALY, equating to an annual saving of £230,620 across carers of AMH New Horizons clients (estimated at 11%).

7.2.4 Total savings from engagement in AMH New Horizons

Economic evaluation is not about saving money but about producing the best outcomes with available resources and budgets. We have unequivocally demonstrated the economic case for investing in the AMH New Horizons programme to address mental health problems in individuals and to produce wider benefits to society. AMH New

Horizons is a highly efficient ‘cost-saving’ programme i.e. it reduces costs while improving health. Investment in the AMH New Horizons programme can help to achieve the objectives and targets related to mental health in Northern Ireland policy through providing a good quality of life and improving employment opportunities (DHSSPS 2003; 2005; 2007). Furthermore, it has been clearly shown that engagement in the programme reduces the need, and associated costs, for high cost HPSS services thus reducing the economic burden of mental health in Northern Ireland. AMH New Horizons is not only economically viable but is a better use of public money than traditional mental health services alone.

A modest economic estimate of the annual saving to society resulting from engagement in the AMH New Horizons programme is £50 million. This equates to annual savings of £27,443 per client and £528 per client per week. The annual Return on Investment is £27.19 for every £1 invested by Health and Social Care Trusts. Such savings are particularly welcomed in light of the continuing financial cutbacks in departmental spending (Appleby 2011). The very important non-financial benefits of improved health and quality of life for clients and carers were also demonstrated.

7.3 Strengths and limitations of study

The main strength of the study is the use of a whole systems economic perspective, using a longitudinal study with a 15-month follow-up period. Our analyses are based on empirical data and extrapolated costs are conservatively based on the proportion of respondents who used services, obtained employment and/or were in receipt of state benefits. Hence, savings are not inflated. Costs are usually higher at diagnosis, however, those individuals with acute mental health problems would not be eligible for the AMH New Horizons programme, hence, estimated savings are not inflated. The study has also, in some small measure, started to address a gap in the literature pertaining to the effects on carers and families of caring for people with mental health problems.

Our study has some limitations. Retrospective data collection can be problematic due to recall bias. However, recall bias was most likely to occur at Point 1 when clients were asked to provide data relating to 3 months prior to entry to the programme and evidence has shown significant under-reporting of frequent events retrospectively over a 6-month period (Jobe et al. 1990). Thus, the estimated saving from participation in the AMH New Horizons programme is most likely an underestimation.

Although the CSRI is a validated tool for use with people with mental health problems, it proved to be a challenge for these individuals to complete. Completion of questions on medications was poor and yielded insufficient information to enable any change in medication to be calculated. However, it is unlikely that medications would have changed to any great extent over an average period of 14 months. Although the measures of clients’ and carers’ health status and wellbeing are subjective, self-reported health has been shown to be a strong indicator of ill-health (Hansbro 1997).

7.4 Unmeasured outcomes from engagement in AMH New Horizons

As a credible valuation has been used for each of these components, the resultant calculated saving from engagement in Action Mental Health's New Horizons programme is a very conservative estimate. The increase in HPSS costs between 2008/09 and 2010/11 has not been accounted for. Furthermore, a number of impacts from the programmes could not be measured:

- enacting Mental Health Order
- savings in welfare and housing benefits, other than Incapacity Benefit
- savings to third sector organisations such as homeless hostels
- savings to the criminal justice system
- social impact on individual, families and wider society
- reduction in medications due to poor completion of this section of the questionnaire and the time-bound nature of study
- potential reduced use of services by carers
- change in use of services associated with client co-morbidities
- savings from carers' retention of employment

7.5 Need for further research to determine full extent of outcomes from engagement in AMH New Horizons

- research to provide insight into the intangible benefits to clients and carers through engagement with Action Mental Health services
- economic impact on carers through lost opportunities for employment and effect on physical and psychological health
- temporal sequence of mental health problems and unemployment
- tangible gains to the Exchequer from AMH New Horizons programme
- quantitative and qualitative research that explores the outcomes and quality of life benefits enjoyed by 'Leavers' from the AMH New Horizons programme

7.6 Recommendations

1. The statutory sector should invest in targeted interventions and services that make a difference to people with mental health problems. Mainstream, recurrent funding should be available for the AMH New Horizons programme.

2. Enhanced investment in the AMH New Horizons programme should be considered to ensure that individual clients remain in the programme based on assessed need and not based on available funding.

3. Services should be developed to deliver approaches that offer support to people who are no longer entitled to remain in the service but may still need support.

4. The exit strategy from the AMH New Horizons programme should be planned sensitively in conjunction with the client and, on the request of the client, relatives.

5. The ‘added value’ of purpose, structure, socialisation and inclusion in a community should be developed through the inception of social activities, including evenings and weekends. This would help in the recovery process and also benefit the carer. Resource implications would be associated with this development.

6. Services should be promoted to the general public and other public agencies by Action Mental Health and mental health professionals. The capacity to deal with increased demand for services would obviously be dependent on levels of funding.

7. Action Mental Health should consider establishing a forum for carers of clients where they will benefit from the support of peers in a caring role. Resource implications would be associated with this development.

References

Action Mental Health 2012 *What do we do*?
http://www.amh.org.uk/about/what-we-do [accessed 15th May 2012].

Appleby J (2011) *Rapid review of Northern Ireland health and social care funding needs and the productivity challenge: 2011/12-2014/15.* Belfast: DHSSPS.

ARK (2007) *Fit and well? Health and health care*.
http://www.ark.ac.uk(publications/books/fio/07_fio-health.pdf [accessed on 25th May 2012].

Barry M M and Jenkins R (2007) *Implementing mental health promotion*. China:Elsevier.

Bartley M (1994) Unemployment and ill health: understanding the relationship. *Journal of Epidemiology and Community Health* 48, 333-337.

Beecham J K and Knapp M R J (1999) Costing psychiatric interventions. *In* Thornicroft G ed. *Measuring mental health needs*. Chapter 12.

Blakely T A, Collings S C D, Atkinson J (2003) Unemployment and suicide. Evidence for a causal association. *Journal of Epidemiology and Community Health* 57, 594-600.

Buckner L and Yeandle S (2007) *Valuing Carers – Calculating the value of unpaid care*. Leeds: CARERS UK.

Buckner L and Yeandle S (2011) *Valuing Carers – Calculating the value of unpaid care*. Leeds: University of Leeds and CARERS UK.

Burns T, Catty J, Becker T, Drake R E, Fioritti A, Knapp M, Lauber C, Rössler W, Tomov T, Busschbach J, White J, Wiersma D, for the EQOLISE Group (2007) The effectiveness of supported employment for people with severe mental illness: a randomised controlled trial. *Lancet* 370, 1146–52.

CARERS UK (2001) *It could be you, the chances of becoming a carer*. London: CARERS UK.

Carers UK (2012a) *Facts about carers in Northern Ireland*.
http://www.carersuk.org/about-carers-northern-ireland/facts-about-carers-ni [accessed 17th June 2012].

Carers UK (2012b) *Carers' health buckling under the strain.*
http://www.carersuk.org/news-northern-ireland/item/2610-cw2012-research [accessed 22nd June 2012].

Centre for Social Justice (2010) *Breakthrough Northern Ireland*. London: Centre for Social Justice.

Chief Medical Officer for Northern Ireland (2010) *Your health matters. CMO NI Annual Report.* Belfast: DHSSPS.

Department of Health (2011) *No health without mental health: A cross-government mental health outcomes strategy for people of all ages.* London: DoH.

Department of Health (2012) *Home Page Carers*. http://www.dh.gov.uk/health/category/policy-areas/social-care/carers/ [accessed 16th May 2012].

Department of Health, Social Services and Public Safety (2001) *Informal carers report. A report from the health and wellbeing survey 1997*. Belfast: DHSSPS.

Department of Health, Social Services and Public Safety (2002a) *Investing for health*. Belfast: DHSSPS.

Department of Health, Social Services and Public Safety (2002b) *Valuing carers – A strategy for carers in Northern Ireland* . Belfast: DHSSPS.

Department of Health, Social Services and Public Safety (2003a) *Promoting mental health – Strategy and Action Plan 2003-2008*. Belfast: DHSSPS.

Department of Health, Social Services and Public Safety (2003b) *Safety first: national confidential inquiry into suicide and homicide by people with mental illness.* Belfast: DHSSPS.

Department of Health, Social Services and Public Safety (2004) *A healthier future. A twenty year vision for health and wellbeing in Northern Ireland 2002-2025.* Belfast: DHSSPS.

Department of Health, Social Services and Public Safety (2005) *A strategic framework for adult mental health services*. *Bamford Review of Mental Health & Learning Disability.* Belfast: DHSSPS.

Department of Health, Social Services and Public Safety (2006a) *Mental health improvement and well-being – a personal, public & political issue*. *Bamford Review of Mental Health & Learning Disability.* Belfast: DHSSPS.

Department of Health, Social Services and Public Safety (2006b) *Protect life: A shared vision – The Northern Ireland suicide prevention Strategy and Action Plan 2006-2011*. Belfast: DHSSPS.

Department Health, Social Services and Public Safety (2006c) *Caring for carers – Recognising, valuing and supporting the caring role*. Belfast: DHSSPS.

Department of Health, Social Services and Public Safety (2007) *Promoting the social inclusion of people with a mental health or learning disability. Bamford Review of Mental Health & Learning Disability*. Belfast: DHSSPS.

Department of Health, Social Services and Public Safety (2008a) *Delivering the Bamford Vision. The response of Northern Ireland Executive to the Bamford review of mental health and learning disability*. Belfast: DHSSPS.

Department Health, Social Services and Public Safety (2008b) *Draft strategy for the development of psychological therapy services*. Belfast: DHSSPS.

Department of Health, Social Services and Public Safety (2010) *Investing for Health Strategic Review.* Belfast: DHSSPS.

Department of Health, Social Services and Public Safety (2011a) *Health survey Northern Ireland. First results from the 2010/11 survey*. Belfast: DHSSPS.

Department of Health, Social Services and Public Safety (2011b) *Transforming Your Care. A Review of Health and Social Care in Northern Ireland*. Belfast: DHSSPS.

Department for Social Development and Department of Health, Social Services and Public Safety (2009) *Review of the support provision for carers*. Belfast: DSD and DHSSPS.

Department for Work and Pensions and Department of Health (2009) *Working our way to better mental health: A framework for action*. London: TSO.

Doherty D T and Moran R (2009) *Mental health and associated health service use on the island of Ireland.* Dublin: Health Research Board.

Donaldson L J and Scally G (2009) *Essential public health* 3rd ed. Oxford: Radcliffe Publishing.

Donne J (1624) *MEDITATION XVII* http://www.luminarium.org/sevenlit/donne/meditation17.php [accessed 3rd March 2012].

Dorling D (2009) Unemployment and health *BMJ,* 338, b829.

Equal Opportunities Commission (2005) *Autonomy, voice and power. Care and support survey by IPSOS MORI*. Chapter13. http://www.equalityhumanrights.com/uploaded_files/triennial_review/how_fair_is_britain_ch13.pdf [accessed 24 April 2012].

EuroQuol Group (2009) *EQ-5D User guide basic information on how to use EQ-5D. EuroQol Group* www.euroqol.org [accessed 14th August 2010].

Fontaine K L (2009) *Mental Health Nursing*. 6th ed. New Jersey: Prentice Hall.

Francis J and McDaid D (2009). SCIE's work on economics and the importance of informal care. In *Personal Social Services Research Unit costs of health and social care*. Canterbury: PSSRU, 27-33.

Friedli L and Parsonage M (2007) *Mental health promotion: Building an economic case*. Belfast: Northern Ireland Association for Mental Health.

Friedli L and Parsonage M (2009) *Promoting mental health and preventing mental illness: the economic case for investment in Wales.* Cardiff: All Wales Mental Health Promotion Network.

Gunnell D, Bennewith O, Peters T, House A, Hawton K (2004) The epidemiology and management of self-harm among adults in England. *Journal of Public Health* 27 (1), 67-73.

Hansbro J. 1997 *Health in England 1996. What people know, what people think, what people do: a survey of adults aged 16-74 in England.* Social Survey Division of ONS on behalf of the Health Education Authority. London: TSO.

Jobe J B, White A A, Kelley, C L, Mingay D J, Sanchez M J, Loftus E F (1990) Recall strategies and memory for health-care visits. *The Milbank Quarterly* 68 (2), 171-189.

King N and Horrocks C (2010) *Interviews in qualitative research*. London: Sage.

Krueger R (1998) *Analysing and reporting focus group results*. London: Sage.

London School of Economics and Political Science (2012) *How mental illness loses out in the NHS. A report by The Centre for Economic Performance's Mental Health Policy Group.* London: LSE.

Mathers C D and Loncar D (2006) Projections of global mortality and burden of disease from 2002 to 2030. *PLOS Med* 3: e442.

Mclean C, Carmona C, Francis S, Wohlgemuth C, Mulvihill C (2005) *Worklessness and health – what do we know about the causal relationship*? *Evidence Review*. Health Development Agency http://www.nice.org.uk/niceMedia/documents/worklessness_health.pdf. [accessed 12th May 2012].

MIND (2012) *How common are mental health problems*? http://www.mind.org.uk/help/research_and_policy/statistics_1_how_common_is_mental_distress [accessed 15th May 2012].

National Mental Health Development Unit (2012) *The costs of mental ill health. Fact file three*. http://www.nmhdu.org.uk/silo/files/nmhdu-factfile-3.pdf [accessed 15th May 2012].

National Suicide Research Foundation (2010) *National registry of deliberate self Harm Ireland Annual Report.* Cork: NSRF. http://www.nsrf.ie/reports/2010AnnualReportNationalRegistryOfDeliberateSelfHarmIreland.pdf [accessed 30th April 2012].

NHS Confederation Mental Health Network (2009) *Key facts and trends in mental health*. London: The NHS Confederation.

Northern Ireland Assembly (2012) *Counselling Services: East Belfast*. http://www.theyworkforyou.com/ni?/gid=2012-04-17.8.6 [accessed 31st April 2012].

Northern Ireland Statistics and Research Agency (2003) *NI Census 2001*. Belfast: NISRA.

Northern Ireland Statistics and Research Agency (2012a) *Statistics Bulletin: Deaths in Northern Ireland 2010.* Belfast: NISRA.

Northern Ireland Statistics and Research Agency (2012b) *Statistics Bulletin: Labour Force Survey October to December 2011*. Belfast: NISRA.

Newell R and Burnard P (2006) *Research for evidence-based practice*. Blackwell: Oxford.

Organisation for Economic Co-operation and Development (2008) *Mental Health in OECD countries. Policy Brief*. Paris: OECD.

Office for National Statistics (2011) *Suicide rates in the United Kingdom 2006 to 2010*. London :ONS. http://www.ons.gov.uk/ons/key-figures/index.html#PopulationandMigration [accessed 20th March 2012].

Owens D, Horrocks J, House A, (2002) Fatal and non-fatal repetition of self-harm: systematic review. *British Journal of Psychiatry* 181, 193-199.

Perkins R, Farmer P, Litchfield P (2009) *Realising ambitions: Better employment support for people with a mental health condition*. London: TSO.

Personal Social Services Research Unit (2009) *Unit Costs of Health and Social Care*. Canterbury: PSSRU.

Platt S and Hawton K (2000) *Suicidal behaviour and the labour market. The international handbook of suicide and attempted suicide.* Chichester: Wiley.

Polit D F and Beck C T (2012) Nursing *research: generating and assessing evidence for nursing practice*. 9thed. London: Lippincott Williams & Wilkins.

Princess Royal Trust for Carers (2011) *Always on call, Always concerned. A survey of the experiences of older carers.* Essex: The Princess Royal Trust for Carers.

RETHINK (2009) *Carers' wellbeing and support measure*. http://www.rethink.org/how_we_can_help/research/research_themes/carers_wellbeing_an.html [accessed 20th March 2011].

Royal College of Psychiatrists. (2002) *Employment opportunities and psychiatric disability*. Council Report 111. London: RCPsych. www.rcpsych.ac.uk/publications. [accessed on 24th May 2012].

Royal College of Psychiatrists (2008) *Mental health and work*. London: RCPsych.

Rinaldi M, Montibeller T, Perkins R (2011) Increasing the employment rate for people with longer-term mental health problems. *The Psychiatrist* 35, 339-343.

Sainsbury Centre for Mental Health (2003) *Policy Paper 3: The economic and social costs of mental illness.* London: The Sainsbury Centre for Mental Health.

Sainsbury Centre for Mental Health and Northern Ireland Association for Mental Health (2004) *Counting the cost*. *The economic and social costs of mental illness in Northern Ireland.* Belfast: Sainsbury Centre and NIAMH.

Sarason I G, Johnson J H. and Siegel J M (1978). Assessing the impact of life changes: Development of the life experiences survey. *Journal of Consulting and Clinical Psychology* 46, 932-946.

Singleton N, Maung N A, Cowie A, Sparks J, Bumpstead R, Meltzer H (2002) *Mental health of carers*. London: TSO.

Social Care Institute for Excellence (2011) *Mental health, employment and the social care workforce*. London: SCIE.

United Nations (1948) *Universal Declaration of Human Rights*. http://www.un.org/en/documents/udhr/ [accessed 12th May 2012].

Vieth H (2009) Mental health policies in Europe*.* *Euro Observer 11,3*. Brussels: European Observatory on Health Systems and Policies.

Waddell G and Burton A K (2006). *Is work good for your health and well- being?* London: TSO.

World Health Organisation (2000) *Preventing suicide. A resource for General Physicians.* Mental and Behavioural disorders, Department of Mental Health. Geneva: WHO. http://www.who.int/mental_health/media/en/56.pdf [accessed 14th May 2012].

World Health Organisation (2003) *Investing in mental health*. http://www.who.int/mental_health/en/investing_in_mnh_final.pdf [accessed 18th May 2012].

World Health Organisation (2004) *Promoting mental health; Concepts, emerging evidence, practice. Summary report.* A report of the World Health Organisation, Department of Mental Health and Substance Abuse in collaboration with the Victorian Health Promotion Foundation and the University of Melbourne. Geneva, Switzerland: WHO.

World Health Organisation (2005) *Mental health action plan for Europe: Facing the challenges, building solutions*. Geneva, Switzerland: World Health Organisation.

World Health Organisation (2010a) *Mental health: strengthening our response. Fact sheet No. 220*. http://www.who.int/mediacentre/factsheets/fs220/en/ [Accessed 16th May 2012].

World Health Organisation (2010b) *Mental health and development*: *Targeting people with mental health conditions as a vulnerable group*. http://www.who.int/mental_health/policy/mhtargeting/en/index.html [accessed 16th May 2012].

World Health Organisation (2012) *WHO Mental health*. http://www.who.int/mental_health/management/depression/definition/en/ [accessed 12th May 2012].

World Health Organisation Europe (2012). *WHO Europe Home Page*. http://www.euro.who.int/en/what-we-do/health-topics/noncommunicable-diseases/mental-health/facts-and-figures [accessed 12th May 2012].

Yates T, Carlson E, Egeland B (2008) A prospective study of child maltreatment and self-injurious behaviour in a community sample. *Development and Psychopathology* 20, 651-671.

Appendices

Appendix 1

Client Invitation to Take Part

***Title*: To understand what savings, if any, are made in relation to the health service as a result of people attending Action Mental Health's New Horizons programme.**

Thank you for showing interest in this economic evaluation of the New Horizons programme. Action Mental Health are keen to ensure they provide the best service they can for the people who attend their programmes and to give good value for money to the organisations that help fund their programmes. To ensure this Action Mental Health have asked two staff from the University of Ulster to conduct an economic evaluation. The aim of this evaluation is to identify savings, in any, to the health service and the Exchequer by a client attending the New Horizons programme and also any indirect benefits to carers of clients on the programme. For example, an improvement in a client's health could mean fewer attendances with services such as doctor or CPN. Another saving could be if the client gains work as a result of taking part in the New Horizons programme and comes off all or some of their benefits

This economic evaluation is not about your right to social security benefits and taking part in this evaluation will not affect your benefits in any way. Only the researchers will see the information you provide and please be assured that all information you provide on the questionnaires will be kept confidential.

We hope you would be willing to take part in the evaluation. An information leaflet is attached explaining the economic evaluation. We will be happy to answer any questions you might have about the evaluation. You can contact us by phone or e-mail using the details below.

Derek McLaughlin	Karen Casson
028 90368113	028 903268293
df.mclaughlin@ulster.ac.uk	k.casson@ulster.ac.uk

Client Participation Information Sheet

***Title*: To understand what savings, if any, are made in relation to the health service as a result of people attending Action Mental Health's New Horizons programme.**

Invitation

You are being invited to take part in an evaluation of the economic benefits in taking part in the Action Mental Health New Horizons programme. Before you decide whether or not to take part, it is important that you understand what the evaluation is for and what you will be asked to do. Please read the following information and do not hesitate to ask any questions about anything that might not be clear to you. Make sure that you are happy before you decide what to do. Thank you for taking the time to consider this invitation.

What is this evaluation about?

The purpose of this evaluation is to identify any savings to the Health Service as a result of people with mental health problems attending Action Mental Health New Horizons services. This evaluation hopes:

1. To identify the range of health care professionals and/or agencies clients use at the point of entry to Action Mental Health New Horizons and at intervals thereafter.

2. To identify the number of contacts and frequency of sessions clients make with each health care professional/agency at entry and at intervals thereafter.

3. To determine the sessional costs of professionals time and calculate change in contacts and costs over time with a view to identifying any overall average savings.

4. To provide examples of key life events and/or experiences impacting upon the clients as reported by the client.

5. To identify what social security benefits clients are on, if there is any change in their benefits through attendance at the New Horizons programme and to identify any savings to the Exchequer.

6. To explore with the carers of clients who attend the New Horizons programme the effects on their self and family and if these indirect benefits result in any savings to the Exchequer.

Why have I been chosen?

Action Mental Health New Horizons Services are keen to evaluate their services to ensure they are providing good value for money and helping the people like you who are using their services. We are keen to understand what impact attendance at Action Mental Health's New Horizons programme has on your use of services within and outside the Health Service. You have been asked to take part as you have been in the Action Mental Health's New Horizons programme between 3 and 6 months and should be able, over the next 9 months, to identify any change in services used.

Do I have to take part?

Participation is entirely voluntary and it is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep. If you choose to take part, you can change your mind at any time and withdraw from the study without giving a reason.

What will happen to me if I take part?

If you do wish to take part the staff at Action Mental Health will organise that you attend on a day you can meet with the people who are doing the study. They will talk to you and explain the study again and answer any questions you may have, if you are happy to take part they will ask you to sign a consent form agreeing that AMH staff can provide the researchers with information on your diagnosis and medication. You will be asked to complete one of two questionnaires on three occasions and the second of the questionnaire on two occasions. You would complete this questionnaire in your own Action Mental Health Unit and the researchers will be on hand if you need any help with the questionnaires.   By completing the questionnaires you will have agreed to take part in the study.

Risks and/or disadvantages?

There are no obvious risks to taking part in this study. It is possible that you may become upset. If this happens, Derek McLaughlin is an experienced mental health nurse and he will offer support and liaise with your Action Mental Health staff and NHS staff as appropriate. There are no disadvantages to taking part in this study. There is no risk to any benefit you receive due to your health problems, or, if you have a carer, to the benefits your carer receives.

Are there any possible benefits in taking part?

By taking part in this evaluation you will help us to see if taking part in the New Horizons programme benefits clients by reducing their use of services and/or medication and if it results in a change in social security benefits or being able to return to work. We hope this will benefit others with mental health problems through the continuation of funding for the New Horizons programme. You may also find that completing the questionnaires at 3-month intervals will let you see clearly the progress which has been made in your health and well-being.

What if something goes wrong?

It is very unlikely that anything should go wrong if you take part in this evaluation. If you do not wish to continue you can stop at any time and your programme will continue at Action Mental Health without any consequences to you. If you are unhappy with anything to do with this evaluation you may complain personally to the Chief Researcher Derek McLaughlin using the contact details below or to your Action Mental Health Service Manager who will pass your complaint on to Derek. This study has been approved by an Ethics Committee within the University of Ulster and a Steering Committee within Action Mental Health. If you would like information on this approval please contact the Research Governance Department at the University of Ulster 028 90366629.

Will my taking part in this study be kept confidential?

All data will be held securely and in confidence and no identifiers will be held about you as required under Data Protection Legislation. However, Under the Freedom of Information legislation certain non-personal or generalised data from the evaluation will be accessible. If you disclose information that puts yourself or others at risk the researchers will report this to the Action Mental Health staff caring for you.

What will happen to the results of the study?

A report will be provided to Action Mental Health who have funded this evaluation and a paper may be prepared for publication.

Contact details

Derek McLaughlin
School of Nursing
Jordanstown
028 90368113
E-Mail df.mc.laughlin@ulster.ac.uk

Karen Casson
School of Nursing
Jordanstown
028 90368293
E-Mail k.casson@ulster.ac.uk

Support Organisations

Action Mental Health
Phone 028 9040 3726

NI Association for Mental Health
Phone 028 9032 8474

Client Consent Form

Title: To understand what savings, if any, are made in relation to the health service as a result of people attending Action Mental Health's New Horizons programme

Chief Researcher: Derek McLaughlin

Please initial boxes

- I confirm that I have been given and have read and understood the information sheet for the above study and have asked and received answers to any questions raised [ ]
- I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason and without my rights being affected in any way [ ]
- I understand that the researchers will hold all information and data collected securely and in confidence and that all efforts will be made to ensure that I cannot be identified as a participant in the study (except as might be required by law) and I give permission for the researchers to hold relevant personal data [ ]
- I understand that AMH staff will provide the researchers with material from my AMH file about my diagnosis and medication I am taking [ ]
- I agree to take part in the above study [ ]

Name of Subject	Signature	Date
_______________	________________________________	
Name of person taking consent	Signature	Date
_______________	________________________________	
Name of researcher	Signature	Date
_______________	________________________________	

AMH Reg. Number ________________ *Questionnaire 1* **Appendix 2**

CLIENT SERVICE RECEIPT INVENTORY: ENDEAVOR STUDY

---

1. When did you start the New Horizons programme? ______________________

2. What face-to-face contacts have you had with these professionals in the 3 months before starting the New Horizons programme?
(Note: only record one-to-one contacts here; see next questions for group activities and inpatient care)

Care provider	***Have you had contact? (circle)***	***Usual location*** 1 = GP 2 =Community centre 3 = Hospital OPD 4 = Own home	***No. of contacts in the 3 months prior to starting New Horizons***	***Average duration (minutes)***
A. General practitioner (GP)	*No Yes*			
B. Psychiatrist	*No Yes*			
C. A & E staff member	*No Yes*			
D. Other doctor Specify ________________	*No Yes*			
E. Psychologist	*No Yes*			
F. Drug & alcohol worker	*No Yes*			
G. Other counsellor / therapist NHS Health and Social Care Private Voluntary	*No Yes* *No Yes* *No Yes*			
H.- Home treatment /crisis team/assessment team member	*No Yes*			
I. Social worker	*No Yes*			
J. Mental health nurse/CPN	*No Yes*			
K. Occupational Therapist	*No Yes*			
L. Rehabilitation and Recovery Team member	*No Yes*			
M. Pharmacist	*No Yes*			
N. Other Specify______________	*No Yes*			

3. <u>In the 3 months before starting the New Horizons programme</u> did you use any day care services over and above the contacts identified above (e.g. group activities, attending a drop-in centre etc.)?

Care provider	***Have you had contact? (circle)***	***Name of centre or facility***	***No. of attendances in the 3 months prior to starting New Horizons***	***Average duration (hours)***
A. Drug / alcohol service	*No Yes*			
B. MH resource centre	*No Yes*			
C. Day hospital	*No Yes*			
D. Day Centre	*No Yes*			
E. Drop-in centre	*No Yes*			
F. Self-help / support group	*No Yes*			
G. Class/group at a leisure centre	*No Yes*			
H. Adult education class	*No Yes*			
I. Meals on wheels	*No Yes*			
J. Home help	*No Yes*			
K. Other (specify) _________________________	*No Yes*			

4. <u>In the 3 months before starting the New Horizons programme</u> were you admitted to hospital as an inpatient? Yes **<u>or</u>** No
(Note: please include any secure hospital stays)
(please circle)

<u>If yes:</u>

Name of hospital and ward	***Reason for admission***	***If detained under Mental Health Order***	***Dates***		***Total days***
			Admission	***Discharge***	

5. In the 3months before starting the New Horizons programme did you have any major event occur in your life such as a death of a loved one, marriage, divorce, start of a relationship?
Yes *or* No (*please circle*)

If ***Yes for any of the events*** please fill in the table below with details
If ***No***, please go to Q5

EVENT	***DATE IT OCCURRED***	***HAS IT BEEN POSITIVE OR NEGATIVE TO YOUR MENTAL HEALTH?***
Marriage/new relationship		*Positive* *Negative*
Relationship breakup		*Positive* *Negative*
Death of close family member		*Positive* *Negative*
Death of close friend		*Positive* *Negative*
Serious illness of close family member		*Positive* *Negative*
Foreclosure of mortgage/loan		*Positive* *Negative*
New job		*Positive* *Negative*
Debt		*Positive* *Negative*
Contact with police		*Positive* *Negative*
In a police cell		*Positive* *Negative*
Prison		*Positive* *Negative*
Contact with probation officer		*Positive* *Negative*
Contact with solicitor		*Positive* *Negative*
Court attendance		*Positive* *Negative*
Other __________________		*Positive* *Negative*
Other __________________		*Positive* *Negative*

6. Please list below use of any medications taken in the 3 months before starting the New Horizons programme

Name of drug	***Dosage (if known)***	***Dose frequency (e.g. daily)***	***For how long have you taken this drug?***	***Are you still taking this drug? (please circle)***
1.	mg			*Yes* *No*
2.	mg			*Yes* *No*
3.	mg			*Yes* *No*
4.	mg			*Yes* *No*
5.	mg			*Yes* *No*
6.	mg			*Yes* *No*
7.	ng			*Yes* *No*

7. In the 3 months before starting the New Horizons programme were you a student at college?

Yes **or** No

If Yes, how many days (if any) did you have off from college in the 3 months before starting New Horizons as a consequence of health problems? _________

The next question asks about any state benefits you received in the 3 months before starting the New Horizons programme. This question is to allow us to calculate any potential savings to the Exchequer which may arise should your circumstances change as a result of being on the New Horizons programme. Like all the other information, this information will treated in the strictest confidence. It will not be seen by anyone other than the researchers at the University of Ulster and will be used only for the purposes of the evaluation study of the New Horizons programme. Please be assured that the provision of this information will not affect your entitlement to benefits.

8. What state benefits (if any) did you receive in the 3 months before starting the New Horizons programme and for how long?

Benefit	***Have you received this? (please circle)***	***For how many weeks did you receive it in the 3 months prior to starting New Horizons?***
Income Support	Yes / No	
Incapacity Benefit	Yes / No	
Employment and Support Allowance	Yes/No	
Disability Living Allowance care component	Yes / No	
Disability Living Allowance mobility component	Yes / No	
Disabled Person's Tax Credit	Yes / No	
Severe Disablement Allowance	Yes / No	
Housing Benefit	Yes / No	
Private Housing Benefit	Yes / No	
Jobseeker's Allowance	Yes / No	
Families Tax Credit	Yes / No	
Statutory Sick Pay	Yes / No	
State retirement pension	Yes / No	
Private pension	Yes / No	
Invalid care allowance	Yes / No	
Attendance Allowance	Yes / No	
Child Benefit	Yes / No	
Industrial Injuries Disability Benefit	Yes / No	
Other Specify ________________________________	Yes / No	

THANK YOU FOR YOUR TIME

AMH Reg. Number _________________ **Questionnaire 2 & 3**

CLIENT SERVICE RECEIPT INVENTORY: ENDEAVOR STUDY

---

1. When did you start the New Horizons programme? ____________________

2. In the last 3 months, what face-to-face contacts have you had with these professionals?
(*Note: only record one-to-one contacts here; see next questions for group activities and inpatient care*)

Care provider	***Have you had contact?*** ***(circle)***	***Usual location*** 1 = GP 2 = Community centre 3 = Hospital OPD 4 = Own home	***No. of contacts in last 3 months***	***Average duration (minutes)***
A. General practitioner (GP)	*No Yes*			
B. Psychiatrist	*No Yes*			
C. A & E staff member	*No Yes*			
D. Other doctor Specify _________________	*No Yes*			
E. Psychologist	*No Yes*			
F. Drug & alcohol worker	*No Yes*			
G. Other counsellor / therapist				
NHS Health and Social Care	*No Yes*			
Private	*No Yes*			
Voluntary	*No Yes*			
H.- Home treatment / crisis team/assessment team member	*No Yes*			
I. Social worker	*No Yes*			
J. Mental health nurse/CPN	*No Yes*			
K. Occupational therapist	*No Yes*			
L. Rehabilitation and Recovery Team member	*No Yes*			
M. Pharmacist	*No Yes*			
N. Other Specify __________________	*No Yes*			

3. In the last 3 months, have you used any day care services over and above the contacts identified above (e.g. group activities, attending a drop-in centre etc.)?

Care provider	***Have you had contact? (circle)***	***Name of centre or facility***	***No. of attendances in last 3 months***	***Average Duration (hours)***
A. Drug / alcohol service	*No Yes*			
B. MH resource centre	*No Yes*			
C. Day hospital	*No Yes*			
D. Day Centre	*No Yes*			
E. Drop-in centre	*No Yes*			
F. Self-help / support group	*No Yes*			
G. Class/group at a leisure centre	*No Yes*			
H. Adult education class	*No Yes*			
I. Meals on wheels	*No Yes*			
J. Home help	*No Yes*			
K. Other (specify) ______________________	*No Yes*			

4. In the last 3 months, have you been admitted to hospital as an inpatient?
Yes ***or*** No (please circle)
(*Note: please include any secure hospital stays*)

If yes:

Name of hospital and ward	***Reason for admission***	***If detained under Mental Health Order***	***Dates***		***Total days***
			Admission	***Discharge***	

5. <u>In the last 3 months</u> have you had any major event occur in your life such as a death of a loved one, marriage, divorce, start of a relationship?

Yes *or* No (*please circle*)

If Yes for any of the events please fill in the table below with details
If No, please go to Q5

EVENT	***DATE IT OCCURRED***	***HAS IT BEEN POSITIVE OR NEGATIVE TO YOUR MENTAL HEALTH?***
Marriage/new relationship		*Positive* *Negative*
Relationship breakup		*Positive* *Negative*
Death of close family member		*Positive* *Negative*
Death of close friend		*Positive* *Negative*
Serious illness of close family member		*Positive* *Negative*
Foreclosure of mortgage/loan		*Positive* *Negative*
New job		*Positive* *Negative*
Debt		*Positive* *Negative*
Contact with police		*Positive* *Negative*
In a police cell		*Positive* *Negative*
Prison		*Positive* *Negative*
Contact with probation officer		*Positive* *Negative*
Contact with solicitor		*Positive* *Negative*
Court attendance		*Positive* *Negative*
Other ____________________		*Positive* *Negative*
Other ____________________		*Positive* *Negative*

6. Please list below use of any medications taken <u>over the last 3 months</u>

Name of drug	***Dosage (if known)***	***Dose frequency (e.g. daily)***	***For how long have you taken this drug?***	***Are you still taking this drug? (please circle)***
1.	mg			*Yes* *No*
2.	mg			*Yes* *No*
3.	mg			*Yes* *No*
4.	mg			*Yes* *No*
5.	mg			*Yes* *No*
6.	mg			*Yes* *No*
7.	mg			*Yes* *No*

7. In the last 3 months have you been a student at college?

Yes **or** No (*please circle*)

If Yes, how many days (if any) have you had off from college in the last 3 months as a consequence of health problems? ____________________

The next question asks about any state benefits you received in the last 3 months. This question is to allow us to calculate any potential savings to the Exchequer which may have arisen as a result of a change in your circumstances since being on the New Horizons programme. Like all the other information, this information will treated in the strictest confidence. It will not be seen by anyone other than the researchers at the University of Ulster and will be used only for the purposes of the evaluation study of the New Horizons programme. Please be assured that the provision of this information will not affect your entitlement to benefits.

8. What state benefits (if any) have you received in the last 3 months and for how long?

Benefit	***Have you received this? (please circle)***	***For how many weeks did you receive it in the last 3 months (max 26)***
Income Support	Yes / No	
Incapacity Benefit	Yes / No	
Employment and Support Allowance	Yes/No	
Disability Living Allowance care component	Yes / No	
Disability Living Allowance mobility component	Yes / No	
Disabled Person's Tax Credit	Yes / No	
Severe Disablement Allowance	Yes / No	
Housing Benefit	Yes / No	
Private Housing Benefit	Yes / No	
Jobseeker's Allowance	Yes / No	
Families Tax Credit	Yes / No	
Statutory Sick Pay	Yes / No	
State retirement pension	Yes / No	
Private pension	Yes / No	
Invalid care allowance	Yes / No	
Attendance Allowance	Yes / No	
Child Benefit	Yes / No	
Industrial Injuries Disability Benefit	Yes / No	
Other Specify ____________________________	Yes / No	

THANK YOU FOR YOUR TIME

Health Questionnaire

English version for the UK

(validated for Ireland)

By placing a tick in one box in each group below, please indicate which statements best describe your own health state **today**.

Mobility

I have no problems in walking about ☐
I have some problems in walking about ☐
I am confined to bed ☐

Self-Care

I have no problems with self-care ☐
I have some problems washing or dressing myself ☐
I am unable to wash or dress myself ☐

Usual Activities (*e.g. work, study, housework, family or leisure activities)*

I have no problems with performing my usual activities ☐
I have some problems with performing my usual activities ☐
I am unable to perform my usual activities ☐

Pain/Discomfort

I have no pain or discomfort ☐
I have moderate pain or discomfort ☐
I have extreme pain or discomfort ☐

Anxiety/Depression

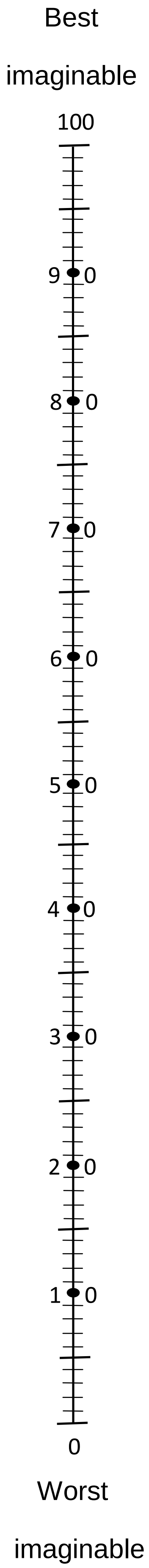
I am not anxious or depressed ☐
I am moderately anxious or depressed ☐
I am extremely anxious or depressed ☐

To help people say how good
or bad a health state is,
we have drawn a scale
(rather like a thermometer)
on which the best state you
can imagine is marked 100
and the worst state you
can imagine is marked 0.

We would like you to
indicate on this scale
how good or bad your
own health is today, in
your opinion. Please
do this by drawing a line
from the box below to
whatever point on the
scale indicates how good
or bad your health state is.

Your own

health state



Carer Invitation to Take Part

Title: **To understand what savings, if any, are made in relation to the health service as a result of people attending Action Mental Health's New Horizons programme**

Thank you for showing an interest in this economic evaluation of the New Horizons programme. Action Mental Health are keen to ensure they provide the best service they can for the people who attend their programmes and to give good value for money to the organisations that help fund their programmes. To ensure this Action Mental Health have asked two staff from the University of Ulster to conduct an economic evaluation. The aim of this economic evaluation is to identify savings, if any, to the health service and the Exchequer by a person attending the New Horizons programme. When someone is caring for a person with mental health needs it can be a real challenge sometimes. It is well recognised that carer's health can suffer and they need more help from the health service. We are keen to try and identify what life has been like for you since the person you care for has started to attend New Horizons. By this person attending New Horizons it may have benefited your health and thus saved money for the Health Service and/or the Exchequer.

This economic evaluation is not about social security benefits and taking part in the evaluation will not affect the benefits you or the person you care for may receive. Only the researchers will see the information you provide and please be assured that all information you provide on the questionnaires will be kept confidential.

We hope you would be willing to take part in the evaluation. An information leaflet is attached explaining the economic evaluation. We will be happy to answer any questions you might have about the evaluation. You can contact us by phone or e-mail using the details below.

Derek McLaughlin	Karen Casson
028 903681113	028 90368293
df.mclaughlin@ulster.ac.uk	k.casson@ulster.ac.uk

Carer Participation Sheet

Title: **To understand what savings, if any, are made in relation to the health service as a result of people attending Action Mental Health's New Horizons programme**

Invitation

You are being invited to take part in an evaluation of the economic benefits in taking part in the Action Mental Health New Horizons Programme. Before you decide whether or not to take part, it is important that you understand what the evaluation is for and what you will be asked to do. Please read the following information and do not hesitate to ask any questions about anything that might not be clear to you. Make sure that you are happy before you decide what to do. Thank you for taking the time to consider this invitation.

What is this evaluation about?

The purpose of this evaluation is to identify any savings to the Health Service as a result of people with mental health problems attending Action Mental Health New Horizons services. This evaluation hopes:

1. To identify the range of health care professionals and/or agencies clients use at the point of entry to Action Mental Health New Horizons and at intervals thereafter.
2. To identify the number of contacts and frequency of sessions clients make with each health care professional/agency at entry and at intervals thereafter.
3. To determine the sessional costs of professionals time and calculate change in contacts and costs over time with a view to identifying any overall average savings.
4. To provide examples of key life events and/or experiences impacting upon the clients as reported by the client.
5. To identify what social security benefits clients are on, if there is any change in their benefits through attendance at the New Horizons programme and to identify any savings to the Exchequer.
6. To explore with the carers of clients who attend the New Horizons programme the effects on their self and family and if these indirect benefits result in any savings to the Exchequer.

Why have I been chosen?

Action Mental Health New Horizons Services are keen to evaluate their services to ensure they are providing good value for money and helping the people who are using their services. We are keen to understand what impact attendance at Action Mental Health's New Horizons programme has on the carers of people who are on the New Horizons programme. You have been asked to take part as you care for a person who has been attending the New Horizons programme for at least six months.

Do I have to take part?

Participation is entirely voluntary and it is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep. If you choose to take part, you can change your mind at any time and withdraw from the study without giving a reason.

What will happen to me if I take part?

If you do wish to take part you will be asked to attend a group discussion with other carers to discuss your experiences of the person you care for attending the New Horizons programme. At the end of the discussion you will be asked to complete two very brief questionnaires. The first on how you view you health and the other about the person you care for. The discussion will take place in your local Action Mental Health Unit and will last approximately one hour. This discussion will be facilitated by the two people named at the end of this document who are completing this evaluation. Refreshments will be provided. Before attending the group discussion you will be asked to sign the attached consent form to indicate your willingness to take part in the group discussion.

Risks and/or disadvantages?

There are no obvious risks to taking part in this study. It is possible that you may become upset. If this happens, Derek McLaughlin is an experienced mental health nurse and he will offer support and liaise with your NHS staff, as appropriate, such as a GP. **There are no disadvantages to taking part in this study. There is no risk to any benefits you may receive for caring, or to the benefits the person you care for may receive.**

Are there any possible benefits in taking part?

By taking part in this evaluation, it will help us to see if those who care for people who are in the New Horizons programme see an improvement in their circumstances, health and/or well-being. You may also find that by completing the questionnaire you will clearly see any progress which has been made in your health and well-being.

What if something goes wrong?

It is very unlikely that anything should go wrong if you take part in this evaluation. If you do not wish to continue you can stop at any time and the programme will continue at Action mental health for the person you care for. If you are unhappy with anything to do with this evaluation you may complain personally to the Chief Researcher Derek McLaughlin using the contact details below or to the AMH Service Manager who will pass your complaint on to Derek. This study has been approved by an Ethics Committee within the University of Ulster and a Steering Committee within Action Mental Health. If you would like information on this approval please contact the Research Governance Department at the University of Ulster 028 90366629

Will my taking part in this study be kept confidential?

All data will be held securely and in confidence and no identifiers will be held about you as required under Data Protection Legislation. However, under the Freedom of Information legislation certain non-personal or generalised data from the evaluation will be accessible. If you disclose information that puts yourself or others at risk the researchers will report this to the Action Mental Health staff caring for you.

What will happen to the results of the study?

A report will be provided to Action Mental Health who have funded this evaluation and a paper may be prepared for publication.

Contact details

Derek McLaughlin	Karen Casson
School of Nursing	School of Nursing
Jordanstown	Jordanstown
028 90368113	028 90368293
E-Mail df.mclaughlin@ulster.ac.uk	E-Mail k.casson@ulster.ac.uk

Support organisations

Action Mental Health	NI Association for Mental Health
Phone 028 9040 3726	Phone 028 9032 8474

Carers Consent Form

To understand what savings, if any, are made in relation to the health service as a result of people attending Action Mental Health's New Horizons programme

Chief Researcher: Derek McLaughlin

Please initial boxes

- I confirm that I have been given and have read and understood the information sheet for the above study and have asked and received answers to any questions raised [ ]
- I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason and without my rights being affected in any way [ ]
- I understand that the researchers will hold all information and data collected securely and in confidence and that all efforts will be made to ensure that I cannot be identified as a participant in the study (except as might be required by law) and I give permission for the researchers to hold relevant personal data [ ]
- I agree to take part in a group discussion and for this to be audio taped [ ]
- I agree that everything discussed in the focus group will be kept confidential [ ]
- I agree to complete two questionnaires [ ]
- I agree to take part in the above study [ ]

Name of Subject Signature Date

_______________ _________________________________

Name of person taking consent Signature Date

_______________ _________________________________

Name of researcher Signature Date

________________ _________________________________

Appendix 4

Interview schedule for focus groups with carers

1. What has life been like caring for a person with mental health needs?
    - how have you coped
    - have you had any support from family/friends/relatives/services?

2. What have the effects been on you and your family caring for a person with mental health issues?
    - health
    - finance
    - emotional wellbeing
    - social wellbeing?

3. What has been the effect on you and your family since the person you care for started to attend AMH New Horizons?
    - health
    - finance
    - emotional wellbeing
    - social wellbeing?

4. What has been helpful about the person you care for attending AMH New Horizons?
    - free time
    - improvement in loved one's health
    - return to interests/work?

5. What has not been so helpful about the person you care for attending AMH New Horizons?
    - transportations
    - duration of daily programme
    - number of days attending

6. Is there anything else you would wish to say?

About the Person You Care For

***Title:* To understand what savings, if any, are made in relation to the health service as a result of people attending Action Mental Health's New Horizons programme**

This questionnaire asks about the person you care for who is on the New Horizons programme. Please respond by ticking the relevant box(es). There is a space at the end of the questionnaire if you would like to tell us about any further caring responsibilities you may have.

1. Who do you care for?

My son/daughter ☐
My partner/spouse ☐
My brother/sister ☐
My parent ☐
My friend ☐

Other (please specify) ___________________________

2. What is their illness/condition?

Psychosis/schizophrenia ☐
Bi-polar disorder/manic depression ☐
Depression ☐
Anxiety ☐

Other mental health problem (please specify ___________________________

3. Do you live with each other at the minute?

Yes ☐
Most of the time ☐
No ☐

If **NO**, where are they currently living?

Own/rented accommodation ☐
Supported accommodation ☐
With other family member/friend ☐
Care home ☐
Hospital ☐

Other (please specify) _______________________________

4. Which of the following statements best describes your role as a carer at the moment?

I am the **only** caregiver ☐
I **share** caring responsibilities with others, but **I** am the **main** carergiver ☐
I **share** caring responsibilities with others ☐
I **share** caring responsibilities, but **someone else** is the **main** caregiver ☐

Other (please specify) ____

5. Which of the following types of support, if any, do you use to allow you to take a break from caring? (Please tick as many as apply)

Friends/family providing temporary care ☐
Paid carers coming into the home ☐
Paid carers providing care away from the home (e.g. care home) ☐
Supported activities out of the home, for the person you care for ☐
Supported breaks for you and the person you care for, away from the home ☐

Other respite care (please specify) ___________________________________

I’m unable to take a break from caring ☐
I do not need support to take a break from caring ☐
I do not need to take a break from caring ☐

6. If you have anything else you would like to tell us about caring please do so below.

____

____

____

____

____

Thank you for your time and co-operation

Health Questionnaire

English version for the UK

(validated for Ireland)

By placing a tick in one box in each group below, please indicate which statements best describe your own health state **today**.

Mobility

I have no problems in walking about ☐
I have some problems in walking about ☐
I am confined to bed ☐

Self-Care

I have no problems with self-care ☐
I have some problems washing or dressing myself ☐
I am unable to wash or dress myself ☐

Usual Activities (*e.g. work, study, housework, family or leisure activities)*

I have no problems with performing my usual activities ☐
I have some problems with performing my usual activities ☐
I am unable to perform my usual activities ☐

Pain/Discomfort

I have no pain or discomfort ☐
I have moderate pain or discomfort ☐
I have extreme pain or discomfort ☐

Anxiety/Depression

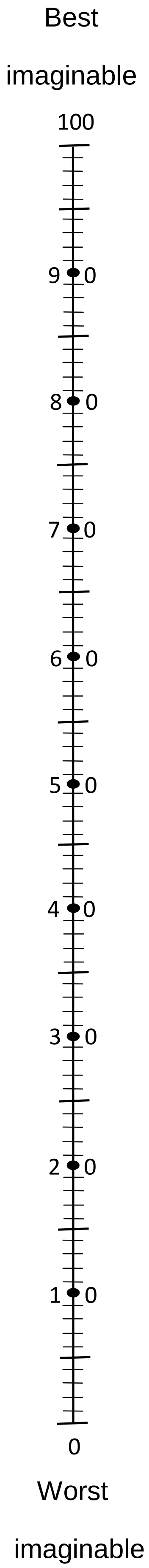
I am not anxious or depressed ☐
I am moderately anxious or depressed ☐
I am extremely anxious or depressed ☐

To help people say how good
or bad a health state is,
we have drawn a scale
(rather like a thermometer)
on which the best state you
can imagine is marked 100
and the worst state you
can imagine is marked 0.

We would like you to
indicate on this scale
how good or bad your
own health is today, in
your opinion. Please
do this by drawing a line
from the box below to
whatever point on the
scale indicates how good
or bad your health state is.

Your own

health state



Appendix 5

Change in median number of contacts with health and personal social services professionals

Service	Point 1 Point 2		Point 2 Point 3		Point 1 Point 3		Point 1 Point 2 Point 3	
	Median No. of contacts	**p**	**Median No. of contacts**	**P**	**Median No. of contacts**	**p**	**Median No. of contacts**	**p**
GP	5.57 3.11	.000	3.19 3.58	.490	5.86 3.50	.000	6.16 3.42 3.68	.000
Psychiatrist	3.24 1.74	.002	2.13 1.67	1.000	2.15 1.85	.221	2.75 1.50 1.50	.011
A & E	2.67 1.33	.317	3.00 1.00	ID	3.00 1.00	ID	ID	ID
Other doctor	2.00 1.75	.705	2.00 3.67	.180	3.60 4.20	1.000	3.60 19.40 4.20	.819
Psychologist	3.25 2.00	.102	1.00 1.00	ID	6.00 2.00	.109	2.00 1.00 1.00	ID
Drug/alcohol worker	11.67 12.00	.317	16.50 20.00	.180	13.80 10.80	.786	16.50 16.50 20.00	.156
NHS counsellor	10.00 4.00	.109	2.00 1.00	ID	24.00 2.00	ID	ID	ID
Private counsellor	ID	ID	ID	ID	ID	ID	ID	ID
Voluntary counsellor	9.00 18.50	.317	ID	ID	ID	ID	ID	ID
Home treatment/crisis/ assessment team	3.50 2.75	.317	ID	ID	ID	ID	ID	ID
Social worker	6.00 5.67	.596	7.60 2.80	.043	6.67 2.50	.042	6.67 22.83 2.50	.008
Mental health nurse	6.78 4.52	.000	2.93 2.50	.929	7.59 2.18	.003	5.33 3.25 2.25	.010
OT	8.50 4.87	.593	6.60 14.00	.357	5.25 5.50	.785	5.25 5.25 5.50	.717
Rehabilitation and Recovery Team	12.00 12.00	1.000	ID	ID	ID	ID	ID	ID
Pharmacist	6.91 7.13	.686	7.40 6.47	.176	7.71 6.76	.249	7.43 7.71 6.71	.223
Other service*	9.00 8.25	.317	ID	ID	ID	ID	ID	ID

Footnote: ID- Insufficient data

*Key worker, pain specialist, physiotherapist, condition management programme, blood clinic, acupuncturist

Appendix 6

Change in median number of attendances at day care services

Service	Point 1 Point 2		Point 2 Point 3		Point 1 Point 3		Point 1 Point 2 Point 3	
	Median No. of contacts	**P**	**Median No. of contacts**	**p**	**Median No. of contacts**	**P**	**Median No. of contacts**	**P**
Drug and alcohol service	5.00 1.00	ID	3.00 4.00	ID	ID	ID	ID	ID
Mental health resource centre	17.5 5.13	.063	10.60 15.40	.416	25.50 10.50	.144	42.00 4.24 14.84	.223
Day hospital	2.00 2.00	1.00	ID	ID	ID	ID	ID	ID
Day centre	12.00 8.67	.317	7.00 12.00	.317	12.00 12.00	1.00	12.00 7.00 12.00	.368
Drop-in centre	15.00 15.00	ID	12.00 15.00	ID	15.00 12.00	ID	15.00 15.00 12.00	ID
Self-help/support group	16.83 29.33	.180	3.00 3.00	ID	36,00 2.00	ID	ID	ID
Class/group at leisure centre	12,00 8.00	ID	ID	ID	1.00 12.00	ID	ID	ID
Adult education class	ID	ID	6.00 4.00	ID	ID	ID	ID	ID
Meals on wheels	ID	ID	ID	ID	ID	ID	ID	ID
Home help	ID	ID	ID	ID	ID	ID	ID	ID
Other services*	18.00 9.00	.317	ID	ID	ID	ID	ID	ID

** Praxis, Mindwise, Starus, Simon Community homeless hostel, Mother helps