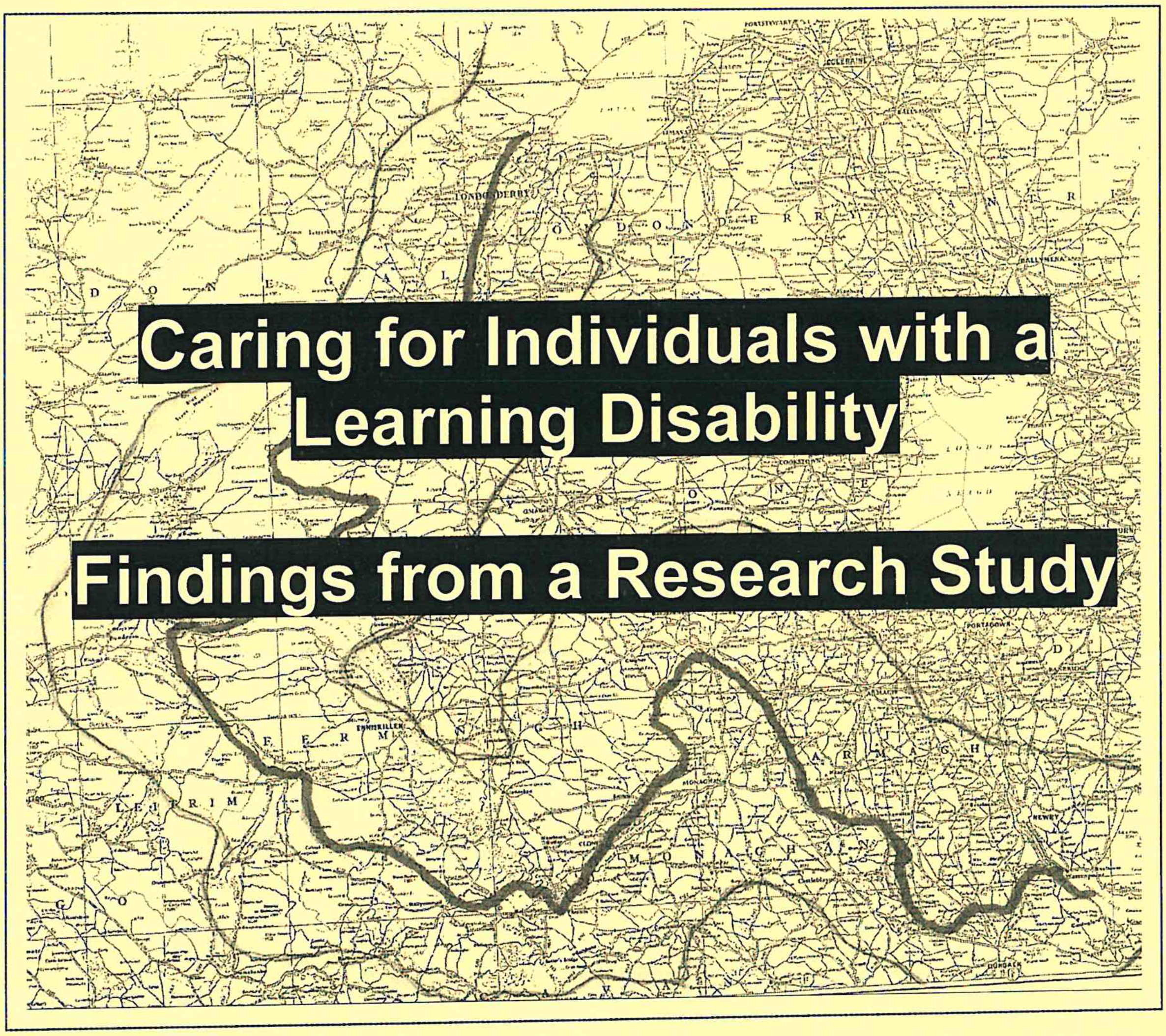
C.A.W.T Carers



Caring for Individuals with a Learning Disability

Findings from a Research Study

a charity at the centre of caring
Praxis
care group

INTERREG IIIA

Project part financed
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CAWT
cooperation and working together

C.A.W.T Carers

Caring for Individuals with a Learning Disability: Findings from a Research Study

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PRAXIS CARE GROUP

Praxis Care Group is a registered charity and a major provider of services for adults and children with a learning disability, mental ill health, acquired brain injury and the elderly. The Praxis Care Group Research Department is responsible for undertaking research and evaluations of projects that promote understanding of learning disability and related health and social care issues.

CAWT

Cooperation and Working Together is a cross border body, formed in 1992 when the North Eastern and North Western Health Boards in the Republic of Ireland (known as the Health Service Executive as of 1 Jan 2005) and the Southern and Western Health and Social Services Boards in Northern Ireland agreed to cooperate in improving the health and social well being of their resident populations.

Names and job titles have not been provided within the report in order to protect the identity of participants.

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The last two decades have seen an increase in awareness regarding the needs of carers across the UK (56). Contributing to this has been the formulation of certain groups, such as, Carers UK and the Carers National Association, numerous articles and research into the many needs of carers (11, 20, 47) and various Acts and Papers published by the Government (17, 18, 19, 23). This growing interest and concern is also notable within Northern Ireland (8, 24, 25, 26) with information on carers also gathered by various population surveys (49, 52, 54, 55, 61) and within the South of Ireland (36, 39, 48, 60, 62).

Part of this interest in carers has seen the Government acknowledge the importance of the role of carers and emphasise that they should be given full and varied support through services and policy development (59):

> *Carers are seen as forming the backbone of care in the community. For the last decade, government policy has led to an increased awareness of carers and an acknowledgement of the work they do* (Informal Carers Report: 2001, p10).

Implemented government polices and Acts have seen the introduction of Carers Assessment (17) Direct Payments (19), easier access to employment and long life learning (23) and an increase in the Carers Grant (2005/6).

Research has also focussed upon various other issues that are of central importance within the unpaid caring role, such as mental and physical health problems often endured as a direct result of caring (11, 20, 25, 26, 47, 48, 54, 59), the role of respite and service support in relieving the care giving burden, and the need for service development for carers, which includes the rights of carers to have their needs assessed separately from those they care for by a social service or health department (12, 16, 21, 30, 31, 35, 42, 46, 56, 59) along with various coping strategies typically endorsed by carers (5, 14, 28, 33, 34, 57). Other issues include the implementation of the Carers Assessment (17) and many investigate this issue from the carer's perspective (8, 12, 21, 42, 43, 56), Carers Allowance and Direct Payments (21, 30, 47, 48, 62) and identifying hidden carers (18).

There has been however a small amount of research that focuses upon some the above issues in relation to the subgroup of carers who care for people with a learning disability, across Great Britain, Northern Ireland (NI) and the Republic of Ireland (ROI) (6, 16, 21, 24, 28, 34, 41, 53, 56, 72).

Research Objectives

This present study aims to examine these issues, the current health status, support service requirements and support available for carers of people with a learning disability across a section of the CAWT region - a 20-mile wide corridor surrounding the 450km length of the North/South Border (Appendices 3 & 4).

Research Aims, to:

- Examine the current mental and physical health status of carers in the CAWT region in relation to demographics, geographical location and service support available
- Assess the current services available for carers and service users in each area
- Explore the potential need for development of Carer Support Groups and specific learning disability Carer Support Groups in the region
- Investigate potential barriers carers may face in attending a Carer Support Group in both their area and across the border, such as access and transport
- Investigate potential difficulties in setting up and maintaining Cross Border Services (i.e. funding, bureaucracy, eligibility criteria)
- Investigate carer access to other forms of support services, such as, respite and domiciliary care across the CAWT region
- Investigate how this sub group of carers cope in their caring role and evaluate the usefulness of potential Carer Support Group development, and the positives caring can bring
- Examine the awareness and utilization of Carers Assessment, Direct Payments and gather opinions on Carers Allowance
- Investigate the information carers require most urgently and in which format.

Mapping of Services in the North and South

Recurrent findings highlight that as well as an inadequacy of services, family carers are still not being informed about all existing and new services within their area (7, 8, 24, 26). This may be due to the absence of a collated list of services within both the North and South of Ireland. The Equal Lives Review (2005) states:

> *'There is no accurate record of all services provided under the learning disability programme of care either by a Health and Social Services Trust or by a sub contractor in the private or voluntary sector…'* (p24)

Within this current study, a geographical mapping exercise was conducted across a 20-mile corridor of the 450km length of the North/South Border. The overall aim of the mapping exercise was to identify:

- Existing statutory, voluntary and community based support services for carers (non-specific groups)
- Existing statutory, voluntary and community based support services for carers who care for people with a learning disability only
- A list of all services for individuals with learning disabilities located within the defined area.

What is Learning Disability?

As 'there is no universally acceptable term that defines people who have such diverse characteristics' (24), learning disability has been described as an 'umbrella term' for many life long conditions associated to 'impaired intellectual and social functioning' which starts before adulthood (72). It includes the presence of 'a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence) with a reduced ability to cope independently (21).

There are no exact figures to pinpoint how many people with a learning disability there are in the UK, as many with the disability often 'slip through the net' especially those with mild conditions who attend college or work (72). Within Northern Ireland, the Equal Lives Review (2005) refers to estimate numbers provided by the Health and Social Services Trusts. In total, they state 11,898 people have a mild/moderate learning disability, with 4,468 having severe/profound learning disabilities, giving a total of 16,366 people in Northern Ireland with a learning disability. However the review does acknowledge that these figures only represent those who are known to a service at a certain point of time, with those with milder impairments and poor social circumstances often excluded, and therefore could suggest that approximately 16,000 people with a learning disability are not known to social services (21, 24).

The National Intellectual Disability Database (NIDD) within the Republic of Ireland (ROI) provides information on the health services used or needed by people with an intellectual disability (36, 53). Those on the NIDD mostly suffer from moderate, severe or profound intellectual disability; those with mild disabilities will only be registered if they are in receipt of a specialised service.

What is an Unpaid Carer?

There are various definitions that define an unpaid carer and their role and it has been observed that these various definitions of 'a carer' can put limitations on what actually constitutes caring work and therefore on the support a carer can receive (48). This current study adheres to the definition outlined by Valuing Carers: A Strategy for Carers in Northern Ireland (2002):

> *'Carers are people who, without payment, provide help and support to a family member or a friend who may not be able to manage without this help because of frailty, illness or disability. Carers can be adults caring for other adults, parents caring for ill or disabled children or young people who care for another family member'* (p6)

Carers assist in many ways, such as providing personal care, administering medicines and providing physical help (18, 44, 54) and often the roles they perform, such as heavy lifting, affects their own health (11, 25).

How Many People are Carers?

Based on the General Household Survey (1995) there are an estimated 5.7 million carers in the UK (18, 71) with the number of carers expected to increase (18,44). This expected rise causes worries regarding carer support services, as there is currently insufficient support for carers, and raises questions as to how services will manage when numbers swell (8).

Carers within Northern Ireland

Within Northern Ireland, there is no exact total for the number of carers, ranging from an estimated 250,000 carers (18, 21) to 185,000 unpaid carers at 11% of the population (8, 47). Whilst out of the entire Northern Ireland 2001 Census survey, 18% referred to themselves as informal carers (179,071 carers) (11, 52).

This fluctuation in carer population totals could stem from the failure to identify 'hidden' carers. Many carers remain hidden as they do not identify themselves as a carer, but rather as a relative or friend of those they love and have a responsibility for (18, 26, 37). The implications of this suggest that a large number of carers are not known or in receipt of any service support.

A quarter of all carers in Northern Ireland provide over 50+hours a week (24%-27.5%), (47) 60% provide between 1-19 hours of care and 15% 20-49 hours (26), with women more likely to be carers than men (64% female carers in comparison to 36% male carer) (11, 25). Over half of the caring population (55%) are 45 years old and over, whilst 21% are 60 years and over, meaning the age range 45-64 provides the most care (25, 26). Caring about Carers: Recognising, Valuing and Supporting the Caring Role (2006) revealed that 90% of carers care for a relative, while 70% care for someone they live with (24).

Carers in the Republic of Ireland

The Census 2002-Disability and Carers, provides a comprehensive breakdown of carers, classified by a range of factors, such as age, hours spent caring and geographical location. 11,806 carers live within the rural border regions, comprising 5.3% of the rural border area total population. Compared to 4.5% in the town border areas, the majority of carers within the overall border region reside within rural areas. The majority of carers fall within the minimum hours spent caring, between 1-14 hrs per week, with the second largest group of carers falling within the maximum caring hours 43+ hours a week. Women form two thirds of the carers who care for more that 43+ hours per week (39, 62).

Similar to carer composition in the UK and the North, female carers outnumber that of males, with 6.1% of the total border female population fulfilling the caring role, with only 3.9% of the male border population acting as carers (39). This finding is also symmetrical to the rest of Ireland, were women are 'traditionally been the principal caregivers' (62). Carrying this burden solely however has been the cause of much 'physical and emotional distress', keeping women out of paid employment, resulting in lack of finances, depression and poor health (62).

Carers of People with a Learning disability

Research acknowledges that carers for people with a learning disability are somewhat different to other types of carers. For instance, they undergo the largest amount of stress in comparison to other carer types, yet have the least amount of service support (6, 28, 34, 40, 41, 56). It is notable from the mapping exercise conducted as part of this research, (Appendices 3 & 4), that there are only **eight** Carer Support Groups specific to learning disability in the North and **five** in the South.

'In common with families throughout the world, those in Northern Ireland who have children with learning disabilities are often under increased stress...'
(Kennedy, McConkey & Roberts: 2006, p2).

Caring for a family member with a learning disability is referred to as a 'lifelong commitment' (21) and with approximately 90% of people with a learning disability live at home with their carers, usually their parents (24, 56, 72). Over 25% of these carers are aged over 65 years old and nearly one in three carers coping on their own (21) suggesting a significant number of people with a learning disability are often not known to statutory agencies until the carer becomes too ill or frail to care themselves. This often causes the parent carer great stress and worry regarding the future care of their child.

Research has indicated that those who care for disabled children are often disappointed with the advice and help they receive from services (7, 21, 24)

'There is little evidence of a flexible and co-ordinated approach to support by health, education and social services, and there is significant unmet needs for short breaks' for parents of disabled children" (Valuing Carers: A strategy for Northern Ireland: 2002)

This present project aims to assess the current services available for carers and service users in each area and investigate the potential need for the development of general and specific learning disability Carer Support Groups within the CAWT area.

The Physical Health of Carers

In an exploration of potential relationships between caring and other health and lifestyle factors such as stress and social support, several surveys have suggested that carers, especially those who provide over 20 hours a week of care, suffer poor health as a direct result of their caring role (3, 11, 25, 49, 54).

Carers are often reported to have poorer physical and mental ill health, lower life satisfaction, greater morbidity and depression due to the stress, strain and burdens of care giving in comparison to non carers (1, 7,8,11, 18, 25, 26). Lelliott et al (2003) suggests informal care comes at 'price', and that price is paid by the carers themselves, who are 'more likely than the general population to be poor, unemployed, have a limited social life and to suffer from ill health, both mental and physical' (p143-144). This section offers a brief review of numerous studies that have assessed the effect of caring on health.

> *'Carers report high levels of stress, anxiety and depression, as well as general health problems and physical injuries such as strained backs associates with lifting'* (NCCSDO: 2004, p5).

The Mental Health of Carers

Caring is also reported to have a negative effect on carers' mental health, perhaps even more so than their physical health (11, 18, 24, 25).

> *'...carers were more likely to report high levels of psychological distress, including anxiety, depression, loss of confidence and self-esteem, compared to non carers'* (Carers UK: 2004, p5-6).

Certain demographics appear to correlate with increased mental ill health, such as, length of time caring, gender of the carer and the characteristics of the caring relationship. Due to the high demands of care giving, carers often find little or no time to look after their own health needs (1).

High levels of care

Carers UK (2004) outline a connection between hours spent caring and the carer's health, with more time spent caring associated with a greater chance the carer would have poor health. Research states that unpaid carers providing 'high levels' of care (i.e. over 20 hours a week defined as 'substantial care') are 'more than twice as likely to suffer from poor health compared to people without caring responsibilities' than those who care for under 20 hours a week (11, 67, 69). Within Northern Ireland, one carer in ten suffers from ill health, whilst one in five carers who provide 'substantial care' reports ill health.

Residency of dependant

Another factor reported to have an effect upon the carer's health is the residency of the dependant. Those who live with their dependant are more likely to have a long standing illness (49%) in comparison to those who do not (36%)' for both men and women (25). Furthermore, those who live with the dependant suffer 'a lot or a great deal of stress' (54%) in comparison for someone caring for the dependant outside the home' (25). Carers with the poorest mental health are those looking after their child (20), which is further increased if they are the sole or sole main carer. This may also be reflective of hours spent caring, as those who are not resident with their dependant and spend the least hours caring per week generally have the 'best levels of health' (ibid, p3).

Gender of carer

66% of carers within the ROI experience extreme physical tiredness, back problems and sleep deprivation linked to caring, women more so than men (62, 63). Women are also reported to suffer more than men from psychological distress, anxiety, depression, physical tiredness, lower life satisfaction and a general decline in physical health as a direct result of their care giving role (62, 63).

'From a health and well being perspective, the constant struggle to balance their role as mothers, carers and workers causes women high levels of emotional and psychological distress...as well as increasing the likelihood for physical exhaustion and illness' (Women's Health Council: 2005, p4).

Lack of support

According to Carers UK (2004), carers suffer from poor physical and mental health due to 'lack of information, lack of support - either the right kind or the right amount'. This can exacerbated by isolation, lack of respite and time off from caring, which affects older carers the most (45, 68). Furthermore, carers who have unmet support needs, or lack of support services, have been found to experience distress. This is highly relevant to the geographical location of the carer. Research suggests that services appear to work on a 'postcode lottery' (30), with where a carer resides heavily affecting the type of services they can receive, especially across the rural/urban divide (37, 38, 60).

Stress is regarded as 'an 'inevitable part of caring'. However, it can be relieved and one suggested way is the provision of tailored support programmes for the carer and their dependant (14). The adverse effects on health have been shown to reduce when the carer has some form of support, through formal support services or informal support from family and neighbours (1). It has been demonstrated that where proper support is available, carers benefit from it, reducing both their stress and poor health levels (41). Carers who have been able to take a break also report lower levels of stress than those who have not (20). Support for carers is therefore seen as having huge potential for relieving stress and therefore improving the health of carers.

AIM - This current study examines the mental and physical health status of a sub group of carers living within the research area. Scores from the GHQ-12 and a self-reported assessment of their physical health will be correlated to carer demographics, geographical location (i.e. rural vs. urban) and support received to investigate any potential relationships.

Service Support and Coping with the Stress of Caring

The style of coping strategy a carer adopts has shown to have an affect on the level of stress they experience. Research has determined two main coping styles:

(i) problem focussed strategies (active coping that alleviates stress, e.g. seeking support through services and groups), and

(ii) emotion focussed strategies (avoidant based where effect is taken to deny problems or detachment) (6, 14).

Problem focused styles (e.g. attending support groups) are reported to be more successful than psychological or emotion-focused styles (14) as these offer carers the chance to build networks and share problems, which will all help carers maintain a good caring role (14, 34):

'Social support is an extremely important part of coping as it satisfies the need for attachment, relieves stress, and bolsters a sense of self-worth, trust and life-direction…it also plays a key role in giving relevant information, advice, assistance and 'emotional support' (Chambers and Ryan: 2001 p100).

Despite the importance of support for carers, lack of service support still appears to be a core cause of frustration for many carers, which in turns creates stress and annoyance, affecting their ability to cope with their caring role:

'The anxiety and frustration associated with inconsistent and irregular support and lack of information was a major source of concern for carers in the study... there is a wealth of evidence to suggest that their needs remain largely ignored' (Chambers and Ryan: 2001, p99).

How do Carers of People with Learning Disabilities Cope?

As discussed earlier, carers who care for someone with a learning disability typically are more stressed and have poorer mental and physical health (6):

'Parents who have children with autism endure more stress than parents with non disabled children...and parents of other disabilities...heightening negative health outcomes like depression...'. (Dunn et al: 2001, p39).

Recurrently named stressors for this sub group of carers include feelings of guilt, lack of support, strain on family relationships, getting respite/breaks from caring, good professional services and ill health (i.e. fatigue) (6). Those who care for people with a learning disability who tend to use emotion focussed coping strategies, such as, denying or ignoring the problem are often more depressed than those who employ problem based strategies (6, 14).

AIM – This study aims to explore the coping mechanism employed by carers living in the research area, and determine whether carers use emotion or problem based strategies.

The Positive Sides of Caring

There has been relatively few studies that investigate the positive aspects of caring with a child with a disability (51, 57, 62) in comparison the abundance of literature that focuses on the care giving burden and stress associated with the role (5, 6, 11, 20, 25, 26):

"Much of the existing research on informal caring has described it largely in negative terms, generally described as a burden, something that costs financially and emotionally" (Heenan: 2000, p862).

Studies which have focussed on the positive and rewarding side of caring have identified these issues as one of the most powerful coping strategies a carer can have. This has been referred to as the 'silver lining effect', where carers cope with their role by placing their focus on the positive of caring (51):

'...there can be positive and potentially rewarding aspects of providing care for a care with a learning disability irrespective of class boundaries, age...and the type and degrees of the child's disability'(www.frontline-ireland.com/article-65-caregiver-strain.htm)

There are many aspects of caring that make carers feel more valued, such as, providing them with a purpose in life and developing new skills (51, 57). Carers have reported gaining great satisfaction from fulfilling their parental role, learning more about themselves, personal accomplishments and becoming more self-confident (Schwartz & Gidron: 2002). Caring can offer carers a 'sense of importance, value and belonging', along with joy and feelings of reward (62). The most frequent sources of satisfaction for carers concern the person cared for, providing pleasure for them, attending to their needs, and maintaining their dignity (51).

AIM -This present study responds to the need to move beyond the burden and stresses of caring, to provide carers in the CAWT region with an opportunity to express the many positive aspects of caring which can be utilised as a coping mechanism.

Support Services for Carers

The fact that carers do not receive enough support from services and health professionals has been a recurrent issue across the North and South of Ireland, as well as Great Britain (8, 13, 18, 21, 24, 25, 26, 30, 39, 62, 63).

'The overall picture emerging from these findings is one of relatively low service provision, compounded by generally low levels of satisfaction with formal support for their child and themselves' (www.frontline-ireland.com/article-65-caregiver-strain.htm)

Research has shown that attention to carers is very limited, with 'no real improvement in the support carers receive', that they are given 'low priority status by professionals', with few consulted about what they actually need. It has recurrently been stated that some carers do get practical and emotional support, whilst many others receive no support whatsoever (26, 30). Often support is regarded as a 'postcode lottery':

"The quality and type of support that carers receive remain a matter of chance. Support depends far more on where carers live and who they are in contact with in social services than on what they need" (Fruin: 1998, p1).

Getting a Break

Respite care, regarded as a service for the person with a learning disability, has often been noted as a valuable form of support for the carers themselves (2, 4, 7, 8, 31, 46). It can include 'in home services', such as, sitting services, or 'out of home' respite, such as, residential hospitals, day centres or short stays in residential homes (16, 24). Respite has proven very beneficial to carers, with carers referring to it as 'mental and physical relief', 'angst free care' and 'stolen moments'. It offers an opportunity to focus on family and sibling relations, restore patience (16) and generally help carers to cope (6, 14, 24, 26, 51). It can provide carers with the necessary relief from the psychological and emotional stresses and burdens associated with caring (16). Respite can also be of great relief to a carer's health, with those not getting a break twice as likely to suffer from mental ill health and have poorer physical health as carers who have had a break (11).

Where the need for respite services has been regarded to crucial for all carers, it is seen as even more so for those who care for someone with a learning disability (6, 16, 24, 34). However, despite the obvious importance of respite, there is still a severe lack of awareness and information about these services amongst carers, meaning that many carers have not had a break since they started caring (16, 18). Various barriers can often prevent carers from accessing respite, such as, lack or absence of respite in some areas, little choice about the type of respite for their dependant and fear about the quality of service and the level of care provided within it (8). Instead, many carers have to rely solely on their family support networks if they need a break from caring.

However, simply having respite services available however is not enough as carers have reported that inadequate, inflexible or poorly run services can be the cause of great stress rather than a helpful resource. Therefore, although respite care can reduces stress in the parents who uses it, the extent to which stress is reduced is dependant upon the type of services available, the quality of care within them and its suitability to their child (11).

AIM - This study aims to obtain the views of both carers and health professionals on what services are currently available in their area and what type of services are most needed. It aims to explore the provision of support services, such as respite, and to examine potential barriers to its use.

Carer Support Groups

Carer Support Groups targeting the specific needs of carers can be of vital importance and are often used as a method of coping with the stress of the caring role and are often regarded as part of' 'a wider network of support for carers' (18, 26). There have been numerous benefits noted by carers for attending a Carer Support Group, including, meeting carers in a similar situation, receiving information on services and caring, obtaining advice on issues that affect carers, getting emotional support, how to cope with the stresses and strains of caring, getting trained in relevant areas and the chance for social or recreational activities. They also offer advocacy, a break from caring duties and can reduce isolation (8, 18, 26).

Furthermore, it has been noted that carer groups which are set up for specific groups are of extra value as the experiences shared and information given isn relevant to all who are attending:

'Groups for carers of people with specific illnesses can be valuable sources of information as well as providing support for carers'
(Caring for Carers - Recognising, Valuing and Support the Caring Role: 2006).

It is recommended that all carers should have access to a local carer support service either run by the voluntary sector or by carers (26). However, there are various barriers which can prevent this. Firstly, many areas within the North and South of Ireland do not have such support groups available, therefore carers must go without, or travel miles to reach their nearest group. Secondly, in areas where carers groups are in place, many carers are not aware of their existence as there is often a lack of knowledge among carers regarding support groups in their area. The absence or inflexible nature of respite cover and carers being too busy due to their caring duties are other significant barriers preventing attendance at carer support groups (14, 24). Although research illustrates that those carers who attend carers groups value them greatly and are more able to continue with their caring role, (8, 26) it must also be noted that not all carers will find a support group helpful or wish to join one.

Such barriers need to be identified and resolved to allow carers to access and use services that may aid their caring role, also taking into consideration the extra problems that an elderly or rural carers may encounter.

AIM – The study aims to assess the range of factors that could prevent a carer living in the CAWT region from attending a Carer Support Group and to investigate how these barriers could be reduced or removed.

Cross Border Barriers

The Equal Lives Review (2005) states that people with a learning disability are often excluded from research undergone on the 'troubles' and its effect within Northern Ireland. Therefore, there is not much known regarding service users' or carers' feelings toward utilising services 'across the border'. And yet, cross border service development may offer one possible solution to the lack of carer support services in the CAWT region (see Appendices 3 & 4), and long travelling distances undertaken by carers to reach their nearest support group.

AIM - This project aims to determine if carers would be interested in using a cross border service and to identify barriers that would hinder or prevent their attendance. It also explores possible solutions to these barriers. Potential problems in developing cross border services, from the perspective of health professionals, are also examined, such as, funding, bureaucracy and different health care systems.

Rural vs. Urban Carers

An important determinant in the availability of Carer Support Groups in often the residency of the carer, in rural or urban areas:

> *'One of the factors inherent in a North/South or within region comparison is the issue of care for urban vs. rural residents. Differential access to services, with rural dwellers having lower levels of access, it a challenge in many countries...'*
>
> (One island- Two systems: 2005, p4).

Informal caring within the rural areas of Northern Ireland have been somewhat neglected within research (37). Carers can experience increased feelings of isolation whilst living in rural areas, which have been found to cause ill health and increased levels of morbidity (11). This is perhaps due to lack of time for outside life or an increased strain on family relations due to caring responsibilities (37, 60).

AIM - Through the service mapping exercise, this current study aims to assess what services and supports are available to carers in the CAWT region, offering a comparison between rural and urban areas within the North/South border region.

Information for Carers

Information can be valuable to carers and access to it can have a moderate to significant positive impact on a carer's health (26). Despite this, it has been frequently established that carers are not receiving the necessary information to assist them in their caring duties (7, 8, 11, 24, 18, 26). Many carers report having no access to information on benefits, where to go to for help, how to find out or access support services in their area or what services are available that would benefit them, with a higher majority of carers not even knowing that this type of information was in existence (3, 11). Information that is given needs to be 'accessible, relevant and comprehensible', however, research continues to show that carers have difficulty in obtaining this information (18):

> *'Easily accessible, relevant, factually correct information is of critical importance to carers. They need the right kind of information in the right format and at the right time. Many are not getting it'* (Valuing Carers: A strategy for Carers in Northern Ireland: 2002, p21).

AIM - Rather than re-establish the fact that many carers lack information, as already stated by numerous other studies, this present study aims to further this issue by asking carers what type of information they rate as being most urgently needed for their caring role, and the most suitable format for the information to be provided. For example, a number of Caring Support Services only provide information on the Internet. The current study investigates the usefulness of this medium to a carer.

What is Carers Assessment?

Carers have their own needs, separate to those of the person they care for, and these needs should be recognised (43). The Carers (Recognition and Services) Act of 1995 was introduced in order to assess a carer's ability within the caring role and came into force on 1st April 1996 (18, 30). Carers Assessment is:

> *'An Act to provide for the assessment of the ability of carers to provide care; and for connected purposes'* (17).

This Act gives carers the right to request an assessment 'of their ability to care and to continue caring' and was designed to provide individual assessments of carers' needs, to assess their support needs and requirements for that carer to avoid breakdown and help them sustain the care they are providing. However, it was heavily criticised as carers could only request an assessment if the person they cared for had been assessed or wanted to be assessed (43, 70). The Carers and Disabled Children Act was introduced in 2002, with the aim to correct much criticism toward the Carers Act, by allowing carers the right to be assessed regardless of their dependant. It also stipulated that local authorities were to supply services to the carers to meet these assessed needs. This meant that all *'...carers now have a statutory right to an assessment of their needs'* (42). The Carers and Disabled Children's Act (Northern Ireland) came into affect in 2002, and under this Act, carers were given the right to an assessment in Northern Ireland.

Problems with Carers Assessment (CA)

Despite CA being law, Carers UK state that only one third of carers in the UK had undergone assessment, with only half of these carers actually receiving services as a direct result. Many did not feel any improvement was made and were still not accessing the proper, or any, services. Furthermore, nearly half of those not assessed had never been informed about the assessment, nor their right to it (10, 13, 70). Similar findings were noted in Northern Ireland amongst carers of people with a learning disability by Robinson and Williams (2002), who assessed the impact of the Carers (Recognition and Services) Act of 1995 and found that carers of people with learning disabilities were still very seldom receiving assessments (56):

> *'Carers' needs assessments are still a very minor feature in the lives of those supporting people with learning disabilities. They are rarely offered and delivered, and even more rarely acted upon' (Robinson & Williams: 2002, p180).*

More than any other sub group of carers, those who care for people with learning disabilities rarely rated the assessment as being of any worth (24, 56).

AIM - This study aims to assess the number of carers in the research area, living in the North, who are aware of the assessment, those who have had an assessment carried out and the outcomes from the assessment. By eliciting the views of health professionals, the study shall also explore if, and why, the implementation of Carers Assessments are 'patchy' and what practical steps could be taken to improve the situation.

Direct Payments

The Carers and Disabled Children's Act also gave carers the opportunity to buy their own services through Direct Payments within Northern Ireland.

AIM - The study aims to determine the number of carers who have heard of, or utilise, Direct Payments, with a further investigation into what they suggest are the positive and negative aspects of using Direct Payments.

Carers Allowance

The current Carers Allowance in the UK currently stands at £46.95 per week and is regarded as 'the lowest benefit of its kind' (9). Based on carer costs in the year 2000, it was approximated that Carers in the UK saved the government 57.4 billion during 2001-2 (9, 67). Therefore, there exists a general feeling amongst carers that they save the government thousands of pounds each year, and that if they were to stop caring and put their dependants into statutory care it would 'bankrupt the government' (7). Furthermore, once a carer is entitled to their state pension at the age of 60, their Carer Allowance stops as government regards the two payments as overlapping benefits, thereby preventing a carer from receiving both. The debate over Carers Allowance has led to carers having feelings of frustration, anger and stress regarding the amount of benefits they receive.

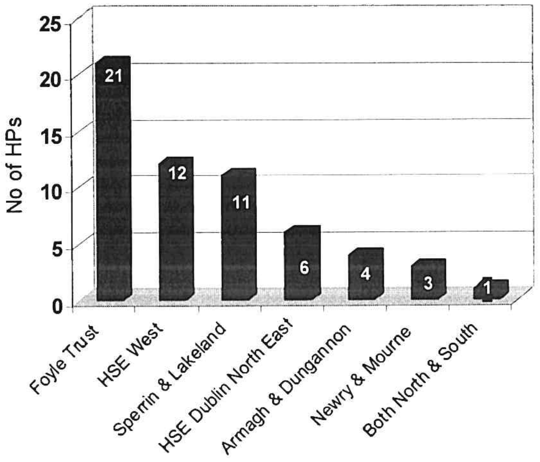
AIM- The study aims to determine the uptake of Carers Allowance within the research area.

It is important to examine issues relating to caring from the perspective of Health Professionals (HPs). As HPs work regularly with carers, plan and manage services, perform referrals and give support, it was important to obtain their views on what they feel are the main issues facing carers, what services they believe are required within each area, and to highlight problems and provide potential solutions to the main issues. This study is not representative of all HPs that work within the CAWT region, rather, it only represents those who chose to compete and return the postal questionnaire (n=58).

Trust / Respondent Response

67% (n=39) of respondents worked within the North, 31% (n=18) came from the South, and 2% (n=1) worked between the two. Fig 1 identifies that the majority of responses came from the Foyle Trust *area* (36% n=21), with the least coming from the Newry & Mourne Trust *area* (5% n=3). (The word 'area' is used for both statutory and voluntary HPs who work within each Trust/HSE geographical area).

Fig 1: Health Professionals by Area



Statutory / Voluntary HPs

69% (n=40) of HP respondents worked within statutory service provision, whilst 31% (n=18) came from the voluntary sector. Although there were no voluntary HP respondents from HSE Dublin North East, their opinions were included at the interview stage (n=2).

Also an Unpaid Carer?

HPs were asked if they were also an unpaid carer, as those who were also carers may hold different views or attitudes towards caring to those HPs who were not carers. 33% (n=19) of HP respondents were also an unpaid carer, 10 of which are statutory HPs (53%) and 9 voluntary (47%).

Key Points

- **These findings are not representative of all HPs within the CAWT region**
- **33% of HP respondents were also an unpaid carer**

This section offers a profile of the carers within the CAWT region who participated in the study. As stressed in the methodology section (Appendix 2), these findings are not representative of all carers in the CAWT region, rather they can only represent those carers who chose to complete and return the questionnaire (n=111).

Carer Demographics

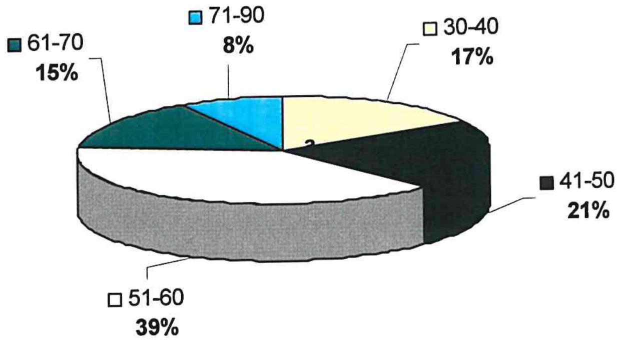
Gender

94% (n=103) of carer respondents within this present study were female and 6% (n=7) male (missing =1). This much higher number of female carers is similar to other research findings (49, 54, 55). However, there may also be a hidden number of men involved in the caring role reflected in the percentage of joint carers who took part in the survey. 43% (n=45) were not sole carers, indicating that each partner may take part in the caring role. Out of these joint carers, it was predominately the women who completed the questionnaire and took part in the interviews.

Age

The highest number of carer respondents (39%) fell within the 51-60 age range category, followed by the 41-50 age group (21%) demonstrated by Figure 2. When collapsed, 60% of carers fell between the 41-60 age range and 23% were over the age of 60. These findings adhere closely to research undertaken on a much larger scale (39, 40, 52, 54) and reflects recurrent literature on the increasing age of carers (24, 25, 26, 55).

Fig 2: Age of Carers



Dispersion across the Area

Table 1 illustrates the distribution of carer respondents across the counties within the research area. The majority of carer respondents come from Tyrone (24%) followed by Londonderry (19%) and Fermanagh (16%). The lower level of feedback from counties within the South (Cavan 8%, Donegal 6% and Leitrim 1%) may be partly explained by methodological and ethical complications (discussed in Appendix 2). Over half the respondents (64% n=69) lived in rural areas within the CAWT region.

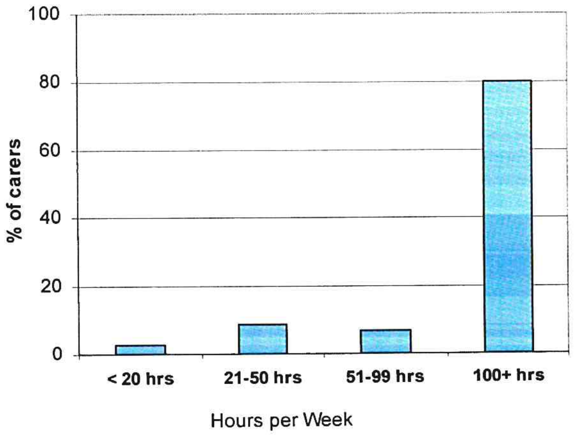
Table 1: County

	Frequency	%
Tyrone	26	23.9
Londonderry	21	19.3
Fermanagh	17	15.6
Armagh	16	14.7
Monaghan	13	11.9
Cavan	9	8.3
Donegal	6	5.5
Leitrim	1	0.9
Total	**109**	**100**

Residency of Carer

Nearly all of the respondents lived with the person they cared for (95% n=103), which has been shown to increase levels of stress and depression, increase support needs and worsen the carers condition of mental and physical health (25, 55). The same has been found for carers who 'provide substantial care', for example; 20+ hours a week (11, 54) or 50+ hours a week (55) Figure 3 offers a visual representation of the hours spent a week caring by carer respondents in this present study. The majority of carers (80% n=86) were found to spend 100+ hours a week caring. As a cumulative total, 97% (n=104) of respondents provided a 'substantial amount of care', over 20+ hrs a week, with a large proportion of this group (88% n=94) caring for over 50+hours a week, where health has often been reported to suffer (11, 25, 54, 55).

Fig 3: Hours Spent Caring



A typical finding of other research states that people with a learning disability often live at home with their carers (usually their parents) (24, 56, 72). In this current study, this is further reinforced by the carers' relationship with the dependant, as 90% (n=94) cared for their child or children, which may partly explain the high level of residency and hours spent caring by carers in the CAWT region.

Years Spent as a Carer

Another factor that can have an affect on carer health or support service requirements is the length of time spent caring. At this stage is it sufficient to simply outline that the majority of carers within the CAWT region who answered this question (n=108), 41% (n=44) had been caring between 16-30 years.

Who do Carers Care for?

This section examines the dependants' profile (people with learning disability **only**) and what caring roles may involve.

Dependant Demographics

Gender

57% (n=63) of dependants cared for were male, and 43% were female (n= 47) (missing n=1). As 90% (n= 94) of respondents were currently caring for their child, the majority of these female and male dependants where sons or daughters.

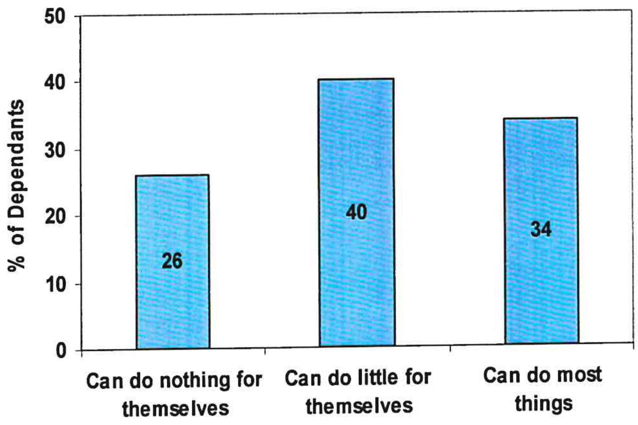
Age

The majority of carers cared for a dependant aged between 16-30 years (38% n= 41) and a significant amount cared for individuals aged over 31years (34% n=37). These results support other research stating that people with a learning disability are living longer and therefore staying with their family carers longer (7, 8, 24).

Capability of Dependant and Carer Duties

Relevant to carer health and support requirements is the capability of the dependant and the duties the carer must perform as a result of this. Dependants in this current study ranged from mild (can do most things for themselves) to severely disabled (can do nothing for themselves) represented in Figure 4. Although 34% (n= 37) of dependants could cope with most things unaided, 66% (n=76) of carers needed to offer a lot or full support to those they cared for. Furthermore, duties performed by the carer, such as heavy lifting, can cause carer ill health (3).

Fig 4: Capability of Dependant



Carer respondents in the CAWT region performed a range of duties listed in Table 2. 'Other' examples of help given noted by the carer included financial assistance, educational activities and protecting the safety of person being cared for.

Table 2: Duties Performed by Carers

Duty performed	**% of carers**
Taking person out	91
Keeping person company	88
Giving medication	85
Personal care	83
Physical help	34

<u>*Key Points*</u>

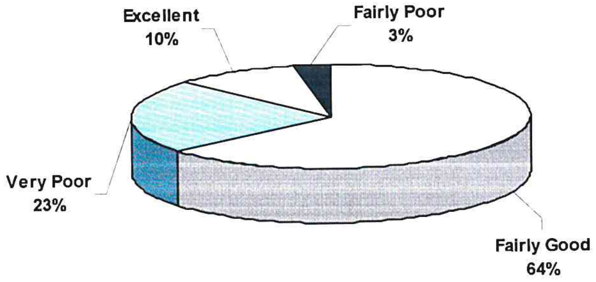
- **83% of carer respondents were over the age of 40**
- **95% lived with their dependant**
- **80% of respondents cared for 100+ hours a week**
- **87% of carers were caring for their child**
- **66% of carers had dependants that needed a lot or full support**
- **Main duties included 'taking the person out' and 'keeping them company'**

Various factors associated with caring have been noted to have an impact on a carer's health such as high levels of care (hours spent caring), the residency of the dependant, a carer's age or gender, the length of time spent as a carer, and the level of support received. Carers' mental and physical health has repeatedly reported to suffer as a direct result especially in comparison to non carers. This section examines these factors in relation to CAWT respondents' mental and physical health to investigate if caring has had a negative effect.

Carers' Physical Health

74% (n=82) of carers rated their health as either excellent (10% n=11) or fairly good (64% n=71) when asked to compare it to other people their own age (Figure 5). This finding illustrates that the majority of carer respondents in the CAWT region are in good health. However 23% (n= 25) of carers rated their health as fairly poor, and 3% (n=3) found their health to be very poor. Although carers within the CAWT region appear to be in better health than those in other studies, 26% (n= 28) are still in poor health. Furthermore 51% (n=55) of carers reported that they had some form of long standing illness, another recurrent finding in literature (6).

Fig 5: Carers' health in comparison to others their own age



What can cause poor physical health?

Carers noted a large variety of physical problems faced as a direct result of caring during the questionnaire stage of the research. Recurrent physical problems included; being constantly tired and feeling drained through sleep deprivation, back pain caused by heavy lifting, heart attacks, arthritis and joint pain and repetitive injury strain. Carers also frequently noted 'lack of free time' or 'having no personal time' for themselves as a cause of ill health, supporting previous research (18):

"He thinks I'm a personal body who is supposed to be on duty all the time...through the years, our lifestyle has become totally unhealthy".
Father of 39 year old son, Londonderry

Carers were also concerned about what would happen to their dependant if they suddenly became ill. Lack of emergency respite cover proved a major worry for many carers, who felt they would have nobody to cover them if they were sick or had to go into hospital:

"When you're sick you just cant stop caring...I think its (sickness) exasperated you know by your caring role because you can't just em say to somebody, "Oh God I don't feel well, I think I'll go here or go there", I mean you have to be there with the person who has the disability, so you've no outlet...for your illness"
Female sole carer, rural Armagh

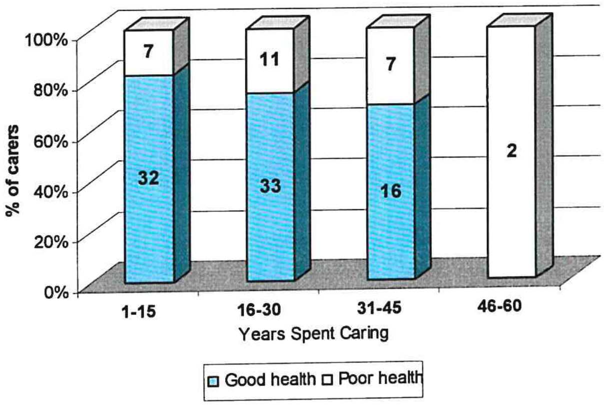
Carers Age

All significant tests were run; however, no statistical pattern emerged regarding age and the health of carers. Older carers did however occasionally claim that they found it harder to care as their age increased. Carers reported '*not being able to do what I used to do since I've got older*' (76 year old carer of 52 years) and *'(I'm) really finding things difficult now I'm older'* (carer aged 78).

Years Spent Caring

As found in other literature (7, 16, 20, 25) this current study also found a general decline in a carers health dependant upon the length of time they had spent caring (see Figure 6). Statistical tests could not be taken any further due to low level of respondents in the 46-60 year age range.

Fig 6: Carers Health by Years Spent Caring



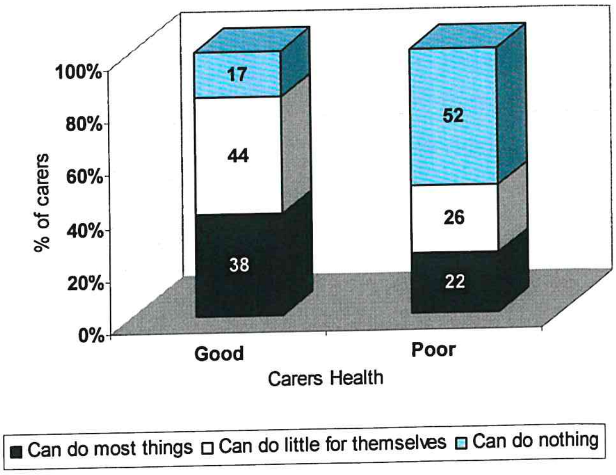
Hours Per Week Spent Caring

Carers' health was also examined in relation to how many hours a week were spent caring. Previous research offers a comparison of carers health in relation to those who care for over 20 hours a week with those who care for less (25, 54) or 50+ hours a week with those who care less (11, 67, 68) and often report an association between poor health and providing 'substantial' amounts of care (11, 25, 44, 54, 68). In this current study, in an examination of carers who cared for 20+ hours a week, only 25% (n=26) of carers were in poor health. As only 3 cared for less than 20 hours a week, no further statistical tests could be run.

Residency of Carer and the Dependant's Capability

Results showed no significant relationship between carers' health and if they were the sole carer, as other research has indicated. However, there was an association between carers' poor health and having a long standing illness and an association between carers' health

Fig 7: Carers' Health and Capability of Dependant



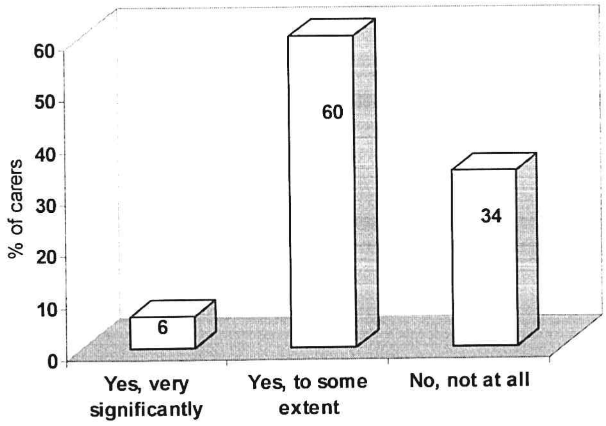
status and the capability of the person they cared for (n= 108, p value .002). Out of the carer respondents who claimed to have poor health (n= 27), over half the carers looked after a dependant who could do nothing for themselves (52% n=14), see Figure 7.

Carers who performed a high level of personal care, such as, washing and changing those they cared for found this to be a great strain and led to back conditions. In answering the question has caring has affected your health, one carer stated:

"Definitely has, ...(daughter) needs a lot of lifting, personal care, which all take their toll on your health"
Mother of 26 year old daughter, rural Armagh

It was important to establish if these health problems had an effect on the carers' ability to carry out their caring duties. To examine this, only carers who had reported physical health problems were assessed (n= 87).

Fig 8: Health Problems Affect Ability to Care



As Figure 8 details, 60% (n=52) of carers who had reported health difficulties found that these problems affected their capability to care 'to some extent', whilst 6% (n= 6) found a very significant impact on their ability to perform their caring duties. Carers who had been physically ill discussed these occasions, where they had no 'back up' support or emergency respite. One carer reported how her illness had affected her ability to care and felt her son 'lost out' as a direct result:

"It would leave me not as well able to care for (son) as I'd like to be, you know... when it flares up...I wouldn't be fit to lift him...or drive him to swimming...".
Mother caring for 11 years, rural Fermanagh

Carers' Mental Health

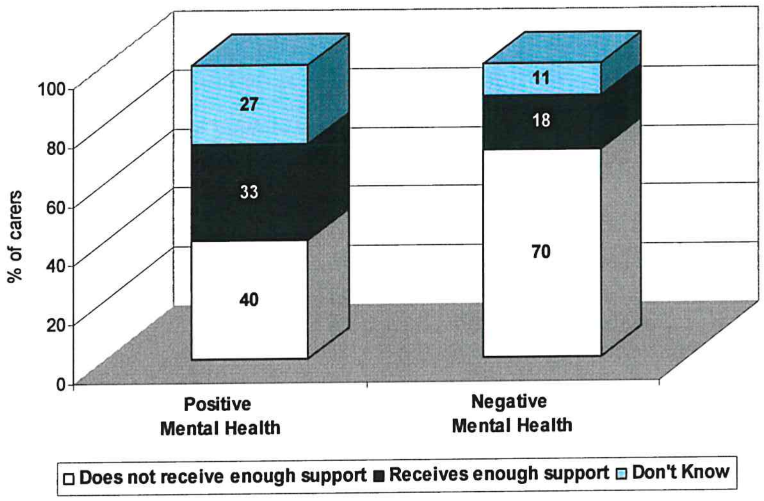
As carers' mental health has been reported to suffer as well as, if not more than, their physical health as a direct result of caring (11, 20, 59) this section examines carers' mental health status via the GHQ -12 questionnaire (refer to Appendix 2 for a full explanation). 45% (n=44) of carers within the CAWT region showed symptoms of poor psychological health (scoring 2+ on the bimodal scoring system). 23% (n=25) of carers had been prescribed anti depressants since their caring role began, and feelings of depression were frequently noted as part of poor mental health:

"...and from time to time I'd have to get anti depressants and I just feel, it's just that I get burdened down"
Female Voluntary Community carer for 25 years, Rural Monaghan

Crosstab case processing was utilised to assess any significant relationships between caring associated factors and psychological health outlined as significant in other research (11, 12, 20, 24, 25, 54, 60). What factors contributed to 45% of carers reporting ill mental health? What prevented 55% of carers from having poor psychological health?

This current study found no statistically significant relationship between numerous factors and poor mental health, such as the capability of the dependant, the residency of the carer, carer relationship and whether they were the sole carers, hours a week spent caring, geographical location (county/rural/urban), carer or dependant gender, or whether the carer was currently in employment.

Fig 9: Carers' Mental Health and Support Received



There was however a statistically significant relationship between carers' mental health and whether they felt they received enough support (p=96). With a p. value of .012, there is a strong association between carers who do not feel they receive enough support, and poor mental health. Of the 44 carers who scored 2+ (case) showing poor mental health symptoms, 70% (n=31) felt that they did not receive enough support (see Fig 9).

Carers often reported feelings of anxiety and mental stress attached to caring. Carers frequently were stressed due concerns about the future provision for their child if they were to become too frail to care, or die. These anxieties are increased by feelings of isolation and remaining unsupported by statutory services, and are often left to cope on their own:

I am 76 years old and I worry about what's going to happen to him or perhaps me taking ill suddenly and him not understanding
Rural carer, Londonderry

Carers also reported 'mental exhaustion', clinical depression, having panic attacks, mental breakdowns due to a mentally demanding and stressful role.

These results may therefore indicate that the receipt of support, either in general (e.g. family or friends) or through support services (e.g. carers groups or respite), is vital to a carer's mental health (Fig 9). These findings corroborate with that of other research, which notes that carers, who receive support are often in better mental health (20, 25).

What could ease these burdens and improve carers' health?

To ease the effect caring has on health, some carers stressed the need for more flexible respite. This would allow carers to be more spontaneous, rather than booking respite months and months in advance:

You have to have them booked into respite, in has to be so organised....if you forget to book it advance you couldn't go down and say I'm going in two or three days time I need to put them in, but that just doesn't happen
Female carer, rural Donegal

The need for emergency respite was also stressed; many carers had to rely on their family if they took ill. Some had to forgo operations they needed as no one could cover their caring duties. Other issues included more domiciliary support, a higher level of Carers Allowance and better acute services for service users. Some carers were stressed due to acute service facilities and how their children were treated while at the dentist for example, and felt that staff needed better training to deal with the situation. Carers wanted their dependants to be treated as equal people:

It would ease the pressure and the tension knowing that there was proper care out there...that (daughter) was having an equal live...the acute facilities in the hospital are not suitable to people with learning disabilities...most of the hospital staff actually are not training adequately to deal with that
Male carer, urban Fermanagh

Overall, carers generally stated that more respite and 'time off' from caring would ease their health problems.

Key Points

- **64% of carers reported 'fairly good' physical health**
- **66% of carers with a health problem found it affected their ability to care to some extent**
- **45% of carers showed symptoms of poor mental health**
- **70% of carers who had poor mental health did not feel they received enough support**
- **Carers felt a greater choice and variety of respite types would ease the burden on their health**

The coping styles endorsed by a carer can have an affect upon their stress levels (14). Adopted from such research, carers within this present study were offered 8 different strategies, four referred to in literature as *problem focussed strategies* (i.e. seeking professional help/service support) and four *emotion focussed* strategies (i.e. realising there are others worse off) (14). Carers were asked to rank how often they employed each strategy, *always, sometimes or never.*

How Carers Cope

Information within Table 3 is ranked by the combined total % of the 'Always' and 'Sometimes' column in order to assess which strategy is used by the most carers. This section does not aim to differentiate between frequencies of use, rather to investigate which strategies are most employed.

Table 3: Coping Strategies Used by Carers

Coping Strategy Used	**Always (n) %**	**Sometimes (n) %**	**Never (n) %**	Total no of carers (n)
Realise there are others worse off	77 74%	26 25%	1 1%	104 100%
Rely on own expertise/experience	61 62%	35 36%	2 2%	98 100%
Live/take one day at a time	73 72%	25 25%	3 3%	101 100%
Realise dependant is not to blame	81 79%	16 15%	6 6%	103 100%
Get as much information as possible	35 39%	42 47%	13 14%	90 100%
Seek professional help/service support	28 29%	51 54%	16 17%	95 100%
Talk problems over with a friend	24 26%	53 57%	16 17%	93 100%
Draw on religious beliefs	42 42%	33 33%	24 24%	99 100%

Table 3 indicates that the top coping strategy employed by carers is what Chambers and Ryan (2001) refer to as an 'emotion based' coping strategy ***'Realising there are others worse off'*** with 99% (n=95) of carers rating this as a strategy they would employ in order to cope with their caring role. This strategy is also referred to as 'avoidant coping strategies' and they lessen the problems of a current situation by denying the problem or wishing it would go away.

The second frequent strategy employed by the carers is a problem focussed strategy. It is regarded as a coping activity, as the carer is using interpersonal effects to reduce their stress (6, 14). The third and fourth top coping strategies are again emotion based. Therefore, 3 of the top 4 coping strategies are emotion based. Although this indicates that carers rely on a mixture of both coping styles (14) relying too heavily on emotion based strategies can have various consequences for the carer. Black & Roberts (2006) for example state that carers for people with a learning disability who rely on these coping methods can often suffer more depression, stress and isolation than those who are problem focused, and for example seek support through various support groups.

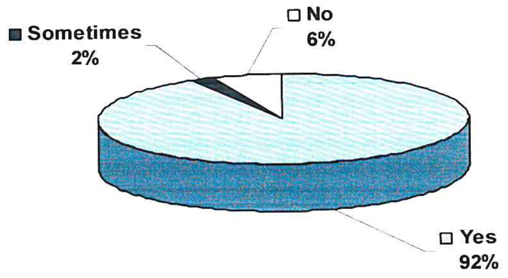
The absence of significant associations found between coping strategies and mental health found may be explained by carers deploying a mixture of emotion and problem based strategies, which according to Chambers & Ryan (2001) is common practice amongst carers for someone with a learning disability.

83% (n=79) of carers claimed they would seek professional help or service support to help them cope, which may indicate that Carer Support Groups may be utilised as a form of coping.

The Positive Side of Caring

Embracing the positive sides of caring can often help a carer continue within their often demanding and stressful caring role. This section briefly assesses what gives carer satisfaction to carers within the CAWT region. 92% (n=100) of carers claimed they received some form of satisfaction from their caring role (Fig 10).

Fig 10: Do you get satisfaction from caring?



What Gives Satisfaction?

Out of a provided list, carers where asked to note all points of satisfaction and then specify the main thing that gave them satisfaction in their caring role.

Table 4: Main Satisfaction from Caring

	No of Carers	%
Making loved one happy	54	50
Providing the best possible care for the person	26	24
Keeping person at home	18	17
Other	3	3
Helping them with personal tasks	2	2
Maintaining their dignity	2	2

The majority of carers stated that *'making their loved one happy'* was their main source satisfaction (50%, n= 54). Providing the best possible care for their dependant (24% n=26) and keeping the person at home out of a hospital (17% n=18) were also often classed as the main cause of carer satisfaction (Table 4). These results support the suggestion that the main sources of satisfaction concern the person cared for, and that keeping the dependant happy and well cared for can be utilized as a major positive coping strategy (33, 51).

The carers own reasons for satisfaction within this study included:

- Their love for their caree:

"My son is the most lovable human being you could ever meet. He just makes everything so worthwhile. I adore him".
Urban carer, Londonderry

- Reciprocal love given by the dependant:

"A smile, a hug can make all that difference, you forget all the bad days really…to feel… that you have achieved something if you're getting a friendly face and a smile…Keeping my daughter happy is what keeps me happy".
Male carer of 25 years

- Their own personal achievements:

Just being able to help somebody get through life and being there for them makes me a better person, Also you become more patient with everybody else
Urban carer, Fermanagh

- Milestones of progress and achievements by their dependant:

"What you put into a child like (son) you get back again, I think it's quite rewarding…these milestones of achievement due to your hard work…a huge victory"
Female sole carer of 11 year old son

Whilst only illustrating a small amount of the pleasure and happiness discovered within this current research, these results identify the existence of many positive caring aspects and rewards that can result from caring for a person with a learning disability and play an important role in coping with the demands of caring (41).

Key Points

- **An emotional coping strategy was the most common form of coping used by carers (99%)**
- **83% of carers coped by seeking professional help or service support**
- **92% received satisfaction from their caring role**
- **Embracing the positives that caring brings can act as an important coping strategy**

This section examines four main issues:

- The type of support carers mostly utilize within the CAWT area, and what services they would most be interested in using if available
- The barriers that can prevent carers attending Carer Support Groups
- The importance of respite to carers in receiving a break
- Issues surrounding cross border service development

Table 5: What do carers use the most, and what would they be interested in using if available? (N=109, Missing n=2)

Services being used, or used in the past	%	Services carers would be interested in, if available	%
Short stay in a residential unit	42%	Short stay in a residential unit	18%
Carers Support Group	27%	Carers Support Group	38%
Leisure schemes for caree	22%	Leisure schemes for caree	45%
Flexi care	17%	Flexi care	37%
Breakaway	15%	Breakaway	25%
Sitting day service	14%	Sitting day time	17%
Sitting evening	11%	Sitting evening	20%
Short stay in hospital	8%	Short stay in hospital	5%
Holiday for both	6%	Holiday for both	39%
Residential trip for both	5%	Residential trip for both	30%
Sitting night service	4%	Sitting night time	21%
Sitting Sunday	3%	Sitting Sunday	21%

Table 5 illustrates that the most frequent form of support utilised by carers is *'a short stay in a residential unit'*. Other forms of respite used include sitting services (14% n=15 daytime, 11% n=12 evening, 4% n=4 night time, 3% n=3 Sunday), flexi care (17% n=19) and breakaway (15% n=16). These alternate forms of respite do not rely on placing the dependant within a residential home or hospital for a short stay, rather they allow them to stay within their own or another person's home, where the carer can also remain if they so wish.

Carers who stated they did not have these alternate forms of respite available to them also demonstrated a high level of interest toward accessing them. For example 37% (n=40) of carers exhibited interest in using flexi care if made available. Sitting services most wanted included night time (21% n=23) and Sunday (21% n=23) sitters, which would allow carers personal time whilst someone sat with their dependant. These services proved more popular that traditional respite services such as hospital respite.

Carers also wanted more after school and summer holiday activities, such as leisure schemes for the dependant (45% n=49) and a holiday where both could travel together (39% n=43). These services not only provide a service for the caree, but also provide more opportunities for carers and dependants to have a break together.

There were no significant relationships between the type of service used and required within each county by carer respondents within the CAWT region, nor was there any difference between service requirements and rural or urban carers.

In response to the question '*Do you receive enough support within your caring role?*' 53% (n= 57) responded "no". Only 26% (n=28) felt they received enough support whilst 21% (n=23) did not know. These results are similar to other research findings, where the majority of carers often do not feel supported in their caring role, often due to little or no services available (8, 13, 18, 25, 30, 42, 55). Statistical tests were run to explore potential relationships between carers feeling unsupported and carer and dependant demographics. No significant associations were found, however, it still remains an important issue that over half the carers do not feel they are receiving enough support (53%) or don't know if they are (21%).

Carers Groups within the CAWT Region

Along with services designed for the service user, carers where also asked about their personal use or interest in a support group **for them**, a place designed to give information, advice and relief from caring. 27% (n=29) of carer respondents stated that this type of service was available in their area and were either currently using them, or had availed of them in the past (Table 6). 38% (n=42) claimed they would be interested in using a Carer Support Group (CSG) if one was made available. Therefore a potential figure of 66% (n= 71) of carer respondents could be attending carer groups and getting support if more were widely available across the CAWT region.The maps (North only) and listings (North and South) in Appendices 3 & 4, illustrate the location of general and learning disability specific CSG's within the CAWT region. In order to establish where CSGs are most used, and where they are required, Table 6 illustrates Carer groups use across the CAWT region.

Table 6: Carer Support interest and use by county (ranked by interest)

County	Currently using or have used it in the past	Would be interested it, if available	Not Interested	Total
Tyrone	6	12	8	26
Londonderry	3	8	9	20
Fermanagh	8	6	3	17
Cavan	1	6	2	9
Monaghan	2	5	5	12
Armagh	6	4	6	16
Donegal	3	1	2	6
Leitrim	0	0	1	1
Total	29	42	36	107

Out of the respondents from each area, carers in County Cavan expressed the most interest in using a service if it was available (67% n=6). 46% (n= 12) of carers within the Tyrone area were interested in using the service if available in their area, followed by County Monaghan with 42% (n=5). Carers are therefore interested in getting support from carer groups. However an examination of Appendices 3 & 4 illustrates a lack of general, and even more so learning disability specific, Caree Support Groups in these areas.

Role of a Carer Support Service

As shown in Table 6, 27% of respondents in this present study were using or had used a carer support service in the past, and 38% would want to use a support group if this was made available. This may be linked to what is important to a carer in their caring role. For example, 76% of respondents (n=76) stated meeting other carers and relieving isolation as really important or important, and 87% (n=89) found it of important to have access to relevant information on caring, also demonstrated in other research (7, 24, 26). This support is often provided via Carer Support Groups.

Meeting other carers and getting information:

"To form relationships with other careers and to find out other entitlements that we may not be aware of"
Rural Carer, Monaghan

"They support your caring role, give information on different services"
Rural carer, Tyrone

For those who found it important to relieve isolation and meet other carers, there was no significant difference between rural (and therefore more isolated areas), than those who lived in urban areas, illustrating that carer respondents, despite their location, find it important to have contact with other carers and relief from their isolation. Carers also found carer groups as an excellent source of information as well as providing the opportunity to discuss their problems with other carers. Therefore Carers Groups can be vital services that help alleviate some of the most important issues for carers.

Barriers to Using a Carer Support Group

There are numerous barriers that can prevent a carer from attending a CSG. This section examines these barriers in relation to the carers' demographics, the capability and age of the dependant and the type of transport available to them. Understanding these barriers may explain why 35% (n=38) of carers are not interested in using CSG, and discussing possible solutions with carers may help those who cannot attend. In order to attend a carer support group meeting or outing, many carers often need some form of respite cover to allow them to attend. 29% (n=24) found this would be their main barrier in attending as they had no one to look after their dependants for the allotted time they would need to

Table 7: Main Barriers Identified by Carers

Barrier	No of Carers	%
No Cover	24	29
Other	20	24
Too Busy	13	15
Guilt	9	11
Worried about standard of care	9	11
Reluctance from caree	4	5
No Transport / Too far away	3	4
Having to Pay	2	2

leave the home. Carers also stated being too busy (15% n=13) and feelings of guilt (11%, n=9) as their main reasons for not using a CSG.

Table 8: Main Barriers identified by HPs

Barrier	No of HP's	%
No Cover	30	56
Guilt	6	11
Worried about standard of care	5	9
Too Busy	5	9
No Transport / Too far away	4	7
Other	4	7

Health Professionals were also asked to illustrate the main barriers that they felt carers faced in attending a CSG. Overall, HPs were aware of the main barriers that could prevent a carer from attending a support group. The majority of HPs regarded having no respite cover as the main barrier (56% n=30) that carers faced (Table 8). 'Feelings of guilt' and 'being too busy' were also in their top three barriers, reflecting the carers' choices. There were no significant associations between barrier awareness, the area in which the HP worked, whether they were statutory, voluntary or also an unpaid carer. It is important that HPs understand the potential barriers carers can face in attending CSGs in order for solutions to be formulated. If HPs are aware of these issues, they can be considered in future service/support group development.

'Other' barriers

Carers also reported various reasons as to why they would not attend a CSG. Some carers had cared for so long without any support, they did not see the point in attending a support group at such a late stage:

Too late now: have been doing this since my daughter was born
Rural Carer, Cavan, aged 76

Others were not interested in talking about their caring issues and problems, especially if they managed to get some time off caring:

Carer support, for us it would be respite, I can understand people on their own needing to talk to other carers, I really don't feel that need
Male joint carer, Londonderry , 65years old

Other barriers centre on the lack of information on carer groups available, with carers frequently reporting not being aware of any in their area. A few carers who had previously attended a carers' support group did not enjoy the contents of their group, whilst others found the times unsuitable for them to attend.

Lack of information/unaware of CSG:

"I'm unaware of carer support service available"
Urban Carer, Tyrone aged 76

"Not knowing what is available or how to access it"
Rural Carer, Fermanagh, aged 47

Potential Solutions

The issues of 'no transport' and 'no respite cover' were addressed in more depth during the interview stage of the study in order to formulate potential solutions for future service development.

No Cover

To create a possible solution to the main barrier of '*no respite cover*', carers and HPs were asked their opinion on bringing dependants along to the meetings. This could be done in two ways: Firstly, a CSG meeting could be held at a day care centre whilst the dependant was in respite. Therefore, the carer would not have to worry about getting cover. This however would only assist those carers who had access to respite. Carers who did not use respite were asked how they would feel about bringing their caree along to a CSG meeting. Both HP and carers were asked if these were practical solutions and to identify potential problems it could create.

Some carers were very interested in attending a CSG where they could bring along their dependants. They felt this would be a solution and would allow them to attend carer meetings and outings:

Of course it would, of course it would...if I didn't have to run round looking for someone to look after her, it would be a big asset
Female Carer, Rural Armagh

However, there were also several issues that could make this a complicated procedure for many carers and Carer Support Groups. One main problem that arose concerned the nature of the dependants' disability. Some carers would not be able to take their child along to meetings as this would cause a break in their routine, or bring them into crowds or interactions with strangers, which would cause great upset. Others felt that it would not allow the carer to have 'a proper break'. There were also issues of building space, insurance, transport and lack of suitable facilities.

Others thought that 'sitting services' or respite services to facilitate carers attending support groups should be more widely available:

"If you had a Carers Organisation or an umbrella group .....to set up a scheme whereby they could identify support workers, or some sort of helpers that will either go in and sit with...to allow the carers to attend the meeting, or indeed that they provide the transport to allow the carers attend the meeting"
Foyle Trust, Statutory HP

One Carer Support Group, through outside funding, was able to provide their carers with a respite allowance, which allows someone to sit in whilst they attend a course or a meeting. However there is limited funding for this. HPs also suggested a range of services for carers as well as counselling groups in order to cater for all needs. Other solutions to these various barriers included more flexible support group meetings and a varied choice of activities.

Support groups need to be varied in what they offer:

"..quite often want carers want is something that is not related to caring...flower arranging or something completely different so they can forget about their carer responsibility"
Sperrin & Lakeland Trust, Statutory HP

Transport

HPs outlined several problems caused by the lack of transport, especially for carers who are elderly and live in rural areas, and discussed various ways this problem could be alleviated. Rural carers in particular can't rely on public transport:

"The public transport system is very poor, you know, there isn't, you can't walk outside your door in the middle of Glenties and get on a bus. People who attend groups are really only those who can get there."
HSE West area, Statutory HP

Those who managed CSGs for example, often did not have their own form of group transport (i.e. group bus), but rather relied on car sharing between those who attended:

"We are reliant on the generosity of other parents...we all look out for each other" *(discussing car sharing)*
Sperrin and Lakeland area, Voluntary HP

Others were in a position to provide 'petrol money' that encouraged a car share scheme, were carers were paid a mileage allowance *(Dergfinn Partnership, Voluntary Carers Support Group).* Overall however, carers who wished to attend a support group had to find their own method of transport.

It was outlined that future service developments must take into account how people are going to reach a service. One possible solution was to localise some of the meetings, to use local community or health centres within each area. Accessing funding to provide a bus for CSGs was also discussed, however this could result in the increase of some carers travel times, especially if the remote rural areas were included.

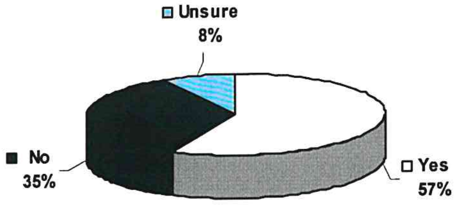
Cross Border Services

In order to assess carers' views on cross border service development, they where asked various questions relating to this issue. Currently, 6% (n=7) of carer respondents were using a service across the border, 4 of respondents from the South and 3 from the North.

Willingness to Use Cross Border Services

57% (n=60) of carers said they would use a support service across the border; however 7% (n=7) of these carers stated that transport must be provided to enable them to do so. 35% (n= 37) were unsure and only 8% (n=9) said they would not use a cross border service (Fig 11).

Fig 11: Willingness to use Cross Border Services



Although no significant associations were found between using a cross border service and support carers felt they received, when carers who agreed to use cross border services were analysed separately, 60% (n=31) felt they did not receive enough support. Therefore, feeling unsupported in the area they live may partly explain a carer's willingness to seek support elsewhere.

Cross Border Benefits

73% (n=67) of carers felt there would be benefits for carers using a cross border carer support service whilst 9% (n=9) were unsure. Reducing travel time was an important issue. Many felt it beneficial to cross the border to use a service rather than travelling miles to their nearest support group in the North or South

I only live 8 miles from Dundalk and 8 from Castleblaney so I could easily join these classes
Rural Armagh aged 47

Similar to benefits of CSGs in their area, carers regarded cross border services as a chance to meet others in the same situation, as a chance to talk over problems and get information. Others thought it would be beneficial to compare services and share information between the North and the South, whilst providing a greater selection of services to choose from.

"It would help people to see what the cross border services differ from ours and may provide carers with better ideas and support"
Rural Carer, Cavan, aged 76

"It would give us a greater choice of services and availability of respite host families"
Rural Carer, Donegal

As CSGs are so limited (Appendices 3 & 4), others thought it would be a great idea if it meant more carer support, regardless of its location:
"Any carer support is welcome and valuable. Disabilities don't recognise borders"
Questionnaire Number 27: Rural Carer, Armagh

Others however felt that cross border services would be of no use at all (17% n=16).

Cross Border Barriers

Carers and HPs where asked to identify potential barriers that may prevent carers from crossing the border to use a carer support service:

Table 9: Cross border Barriers Identified by Carers (selecting main barrier)

Barrier	**% of carers who recognise this as a potential barrier**	
Not aware of services available	82%	n=84
Lack of knowledge regarding their eligibility	44%	n=45
Cost of travel/time spent travelling	32%	n=33
No transport	11%	n=11
Feelings of mistrust	9%	n=9
No barriers	8%	n=8
Religious background	**3%**	**n=3**

Table 10: Cross Border barriers Identified by HP (tick all that apply)

Barriers	**% of HPs who recognise this as a potential barrier**	
Carer may not be aware of services available	85%	n=46
Lack of knowledge regarding their eligibility	83%	n=45
No transport	74%	n=40
Cost of travel/time spent travelling	65%	n=35
Religious background	33%	n=18
Feelings of mistrust	30%	n=16
No barriers	7%	n=4

Overall, HPs were aware of the main barriers that carers can face in attending a carer support group. All statistical tests were run. There was no significant differences between Trust areas or voluntary or statutory services.

Lack of Information

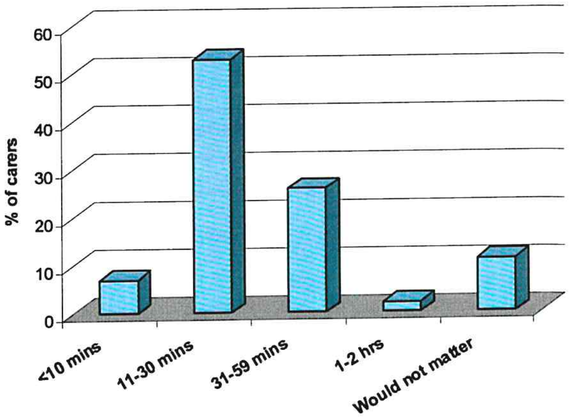
Carers felt that being unaware of services available to them across the border would be the main obstacle to their attendance (82% n=84), reflecting other literature that suggests carers rarely even know of the support available within their area (14, 18)):

"I'm unaware of any support groups over there, I wouldn't know if they exist"
Female carer, caring for 6 years, rural Fermanagh

Cost or Time Travelling

Overall, 32% (n=33) of carers regarded the cost or time spent travelling as a problem in utilizing cross border services, therefore the time a carer is willing to travel needs to be considered in the location of any new service. The majority of carers were willing to travel 11-30 minutes one way (53% n=51) to reach a CSG whilst 12% (n=11) claimed that travelling distance would not matter (Fig 12).

Fig 12: Length of time carers willing to travel to attend CSG



HP views on Potential Problems and Benefits

In order to assess potential problems and benefits of developing cross border services, HPs were asked to outline the main problems that could arise from cross border service development, and how these problems may be addressed. Results are divided into HPs who had experience working cross border, and HP who had no experience but could speculate as to what potential problems could arise.

HPs with Cross Border Experience

Those with past experience of cross border carer projects reported it as having great benefit to the carers. It offered carers the chance to get involved with others across the border and learn what other services were on offer in a different area:

It worked very well…the carers really enjoyed it and they enjoyed getting involved with cross border carers even though we did feel that the services were different to ours. Carers loved…meeting up with them, they learnt different ways that they cope with…that their situation compared to us on this side…
HSE Dublin NE area, Voluntary HP

Another benefit to cross border services meant that travel time for the carer or service user could be greatly reduced:

"Its closer, it's very close here to us you know...the North is very near us"
HSE Dublin NE area, Voluntary HP

Problems encountered

Problems faced by HP involved in cross border projects outlined three recurrent problems encountered:

- **Transport issues**

"One of the biggest problems is transport, transport for both groups because there is very little statutory funded in the South, it's all sort of voluntary"
Newry and Mourne Trust, Statutory HP

- **Legislation**

"We don't have mirror legislation, so therefore it's not just as easy…and it's very difficult for people to understand where responsibility starts and stops because we're talking two different languages".
Newry and Mourne Trust, Statutory HP

- **Resources**

The willingness is there, the resources aren't there"
HSE West, Statutory HP

HPs without Cross Border Experience

Many of the HPs who had not cross border experience felt that a major benefit of cross border services for carers and service users would be:

- Reducing travel time and travel expenses with small, isolated communities benefiting the most:

- The social aspect of having closer services was also underlined, especially for rural or elderly carers, or those who have no other form of support:

- It would increase choice:

It would probably increase choice for them because there is such lack of resources anyway. If someone wanted respite or a support group, it would offer more choices to help them make informed decision"
Foyle Trust area, Voluntary HP

It was also felt that developing cross border services would provide an effective method of accessing funding as carers who live in isolated areas can come together from both sides and form a large organisation. Similar to HPs with experience in cross border work, problems were seen as potentially arising from lack of resources, different jurisdictions and legal issues.

Using facilities already available, such as community services or churches, was one possible suggestion to combat this problem, which may also partly reduce the transport issue:

"Its not good to bring 100 people into a building and try to occupy them, its important to use local facilities, community centres and so on, and try and develop what we call Satellite Units in outlying areas, so it reduced the travel costs, its much more appropriate and accessible for people if their centres at the end of their street"
Foyle Trust area, Statutory HP

Overall, HPs felt that these problems and differences between the North and South need a great deal of exploration and must be addressed when considering future cross border service development:

"It's all those sameness and differences that have to be rolled out and we need some common currency and language, and we haven't got that as yet"
Newry and Mourne Trust, Statutory HP

Despite these potential difficulties, cross border carer services were regarded as a form of support that was definitely needed.

"Yes, definitely would of benefit, it could be a lifeline in a lot of cases...it has health and social benefits, especially elderly carers who could have someone to talk to. It's something that is definitely needed"
HSE Dublin NE, Statutory HP

Getting A 'Break' - Respite for Carers

Carers were asked to rank the importance of '*Getting time off*' from their carer duties. In total 86% (n=89) of carers found 'getting time off from caring' as either really important or important. The majority of carers who found getting a break 'really important', had had a break within the last 6 months (52% (n=27). Although typically respite is a service for the service user, the 'spin off' support retrieved by carers through it means it is vital to the caring role:

"Respite for the person with a disability is support for the carer".
Voluntary Carer Support Worker, Armagh

Many carers in this current study who had had some sort of break felt it was of benefit to their mental and physical health and offered relief from constant stress and strain. Carers reported feeling refreshed and recharged, leaving them more capable to carry on caring. Many carers found they could not manage without one. Getting a break could also be simply having a few hours off to get away from caring duties, emphasising the need a range of respite forms:

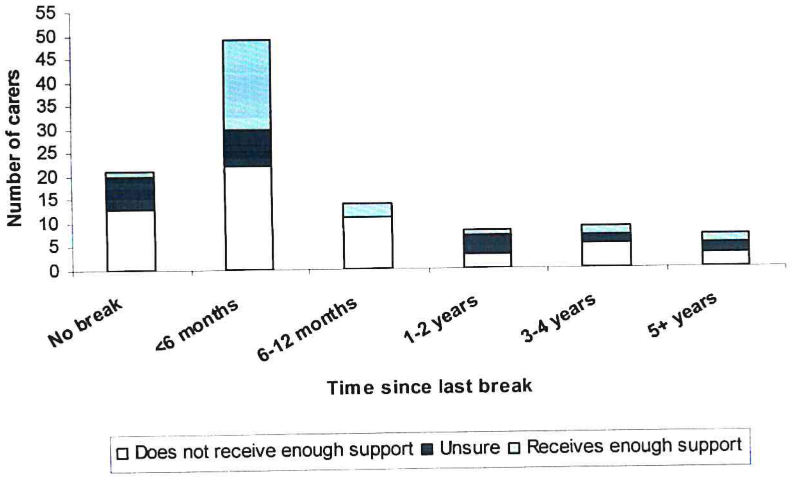
"A break to us could be just staying at home, going out for meal, whatever, if we had a sitter"
Joint carers (65 & 60 yrs), urban Londonderry

"..it would be nice for me to be able to get somebody to come, you know where I can have a night out maybe, or where I could even go and have a nice soak in the bath and not have to worry about (daughter) pulling something down round herself".
Female Carer, rural Armagh

Length of Time Since Having a Break

Despite the importance of getting a break, 19% (n=21) of carers within the CAWT region had not had a break since they began caring. This had a notable effect on whether the carer felt supported. 62% (n=13) of the carers who had **not had a break** since they began caring felt that they **did not** receive enough support, whilst 33% (n=7) where unsure (Figure 13).

Fig 13: Support received in relation to time since last break

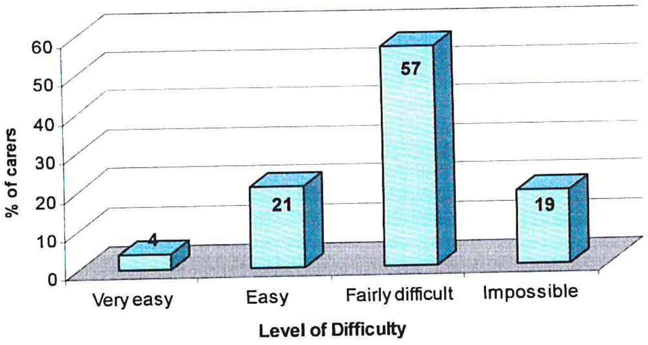


For all carers who had some form of a break, they mainly relied on family or friends for cover (39% n=42) or used a respite service (38% n=41), which indicates an even reliance on both support services and family support.

Carers were asked to rate the level of difficulty faced in arranging a break from caring. Only 25% (n=26) found it easy to arrange cover if they wanted 'time off' (4% very easy: 21% easy). 57% (n=60) found it difficult, whilst 19% (n=20) found it impossible to ever arrange time off from caring (Figure 14).

Literature suggests that those with who never get a break are more likely to suffer from ill health (11), therefore the next section **only** focuses upon the 19% (n=21) of carer respondents who had **not had a break** since they began caring.

Fig 14: Level of difficulty in arranging a break



The majority of carers who had never had a break had been caring between 1-15 years (48% n= 10). 38%

(n=8) had not had a break in 16-30 years, whilst 14% (n=3) had been caring for 31-60 years without time off.

Not all carers however expressed a desire to have a break from caring. Some carers, for example, thought that using respite for a break would not bring any benefits to them, despite the strain on their health. They did not feel confident in the services available to them; and often did not want to leave their child as this would increase their anxiety. Carers also worried about the standard of care at respite centres, mainly due to bad past experiences where a child had been hurt during respite.

"*I don't* (use respite), *from my own point of view, I don't think it would benefit me an awful lot, certainly if I had services built that I was confident in, then yes it would benefit me as I could go then and relax...to actually go at this moment in time...I would just be going away actually to brood even more...".*
Male Carer, Urban Fermanagh

Another recurrent barrier concerned unsuitable respite. Various carers found the respite available to them was not suitable for their child's level of disability; often the child would not be happy there:

"Anything that has been offered on a respite, really hasn't been suitable for her...she refuses to attend her day-care...because it's too large a group and she's not happy there"
Male Carer of 26 yr old daughter, rural Fermanagh

These carers expressed an interest in a sitting service a few hours a week, rather than a week long or weekend respite. They acknowledged that getting a break may aid their health, but they were not interested in spending too long away from their children, or that they children were reluctant to go into respite.

Rather than making the direct assumption that all carers would want a break from their caring role, this current study also asked carers who had never had a break, to rate how important getting time off was to them in their caring role.

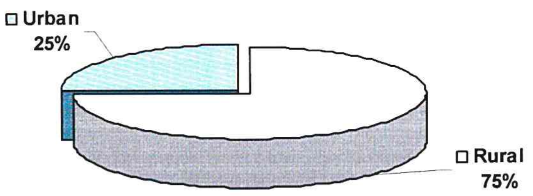
Sometimes carers felt that only they could provide the best level of care:

"I wouldn't have looked for breaks, I was quite happy to bring (son) any place with me, in fact I'd be happier to do that than to leave him... I sort of feel that I have to be with him, and you know I know all his needs, I know what he wants, and I suppose I can anticipate them better than anybody else".
Female carer of 11 years, no break since started caring, rural Fermanagh

78% (n= 14) of carers who had not received a break since they started caring stated they **did** find it either really important (39% n=7) or important (39% n=7) to get time off from caring. Therefore, the fact that these carers have not had a break is not because they do not want or need one, but rather because they find it too difficult (45% n=9) or impossible (50% n=10) to arrange. This level of difficulty in arranging cover, such as family, neighbours, or respite, could be a direct result of the carers' geographical location.

75% (n=15) of carers who had never had a break lived in a rural area (see Figure 15). This supports other literature that suggests carers in rural areas do not have enough access to the support they need, and have a poor level of contact with support services (37).

Fig 15: Rural and urban carers who have never had a break



This lack of respite and support services meant carers were often very limited in what they had available, many carers wanted a greater choice of respite services and respite types rather than just residential or hospital respite (also demonstrated in Table 5).

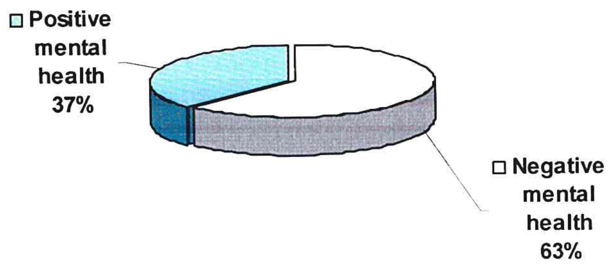
Getting time off from caring can help carers stay positive, it gives them something to remain focused upon and benefit their caring role. Respite was referred to by one carer as a 'God send':

"If your looking after somebody with a profound learning disability, for 24 hours a day, 7 days a week, I mean, when are you going to get this, this rest, you know...so that's where the respite comes in, I mean its a God send to most people...it's the sense of freedom I think".
Mother of 28 yr old daughter, rural Armagh, uses hospital respite and family support

Not Getting a Break and its Affect on Mental Health

Literature frequently states a direct link between poor mental health problems and not getting a break from caring (11). When carers who had never had a break were examined in relation to their GHQ score (n=19), 63% (n=12) of these carers reported negative mental health symptoms (Fig 16).

Fig 16: Mental health of carers who have never had a break



Many carers who had not had a break, or not had a break in a long time, found it had an affect on their health:

"Yes it would have an affect...mentally...my personality has changed...I've become more aggressive...frustrated"
Male carer, rural Fermanagh, no break in 15 yrs

Some carers who felt they had not had a proper break since caring began could see the benefits it could bring for their mental health:

"It would take you away from the pressure of caring for that time...I suppose everybody has to get away from what they're doing some of the time"
Father and mother of 3 children, caring for 26 yrs, rural Donegal

Key Points

Carer Support Groups

- **53% of carers did not feel supported within their caring role**
- **35% of carers were attending or had attended a CSG**
- **High level of interest in attending CSG if made available across the entire CAWT region (38%)**
- **Benefits of CSG included 'discussing problems with others in a similar situation' and 'getting information'**
- **Having 'no cover' was the main barrier in preventing carers from attending a CSG (29%)**
- **HP were aware of these main barriers**

Key Points

Cross border

- **Only 6% had used cross border services**
- **73% felt there would be benefits for cross border such as reduced travelling and additional support**
- **57% were willing to use cross border services, 35% din't know**
- **Main issues that could prevent use is being unaware of services available 83%**
- **HPs issues in service development include transport, funding and getting the information to carers**

Key Points

Respite

- **86% stated that getting a break from caring is important**
- **Residential respite is the most commonly used form of respite for the carer**
- **Carers expressed great interest in different respite forms being made available**
- **19 % of carers had never had a break since they began caring, the majority of these carers coming from rural areas**

By its definition alone, the Carers Assessment (CA) was designed to provide an overall assessment of each carer's support needs in order to provide them with the services they require to aid them in their caring role (17). Recurrent literature has described its implementation as 'patchy', (30). and research into carers of people with learning disability who have received the assessment have remained largely confused regarding its purpose and extremely disappointed with its outcomes (56).

This current section firstly investigates the number of carer respondents within the CAWT region who are:
(i) aware of CA and
(ii) have been assessed

Those who had been assessed were furthered asked what benefits (if any) the CA had brought to them as a carer. This was examined according to county, length of time as a carer and the dependant's capability.

Health Professionals were also asked their views on CA, and opinions were compared across a range of statutory and voluntary workers within each area. (This section can only focus on carers in the north as no equivalent to CA as yet exists within in south. The questionnaire did however, after providing an outline of CA and its role, ask carers within the South if they would find this type of assessment useful. 52% (n=14) of carers said yes, whilst 44% (n=12) were unsure, only 1 carer (4%) said no (n=27) missing (n=2).

Carers Who Had Heard of the Carer Assessment

Only 34% (n=27) of carer respondents across the North CAWT region had heard about the Carers Assessment. Figure 17 offers a further breakdown of the awareness of CA within each county (n= 78, missing = 4). Those living within County Armagh had the highest awareness (56% n=9), followed by County Fermanagh (53% n=9). County Londonderry had the lowest level of awareness (9% n=2) amongst its carer respondents.

Fig 17: Awareness of CA by County

Dependant's Age and CA Awareness

There was a descending pattern between the age of the dependant, and whether their carer had heard of the CA (n=77, missing =5). 46% (n=12) of carers who had heard of CA had children aged between 1-15 yrs old. This may be explained by the age of the Carers Assessment itself. It was introduced in 1995 in the UK and then in Northern Ireland in 2000 under the Carers and Disabled Act (19). Therefore carers with younger children may be more likely to have been informed about CA by HPs. Carers with dependants aged 1-15 years may also have a higher chance of hearing about CA via carer support group meetings, school networks and other carer friends.

Those who attended Carer Support Groups were also more likely to have heard about the assessment. 52% (n=12) of carers currently or previously attending a Carer Support Group were aware of CA. Although one carer heard through a social worker, the majority of carers reported learning about CA through support groups such as Mencap, Autism NI/PAPA group, or meetings set up by Carer support workers.

"...but it had never been mentioned by social services...I think actually that most carers don't even that it exists"
Male Carer, Fermanagh CA performed February 2006

Carers who had a Carers Assessment

Results were further filtered to assess how many carers, out of those who had heard of CA (n= 26), had one performed. 62% (n=16) had one performed, only 20% of the overall respondent total. Some carers reported great difficulty in achieving this:

"I forced my social worker to do it...my social worker was very much kind of 'you realise you won't get anything from this"
Female carer for 6 years, rural Fermanagh

"I had to threaten court to get it"
Carer in Rural Armagh

To assess the benefits for those who had the assessment, carers where asked both in the to give their opinion on its outcomes, and what they thought of it in general.

Negative Aspects

Many carers regarded their CA as a 'paper exercise' due to two main reasons.

(i) A number of carers who had received an assessment never received any feedback:

... whether it's a lack of funding or lack of not caring, we never heard anything back from carers assessment...it's a wasted paper exercise"
Male carer, urban Fermanagh, had CA February 2006

"I waited $1^{1/2}$ yrs to get one, still 6 mths later waiting for it to be typed up. Social Services left unmet needs page out, I disputed this and they said they are not putting it in, I said I want it in. They haven't come back to me yet."
Carer in Rural Armagh

(ii) Carers reported that they received no extra resources, services or support as a result of their needs assessment; nor were they signposted to existing services that could help.

Positive Aspects

Not all carers thought the CA as an entirely negative experience. Some carers felt that although no extra resources were available, it gave the opportunity to discuss **their** problems and needs, it recognised their caring role. Furthermore CA offered the chance for unmet need to be recorded, which can help advocacy or future development.

"... the advantage of them is that,, you know you're recognised as a carer and also that any unmet need or anything has to be recorded and then looked at...how else would anybody ever know about it?"
Rural carer, Armagh

Some carers had benefited directly from CA in other ways. Becoming eligible for Direct Payments through the Carers Assessment gave some carers the chance to 'buy' more help whilst one carer was allocated sitting services and respite cover within the home:

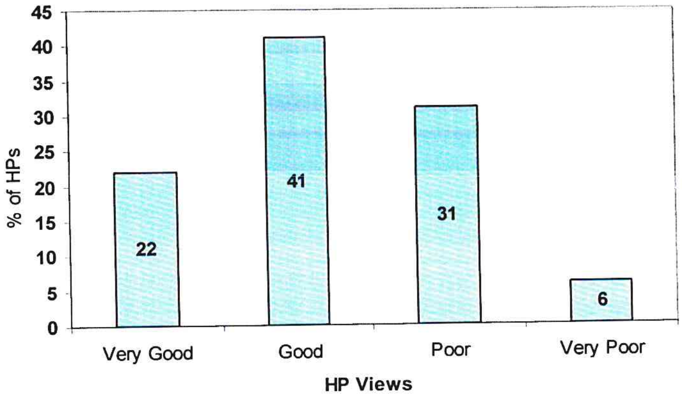
"Received direct payments, I have an hour each day to help my son with his homework"
Rural carer, Armagh

Health Professionals' Opinions toward Carers Assessment

HPs were also asked to give their opinions on the CA in an attempt to explain such low levels of knowledge and such a poor implementation of the CA across the CAWT north region (n= 32, missing=7). All significant tests were run to assess influencing factors on these attitudinal differences, such as voluntary or statutory HPs and by Trust area, however none where found.

Overall, 62% (n=20) of HPs within the North rated the CA as good, ('very good', 22% n=7, 'good' 41% n=13). 31% (n=10) regarded it as 'poor', whilst only 6% (n=2) viewed it as 'very poor' (Fig 18).

Fig 18: HPs views on CA



HPs were asked whether or not they felt the CA had been beneficial to those carers who had received it. Although 42% (n=13) felt it had been beneficial to carers, 42% (n=13) did not know if it had any benefits and 16% (n=5) felt it was not beneficial at all. HPs were asked why they held these opinions, and several main themes emerged, many of which echoed those held by the carers themselves.

Positive Opinions

As with a small number of carers, some HPs outlined the positive aspects of having a CA performed, despite lack of resources. HPs recognised that CA offers carers the opportunity to discuss over their problems and have their feelings considered, to have their needs recognised and recorded, and to be regarded as separate to the person they care for:

Negative Opinions

Negative attitudes toward Carers Assessment centred around two main themes.

(i) Limited resources (often due to lack of funding), to follow through after the CA, which often leads to carer dissatisfaction, creating feelings of frustration and anger. Linked to this is another recurrent theme,

(ii) CA unnecessarily raises carers' **expectations** regarding the services and support they may receive.

Carers Assessment can give false hope:

"I think that the concept is good but not every carer has an assessment completed. If an assessment is completed there are very limited resources to follow through on the recommendations"
Foyle Trust area, Voluntary HP

These negative attitudes held by HPs may partially explain why carers are unaware of CA and their rights to it, and may even explain why those who are aware have not received it (n=10). Due to a lack of resources to provide extra services, some HPs remain reluctant to offer CA to a carer, feeling that it will only create 'false hope', 'expectations which can't be met', which in turn would only led to more upset and anger on behalf from the carer. This negative attitude may affect how CA is portrayed to the carers, focussing on the lack of resources and informing carers that the whole procedure was 'pointless' often meant a poor uptake:

"They were sort of saying to the carer "well look you can have this carers assessment, but to be honest like you'll not get anything more out of it" therefore uptake was poor as being told it was pointless"
Sperrin & Lakeland Trust, Statutory HP

There was also the issue of the CA adding to an already heavy workload amongst HPs:

"...there has been a slight reluctance on part of the staff to take on carers assessments. One is that it is an additional role that they're being asked to do, and they're very heavy case loads as it is and they're saying this is an extra thing that they're being asked to do"
Sperrin & Lakeland Trust, Statutory HP

Potential Solutions

HPs were asked how these issues could be rectified so more carers would be informed of CA and choose to have it performed. One frequent solution involved the re-training of staff, to change their attitude toward CA and how they portray it to the carers. HPs noted that training must emphasise that despite a lack of resources, carers must be informed of the other positive aspects that CA can bring:

"..Making sure that the staff are making people aware of the fact that yes you may not get anything out of this at moment, but there are other benefits...also I need to have statistics to bring back to the managers to say look, here's the carer assessments that are being completed and this is the unmet need"
Sperrin & Lakeland Trust, Statutory HP

"There's certainly a wealth of training that needs to be done in my understanding from the...training that we've begun...what carers assessments are and about expectations...a change of mindset is required...staff must be retrained with a more positive attitude"
Newry & Mourne Trust, Statutory HP

A possible new format for Carers Needs Assessment was discussed, to make it more like a conversation or dialogue with a focus more on positives of caring. Apart from giving the carer an opportunity to discuss over their problems and support needs, Carers Assessment must be done to in order to record carers unmet needs. This is vital for advocacy work and campaigning for services. Furthermore if funding is allocated for such services, HP will know exactly what is needed.

New literature and information regarding CA must be passed onto the carers in new and insightful ways. One possible idea put to HP during the interview sessions involved the provision of leaflets and informing those who ran services for service users, such as day centres or residential respite, of the CA, who could then in turn pass the information on to carers. Other methods of informing carers involved promoting it through carers groups and the voluntary sector as they may have a higher level of contact with the carers than Trust staff. However this is not an overall solution as many carers do not have access to a carer support group (already noted in Table 5).

Information on the assessment should also be passed out when assessments take place for the person with a learning disability.

" I think that every facility, every office should have information and leaflets available to be handed out. I think every social worker, community nurse, Trust employee, when they're going out to do initial assessments for a new referral should be taken information out with them and leaving them with people"
Foyle Trust, Statutory HP

However, as carers are often inundated with information, they can become overwhelmed so information can easily be put aside or left unread. Therefore, carers must be informed about the CA on several occasions and offered at each point of review rather than have it as a 'one off' event.

New procedures are also being in place that makes the CA procedure more formalised. Within the Newry and Mourne Trust area for example, HPs will have to demonstrate that a discussion of CA with the carer took place. HPs now have to complete formal reports on how many CA are being offered, performed and declined along with reasons why it was rejected. All information is to be returned to the Southern Board capturing activity levels.

Changing the procedures and title of Carers Assessment is another strategy under review in order to increase its uptake. This includes the involvement of carers in the training of staff to make staff more aware of carer's issues and what is of importance to them. These issues should then be included within the assessment and allows it to be more individualised and updated.

"... so we've involved the carers in training of the staff in Carers Assessment... it was seeing things from the Carer's perspective...it was very useful training exercise".
Newry & Mourne Trust, Statutory HP

Direct Payments

The Carers (Recognition and Services) Act (1995) (17) and The Carers and Disabled Children's Act (2000) (19) were designed to make direct payments available to carers to enable them to purchase their own services, rather than rely on provision from social services, providing more flexibility and choice. To access Direct Payments, carers must firstly undergo a Carers Assessment, and are only permitted to purchase services permitted by that CA. To assess the extent of knowledge regarding Direct Payments across the CAWT region, carers where provided with a short description of DP, what they were used for, were asked if they were familiar with the scheme and if so whether they made use of it.

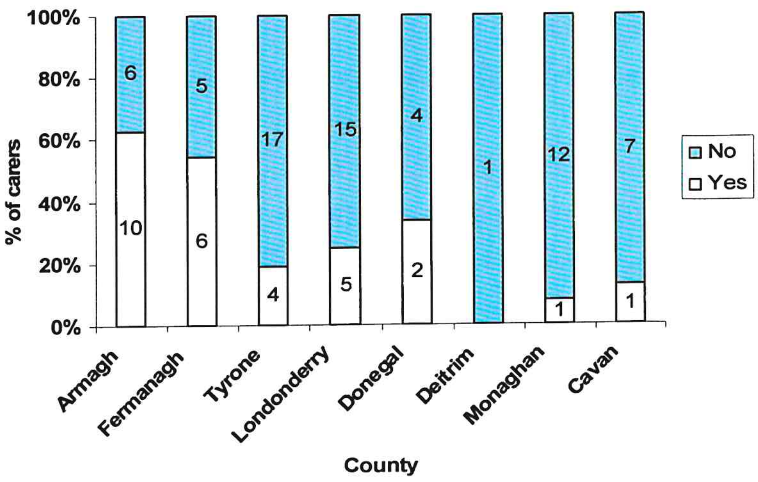
Carers Familiar with Direct Payments

Results show that 67% (n= 67) of carers were not familiar with Direct Payments, 4% (n= 4) were unsure and only 29% (n= 29) had heard of the scheme (total n= 100). Similar to findings on Carers Assessment, these results show a general lack of knowledge amongst carers on another service available to them.

Awareness by County

With regard to knowledge of Direct Payments within each County (n= 100, missing = 11), carers in Armagh appear to be the most aware of the benefit (63% n=10) followed by Fermanagh with 46% (n=6) with a lower level in all other areas (Figure 19).

Fig 19: Awareness of Direct Payments by County



Direct Payments were initialised by the government in an aim to offer the carer a wider and more flexible choice in the services they receive. The scheme offered a chance for carers to bring in somebody else (as long as they did not live in the same household as the dependant) as a form of respite cover, as and when it suited them. It also offered them the opportunity to purchase agency nurse cover, or private services (19). If 67% (n=67) of carers within the CAWT region are not aware of this benefit, they are not being given the opportunity to utilise this method of receiving respite and getting a break from caring, something which 86% (n=89) of carers stated as being important to them within their caring role.

Advantages and Disadvantages of Direct Payments

Of those carers who stated they were familiar with direct payments (n=29) only 8 (28%) made use of them. In order to investigate why 72% (n=21) were not using direct payments, carers were asked to select what they thought were the disadvantages and advantages of DP.

Carers who Used Direct Payments

Table 11: Advantages and Disadvantage of DP (n= 7, missing =1)

Advantages	**No of carers (n= 7)**	**Disadvantages**	**No of carers (n=7)**
Gives carer flexible support and independence	4	Having to organise and pay separate insurance	3
More flexible services available which also benefits caree	4	Only allowed to use services as allocated by Carers Assessment	3
Allows carer to buy the support they need	3	Finding someone in area to work as a carer	2
Gives carer control over own life	3	Too much paperwork	2
No benefits	2	Having to apply/go through a Carers Assessment	2
Other	1	No disadvantages	1

In keeping with other literature, access to more flexible support and flexible services were the two main advantages for carers who used direct payments within the CAWT region (Table 11). This appears to resolve many issues brought up by carers at interview level, who feel that respite is not flexible and often not suitable for their child. This would also allow carers to employ someone to 'sit' with their dependant which may help resolve the main barrier to carers attending Carer Support Groups.

However, the Direct Payments Act is not without its problems, and can be the cause of great difficulty to many carers. Becoming an employer was the main disadvantage noted by carers within this current study in using DP involving paperwork and insurance problems. However carers can get help with these matters. 2 carers found a problem in finding somebody to employ as a substitute carer. This was highlighted as problem in rural areas, where carers stated there would be nobody in their area to become an employed carer, despite their efforts.

"As I live in such an isolated area, there is nobody remotely close that I could ask to cover for me, even for payment"
Rural Carer, Fermanagh

Carers Who Do Not Use Direct Payments

From those carers who had information on DP (n=29), 21 carers decided **not** to use it. The top three disadvantages to using direct payments were perceived to be 'too much paperwork' (75% n=15), 'having to organise and pay separate insurance' (65% n=13) and 'finding someone in my area to work as a carer' (65% n=13).

HPs demonstrated a wide knowledge of the various advantages and disadvantages that utilising direct payments can involve. Frequently noted positive aspects included benefits for both the carer and the service user, such as 'greater choice for the carer', 'flexibility and independence', and 'freedom to choose service and hours to suit clients needs'. Negative aspects outlined many of the major concerns of carers, such as 'fear of becoming an employer' which can lead to 'too much responsibility', 'fear of paperwork'. Other main concerns regarded the carers chances of finding somebody to work as a carer, 'difficulty getting personnel', 'no carer available where they live'. Lack of information on DP was also noted as a potential disadvantage due to 'Staff not telling you about them' and 'poor publicity'.

Key Points

Carers Assessment

- **34% (North carers only) were aware of Carers Assessment**
- **46% of these carers had a dependant aged between 1-15**
- **62% who were aware of CA had an assessment**
- **31% of HP rated the CA as 'poor' and 6% 'very poor'**
- **Negative attitudes held by HP may explain the lack of awareness amongst carers**

Direct Payments

- **29% of carers had heard of the direct payments scheme**
- **Top disadvantages of using direct payments were 'too much paperwork' and 'having to find someone in my area to work as a carer'**

The fact that carers often lack information regarding various important issues, such as services available in their area or information on benefits has been well established, despite its critical importance to carers and their health (8, 11, 13, 18, 24). Rather than receiving the majority of information provision from health professionals, most family carers are constantly searching for information and discover much via 'word of mouth' (14).

Rather than re-establishing this recurrent finding, this section examines the importance of information to carers within the CAWT area, and how they currently gain access to it. HPs were also asked how they inform carers of services in their area, and if they take any steps to reach 'hidden' carers.

What Information do Carers Want?

Within this current study, 87% (n=89) of carers found it important to their caring role to have relevant information on various aspects of caring. Carers were most interested in accessing information on carer services available in their area (80%, n=81 see table 12). This figure not only demonstrates an interest in Carer Support Groups, but the need for existing services to be widely promoted by HPs in the area.

Table 12: Information Required – Carers Views

Information on…	**% of carers (n=101)**
Carer services available that would be of benefit	80% (n=81)
Where to get financial help	45% (n=43)
The condition of dependant and their treatment	34% (n=34)
Dependants health needs, medication and side effects	33% (n=33)
How to get in touch with other carers nearby	31% (n=31)
What is expected of the carer in their role	28% (n=28)

HPs were also asked to rank what information they felt that carers wanted and needed the most.

Table 13: Information Required – HPs Views

Information on…	**% of HP (n= 49)**
Carer services available that would be of benefit	27% (n= 13)
Where to get financial help	27% (n=13)
The condition of dependant and their treatment	24% (n= 12)
What is expected of the carer in their role	14% (n=7)
Dependants health needs, medication and side effects	8% (n=4)
How to get in touch with other carers nearby	0% (n=0)

HPs agreed with carers on the top 3 types of information that are most important. Getting information on *'Carer services available that would be of benefit'* and '*Where to get financial help'* were regarded as the most important information types, followed by information on '*The condition of dependant and their treatment'*. They did however differ on the importance of the last 3 information types, with 0% of HP regarding *'How to get in touch with other carers nearby'* as important whilst the carers ranked this of 5th importance (n=31).

How Carers Currently Receive Information

Service Knowledge

A main finding throughout literature suggests that carers are not aware of the services available within their area (7, 12, 18, 25, 26, 30, 55). Carers within the CAWT region repeatedly referenced 'word of month' as the main way they found out about information regarding services via school networking or other carers they knew,. Many carers claimed that they had not been informed about any services or support though statutory channels. Many carers feel that they are 'on their own' when it came to finding out about their entitlements, existing services and support groups within their area.

Lack of information on services:

"Anything that I have found out about carer support or whatever has been done of my own back... there's a lot of people out there that don't know what they're entitled too"
Female rural carer of 6 years, Fermanagh

Health Professionals and Service Information

One key finding from the mapping exercise within this current research demonstrated a low level of knowledge held by HPs (both statutory and voluntary) on Carer Support Groups in their local area. To assess how HP informed carers about services and support groups in each area, those who manage services were asked how they advertise their service. Other HPs, such as carer support workers, were asked how they make carers aware of what is available. Various methods of raising awareness of services available involved sending information packs to registered carers who were often identified by their GP.

Carer's information packs contain support group information, benefit and direct payment information, carers assessments, and service information (although not comprehensive). GPs were frequently referenced as a main form of passing out information, as were articles and advertisements in the local press, newsletters sent to all homes, community and church groups, and community pharmacists. These methods were also cited for reaching 'hidden' carers, those with no links to social services and isolated, rural carers.

"The only way to get to hidden carers is to go via the GPs...community pharmacists"
Sperrin & Lakeland area, Statutory HP

However not all areas had a directory that included both statutory and voluntary support groups, that was readily available and specific to carers:

"We have been struggling for years I suppose to come up with a booklet, outlining the services that the Trust have available and the types of staff that the carers can have access too...as well as what's out there in the wider field in terms of voluntary groups, community groups, the independant sector"
Foyle Trust, Statutory HP

Statutory and voluntary service managers (for service users services and carer support groups) were asked how they would usually inform carers about their service. Voluntary HPs that manage carer support groups rely strongly on word of mouth mainly from other carers who use the support group. Active advertising included advertisements in the radio, within newspapers, and parish bulletins. These groups tended to place adverts around the community setting, such as the local post office or supermarket, where carers may go at some time or another. Carers were also informed of statutory services for the service user through a referral from their HP or hospital, through the Trust or HSE.

One carer reported on the usefulness of a Carer Support Worker (Sperrin & Lakeland Trust area), who advertised and set up meetings that carers could attend for information. However if these meetings were missed for any reason, the carer felt they missed out, especially as the meetings were so sporadic, it would be a while before another may be organised. Carer support workers also reported going out to multi teams and social services to raise awareness and inform staff of services and carer support groups within the area.

Currently, there is a lack of knowledge regarding carer support groups amongst statutory and voluntary HP workers, who are often a carer's only information contact. The idea therefore that all HP's should have a healthy knowledge regarding all services in each area, including carer support groups, was strongly embraced:

"The vast majority of families ...would have some contact with the community learning disability staff member...if those staff are aware of the range of services and take a more broad based approach...then we should be in a position where families are aware of the range of services available".
Armagh and Dungannon Trust, Statutory HP

"I believe there's a need for development of carers services and also for maybe voluntary organisations to be aware of what support services there are because if a parent comes into us and discusses a need, it would be nice to know what actually is out there"
Foyle Trust area, Voluntary HP

Some HP stressed the importance of 'drop in' centres or 'carers' clinics, held in a community centre that allows carers to come by to speak with a HP and gather information. These were seen especially useful when a carer lives in an isolated, rural area or within an area were no support groups or services are readily available.

What are Carer Support Groups role in information provision?

78% (n=82) of carers claimed they would attend a carers group to find out information related to their caring role. For those already attending carers groups, retrieving information was regarded as a main benefit. Many felt they only were aware of services and benefits because of their carer groups:

"I get all my information from Cavan and Monaghan Carers Support group; I don't get any statutory support or advice"
Voluntary Community Worker, Rural Monaghan

Carers groups are therefore an extremely useful medium for carers to gather information on services and how to access help in their area. Although support groups open to all carers offer support and encouragement to carers, groups for carers of people with a certain disability can be extremely valuable for the precise information carers need, with others there who share the same difficulties or problems (26). Yet, Appendices 3 & 4 illustrates a severe lack of specific Carer Support Groups in reference to Learning disability across the CAWT region.

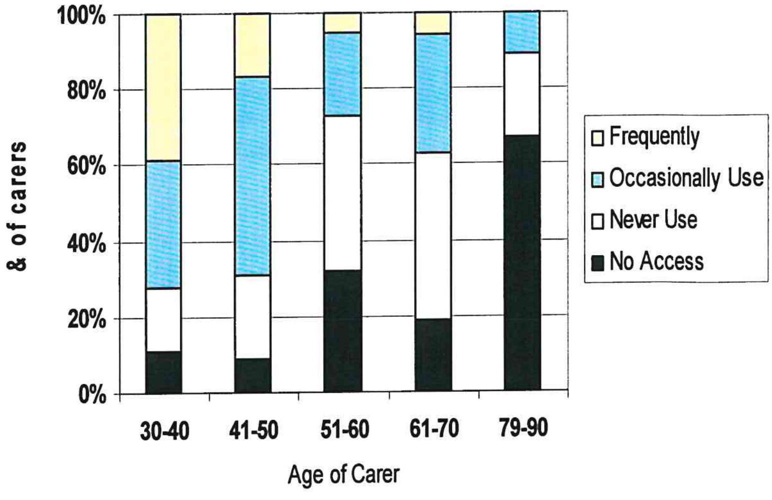
Is the Internet a successful communicative tool for carers?

Due to the increasing number of Carer based websites used to provide information to carers (*i.e. Carers Information Network, Carers UK/NI*) this study examined the usefulness of this medium to carers living within the CAWT region.

Our findings suggest that 24% of (n=26) carers have no access to the internet (i.e. computer in their home), and 32% (n= 34) never use the internet. Out of all carer respondents, only 13% (n= 14) frequently made use of the internet and 31% (n=33) occasionally made use of it. Therefore providing information on the internet will only be of benefit to a small amount of carers within the CAWT region as the majority (56% n= 60) do not access it.

As seen in Figure 20, as a carer's age increases, the use of the internet decreases. Therefore, older carers may need alternative forms of attaining information, such as carers' packs or interacting with a HP and / or their GP.

Fig 20: Internet Use and Carer Age



What suits carers best?

During the interview stage, carers were shown a range of information formats, such as *Help for Carers Living in The Craigavon and Banbridge Area*, (which comprises all carers information on issues such as carers assessment, where to go for help, carer and service user services in the area etc), leaflets that list services in the area and *Supporting Carers Pack Carers UK* (a compact booklet with individual information sheets on major topics, i.e. Direct Payments). Carers were questioned on the format they would prefer and why.

Some carers like to read as much information as possible, and so found a Handbook precisely what they wanted.

"This would be very useful, everything is together in one book and easy to reference. It would also be easy to find, whilst loose leaflets are easier to get lost".
Rural carer, Fermanagh

Other carers were not happy about receiving information through the post as they would usually put it to one side or throw it away; these carers felt that a one-to one visit from a HP would be best to update them on all services and benefits.

"Someone like you coming out ... you know, because it will trigger things off... I have enough to do without having to find out information and read lots of it"
Male carer, urban Londonderry

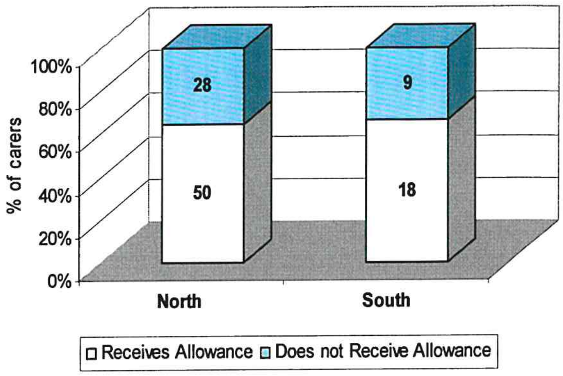
Key Points

- **87% of carers found it important to their caring role to have relevant information on various aspects of caring**
- **Carers most wanted information on services which were available to them in their area**
- **The majority of carers did not use internet (57%) and older carers were less likely to use the internet than younger carers.**

This section briefly examines the number of carers in receipt of Carers Allowance within the CAWT region. In both areas, around two thirds of carer received Carer Allowance. Carers Allowance was found to be a cause of stress and frustration for from those who care but cannot access it:

"I believe that Carers Allowance should be given to all carers irrespective of earnings. I care 100+ hours a week for my child yet cannot claim allowance or allocate against child care costs, am I being punished for working?"
Fermanagh Carer

Fig 21: Receipt of Carer Allowance North and South



There was also frustration from carers who do not believe they receive a sufficient amount in terms of the care they provide, that they save the government thousands each year but yet this is not reflected in the financial support they receive:

"As I save the government thousands of pounds surely a bit more money in our attendance allowance would not go a miss"
Tyrone Carer

"You get a pittance anyway...if we decided. if we had put (son) into care all these years I mean it would cost the government a hell of a lot more"
Londonderry Carer

Employment and sole carers
As well as increasing isolation and depression faced by unemployed carers (20, 25, 26), receiving no other financial income can create a heavier reliance on Carer Allowance and can cause financial strain.

We don't get carers allowance each we only get one and a half, we get 270 euros for two carers per week...things financially are very tight
Joint carers for 3 children, rural Donegal

43% (n=44) of carers within this study claimed they could not work due to their caring duties (n=102, missing n=5). With a specific focus on this sub group of carers 67% (28 out of 44) of those unemployed due to caring duties, were sole carers, and therefore did not have a partner in employment, creating full reliance on Carers Allowance and benefits.

Key Points

- **The majority of carer respondents are in receipt of CA**
- **CA is a major cause of stress and frustration for carers, often in regards to how little they receive**
- **Nearly half the carers (43%) cannot work due to their caring duties**

At the end of the research project, Praxis Care Group and CAWT hosted a workshop in order to disseminate key findings from the research and to engage carers, service managers and other health professionals working in the learning disability field in determining ways in which the key issues raised could be taken forward. Delegates at the workshop were split in to 4 groups and each group was asked to discuss one of the following topics:

- Carer Support Groups and Cross Border Developments
- Respite
- Carers Assessment and Direct Payments
- Information

The information from the group discussions was used as the basis for drawing up a series of recommendations.

Carer Support Groups and Cross-Border Development

- All Health Professionals within the statutory and voluntary sector who work in the CAWT region should have access to the list of Carer Support Groups detailed via the mapping exercise in this project. HPs should use this information to signpost carers to Carer Support Groups in their area.

- HPs should highlight the benefits to carers in attending a Carer Support Group, such as, having an opportunity to discuss problems with other carers and obtaining information on issues related to caring and to encourage carers to attend a group for support.

- The possibility of attaching a Carer Support Group to an already existing respite service for people with learning disabilities should be further explored.

- Existing Carer Support Groups should continually review how they advertise the service, the programme they provide and the time the meetings are held, to try to engage and support as many local carers as possible.

- The proposal for developing a drop-in centre for carers (a place for carers to call in and obtain relevant, up to date information and to meet with a health professional) warrants further exploration.

- As carers generally welcomed the opportunity to attend a cross border support group if one were available to them and that such a service may reduce travel time for carers and provide additional support, the development of such services should be actively pursued.

Respite

- The research highlighted a lack of respite service provision across the research area. For those areas were provision is very limited, further consultation is required to determine the best way to meet carers' need to get a break.

- Providing a variety of types of respite should be explored to enable a greater number of carers to benefit from respite services, for example, a sitting service where the carer and the dependant can be at home together.

- The provision of more flexible, multi-skilled staff for respite services should be provided in order to encourage carers who do not currently use respite due to concerns about the standard of care provided, to benefit from having time off from their caring duties.

- The role of multi-agency partnerships in designing and delivering respite services should be further encouraged and supported.

Carers Assessment and Direct Payments

- Information on Carers Assessment should be available in all services where a carer may contact i.e. respite centres, workskills, schools and hospitals.

- Research indicated that staff members working in respite services have little or no knowledge about Carers Assessment. Such staff should be made aware of CA and its benefits, in order to inform and signpost carers to professionals who can undertake a Carers Assessment.

- As Trusts are developing and implementing various strategies to improve and promote Carers Assessment, these should be shared through networking across the various Trusts.

- Research indicated 'too much paperwork' as a main drawback for accessing Direct Payments. All carers should be informed that assistance is available to help with this matter.

Information

- Research into current methods of disturbing information across the Trusts and HSEs should be undertaken in order to identify and further develop successful and innovative distribution methods. Any good practice established from this research should be shared amongst each area to establish the best way forward in getting information out to carers.

- All direct line Health Professions should be provided with relevant and up to date information to pass on and signpost carers.

- Information given to a carer in any given period of time should be relevant to their needs and their dependant. It should grow and change with the carers' circumstances over time, providing only the information they currently need and want, which may also prevent information overload at the beginning of the caring role.

- New literature and information must be passed onto the carers in new and insightful ways; therefore, various formats of delivering information must be investigated, such as home visits from a HP, carer information pack or the internet.

Although the internet provides a wealth of information on caring, the research indicated that the majority of carers do not use, or have no access to this method. Health Professionals should further encourage carers to access the internet by signposting them to IT training courses and computers for public use (e.g. public libraries, community centres).

APPENDIX ONE

Glossary of Terms

Glossary of Terms

Term	Abbreviation (if relevant)
Carers This current study adheres to the definition outlined by Valuing Carers: A Strategy for Carers in Northern Ireland (2002): *Carers are people who, without payment, provide help and support to a family member or a friend who may not be able to manage without this help because of frailty, illness or disability. Carers can be adults caring for other adults, parents caring for ill or disabled children or young people who care for another family member'* (p6).	
Carers Support Group Support group specifically for unpaid carers, can be general (i.e. Cavan and Monaghan Carers) or specific (i.e. PAPA Autism NI)	**CSG**
CAWT Region CAWT region defines the 20-mile corridor of the 450km length of the North/South Border.	
Cooperation and Working Together CAWT is a partnership agreement which facilitates collaborative working between health and social care organisations and staff on a cross border basis. CAWT, which comprises the four Health Boards and seven Trusts located along the border between Northern Ireland and the Republic of Ireland, was established in 1992 with the aim of improving the health and social well-being of the resident population.	**CAWT**
GHQ -12 Questionnaire The General Health Questionnaire (GHQ-12) (Goldberg: 1978) assesses mental health and is designed to detect psychiatric morbidity in the general population. The GHQ assesses a person's 'inability to carry out one's normal healthy functions' along with the 'appearance of new phenomena of a distressing nature' hence only examining 'the "hinterland" between psychiatric disturbance and normal functioning, rather than ranging over the whole spectrum from normality to severe disturbance' (Goldberg & Williams: 1988, p5).	**GHQ-12**
Health Professional/ Service Manager These include directors, assistant directors, area managers of disability and learning disability services, carer support workers, carer development officers, social workers, public health nurses, managers of support services for the service user and managers/chairpersons of carer support groups.	
Northern Ireland Refers to all areas of study North of the border.	**NI**
Praxis Care Group Praxis Care Group is a registered charity and a major provider of services for adults and children with a learning disability, mental ill health, acquired brain injury and the elderly. The Praxis Care Group research department is responsible for undertaking research and evaluations of projects that promote understanding of learning disability and related health and social care issues.	**PCG**
Republic of Ireland Refers to all areas of study South of the border.	**ROI**

APPENDIX TWO

Methodology

Methodology

The research was carried out over a 9-month period, from June 2006 to February 2007. Its aims were two fold, ascertaining the views of carers and health professionals regarding support services in their area, and the compilation of a list of specified services within the 10 mile corridor either side of the North/South border.

The regions for study within this research fell under the Trust and Health Service Areas listed below:

- The HSE – Dublin NE (parts of Monaghan/Cavan/Louth)
- The HSE – West and NW (Leitrim, and Donegal)
- Foyle Trust – (parts of Londonderry)
- Sperrin Lakeland Trust –(parts of Fermanagh and Tyrone)
- Armagh and Dungannon Trust (parts of Armagh)
- Newry and Mourne Trust

Ethical Considerations

North

Ethical approval was sought from the Office for Research Ethics Committees Northern Ireland (ORECNI) and approved by the Central Office for Research Ethics Committees (COREC) on the 8th August 2006. All Trusts in the catchments area of study (see above) were notified of the research and forwarded a copy of the favourable ethical opinion letter.

South

Enquiries into the ethical approval process within HSE West and HSE Dublin NE began in June 2006. Due to the recent HSE reform, it proved extremely difficult to gather any information regarding the necessity of, or application for, ethical approval in either area.

After a significant amount of investigation and difficulty in locating various correspondents, ethical approval was granted on 6th November 2006 and officially recognised by the HSE Research Ethics Committee on the 14th December 2006. The Regional General Manager of Disability Services in HSE West informed the project on the19th October 2006 that ethical approval for community projects did not yet exist in the HSE at present, therefore the study could commence in this area.

These considerable delays regarding ethical approval had a significant impact upon the time period for questionnaire distribution and data collection within the South of Ireland, resulting in a lower response rate than the North.

Questionnaire Construction

Given the wide geographical area to be covered in the research, and the fact that much of the area was rural, a profile of carers was ascertained via a postal questionnaire. This method aimed to offer the greatest number of carers an opportunity to participate in the research.

Both the carer and health professional questionnaires were compiled from a wide range of literature on topics concerning for example, carers' mental and physical health, carer support services, how carers cope, carers' assessment and direct payments. These issues were examined from an overall carer's perspective as well as a specific focus on carers for people with a learning disability. Carers Web CT discussion boards posted on carers Internet sites (www.carers.org/messageboard) were analysed to investigate recurrent and important issues for carers. Various questions in the carer and HP questionnaire mirrored each other to permit comparison between carers' and professional's attitudes toward various issues, such as barriers carers face in attending a support group, what they think of the Carers Assessment, and direct payments.

The carers questionnaire also included both qualitative and quantitative questions along with socio-demographic questions, such as, gender, age, marital status, postcode; age of person being caring for, relationship to person being caring for, housing situation, if in receipt of carer allowance etc.

Both sets of questionnaires were piloted by members and managers of various voluntary learning disability carer support groups and professionals within Praxis Care Group. Necessary amendments were made before the final questionnaire was distributed.

GHQ-12

The General Health Questionnaire (GHQ-12) (32) assesses mental health and is designed to detect psychiatric morbidity in the general population, it was included in the Carers questionnaire only. As it only addresses symptoms present for two weeks or less, it 'focuses on breaks in normal functioning, rather than lifelong traits'. The GHQ assesses a person's 'inability to carry out one's normal healthy functions' along with the 'appearance of new phenomena of a distressing nature' hence only examining 'the "hinterland" between psychiatric disturbance and normal functioning, rather than ranging over the whole spectrum from normality to severe disturbance' (32) . Although there are several alternative methods for scoring the GHQ, this current study utilised the GHQ bi-modal scoring method below (32):

GHQ scoring: 0 0 1 1

Benefits of which include counting how many symptoms are present, it dissolves the problem of 'middle users' and is simple yet effective and is sufficient for this current study and its aims. Carers who score 2 or more on the GHQ-12 are considered to show evidence of poor mental health. This study does not however offer a scale of mental health illness, all carers who have a score of <2 or 2> shall be classified as a 'non case' or 'case' accordingly.

Questionnaire Distribution

An outcome from the mapping exercise was a thorough list of all community, voluntary and statutory learning disability services, carer support groups, and HPs working within the area of learning disability, within the defined geographical area. Ethical circumstances did not allow these managers and HPs to pass on contact details for individual carers, therefore managers from each of these services, carers groups and HPs were contacted and asked to personally administer questionnaire packs to carers who come into contact with their service.

However, this excludes those carers where the person being cared for, or carer, is not availing of current support services. According to Taylor et al (1995) these ' design shortcomings' arise from the recruitment of carers taking place from those carers already in contact with or making use of a carer service. Research has claimed that the carers 'with the greatest need' are often those within isolation, which do not have or do not make use of any services (8, 14), therefore respondents should come from both carers who use, and do not use, support services. One aim of the current study concerns the identification of these 'hidden' and 'hard to find carers', carers who do not make use of a carer service, those who may not even class themselves a carer, but rather 'doing their job' as a parent, spouse or partner (11, 12, 37, 56). Carers were recruited using three methods:

1/ Snowball sampling techniques
2/ Attending carers' days and events
3/ Advertising in newsletters and magazines

The use of the snowballing strategy provides a means of accessing vulnerable and more impenetrable social groupings. This is therefore an ideal sampling technique for accessing carers, who are often a 'hidden' group within the population. Carers who avail of current services where asked to identify another carer who may or may not use a service, who were then asked to identify another carer, and so on. Using this method it was anticipated those carers who avail of no service support, could be reached. Numerous Carers Days and events were also attended in order to personally distribute questionnaires, adverts were placed in various newsletters and articles, such as *Health Bytes, Manorhamilion News, Care Alliance Ireland Newsletter, Wraparound Parents Newsletter,* requesting carers to get in contact if they wished to participate. Combining these methods aimed to maximize the number of carers had the opportunity to participate in the research; however this current study is not representative of all carers.

Statutory professionals from the Health Boards/Trusts, managers from statutory and voluntary services and voluntary carer support services were also asked to distribute and complete a short HP questionnaire. Each carer and HP received a questionnaire pack containing:

- An information leaflet explaining the research
- Contact details of the researchers
- A structured Questionnaire and (carers only) standardised GHQ-12 questionnaire
- A pre-paid response enveloped marked 'Confidential'

Both sets of respondents where asked to complete the questionnaire and return it via the prepaid, preaddressed envelope to the Research Department.

Each questionnaire was coded prior to being administered to those receiving packs of 3 questionnaires or more. Those who requested two or less where not coded as this may have aided identification of the respondent. This allowed follow up phone calls to those distributing the questionnaires if their response rate was very low. Floyd (1988) claims 'follow ups' can improve response rate and can increase it up to 20 %. Within this present study, second and third follow ups saw the questionnaire response rate increase in most areas.

In total, 1275 carer questionnaires and 500 health professional questionnaires, where distributed across the CAWT region to a mixture of statutory services for services users, HPs, such as Carer Support workers and Area Managers of learning disability services, and voluntary carer support groups, both general and specific to Learning disability. Altogether, 111 (valid) carer questionnaires and 58 (valid) HPs questionnaires were returned and analysed. 25 questionnaires were excluded for various reasons, for example the carer lived outside the CAWT area (8), the respondent did not care for someone with a learning disability (i.e. an elderly parent) (9), or if the respondent was a paid carer (4). The response rate for HP response in this current study falls within the 10%-20% response range at **12%,** however that of carers is just below at **9%.** These low response rates of 10 to 20 percent are however common in postal questionnaire research (29).

Limitations of the questionnaire data collection method

There are potential explanations that may elucidate why carers response rate was below the 10% mark:

- Carers are a small minority within Northern Ireland, many of which still remain unknown to social services (26). This current study limited the amount of potential respondents further, with a focus on carers for people with a learning disability **only** (the smallest sub group of carers) **over 18** years of age, within a **specific, geographical radius** (10mile corridor either side of the 450km length North/South Border. These criteria automatically limit the amount of potential participants
- Questionnaires were rarely passed straight to the carers themselves (except at carer events), rather they were distributed by HPs and managers, creating a second level of administration
- Some HPs and carers were sceptical of the research, often requesting information on its practical outcomes, due to the saturation of research related to caring, especially within the ROI
- Carers are often extremely busy with their caring duties and simply do not have time
- The problems encountered regarding ethical approval in the South delayed the questionnaire distribution process within the ROI, leaving only approximately two-three months for data collection instead of the six month time span in the North.

Although this current research took all precautions to ensure an even distribution across the CAWT region, this current study is not representative of all carers (i.e. age, gender and location) across the CAWT region, as data is taken from a volunteer sample. In addition no ethnic minorities took part in this research, potentially due to the area under study, which provides scope for further study. It also cannot offer a direct comparison between carers and non carers in issues such as mental and physical health, as non carers in the same region were not examined. Results on such issues from this current study are examined in relation to the findings within other research to assess if carers in the CAWT region differ in anyway.

Interviews

Face-to-face interviews where also employed to explore some of the issues arising from the postal questionnaire findings in greater detail. Semi structured interviews were carried out with both carers for people with learning disabilities, and health professionals who worked for or ran services provided for this sub group of service users, across the defined geographical area.

Information obtained from the questionnaire, combined with information from the literature review, were utilised as a basis for drawing up the topic guide to be used in the carer and HP interviews.

Interviews were conducted with 10 carers and 16 HP across the CAWT region. They were carried out either at the carer's own home, or the HPs place of work. Locating carers that wanted to take part in the interview section of the present study proved extremely difficult. Numerous recruitment methods were utilised, such as snowball sampling, and requesting HPs to recruit carers personally. The questionnaire also explained this interview stage and requested that the carer would make contact if willing to take part.
Each carer and HP was asked to sign a written consent form and confidentiality was always assured. Each interview was taped, with the carer's or HPs permission, transcribed and stored onto an excel database. Main and recurring themes were identified, analysed and coded via framework analysis, a matrix-based approach to qualitative data analysis (NatCen). The transcripts also provided useful quotes to add depth and understanding to the final report.

Limitations of interviews

The sample of carers and HPs who agreed to participate in a face-to-face interview consist only who agreed to participate as opposed to a representative sample across the CAWT region. However 'quotas' of gender, Trust/HSE are of work and 'voluntary/statutory', where adhered too in an attempt to obtain interviews from a broad range of carers/HPs from each side of the border boundary.

Despite the use of numerous recruitment methods, it proved very difficult to recruit carers for interview, especially South of the border. As with questionnaire completion, carers are very busy due to their caring duties, furthermore a saturation of research within the South may make carers reluctant to take part. Due to ethical complications within the HSE areas, questionnaires could not be sent to the South as early as anticipated, and therefore carers in this area had less time to come forward for an interview. A lower number of services in this area (appendix 4) which caused limitations within the questionnaire distribution stage also have decreased the number of carers aware of the study within the South.

Mapping Exercise

A geographical mapping exercise was conducted across a 20-mile corridor of the 450km length of the North/South Border. Once a geographical boundary had been clearly delineated, the next stage of the mapping exercise was three fold, to identify:

- Existing statutory, voluntary and community based support services for carers (non-specific groups)
- Existing statutory, voluntary and community based support services for carers who care for people with a Learning disability only
- A list of services for individuals with learning disabilities located within the defined area including day care services, work-skills, training and employment services, respite services and accommodation services.

As one single database detailing the names of learning disability services across this region did not exist ([24]), a Snowball Research Strategy was employed to generate this information.

Using the snowball technique, information for statutory services were gathered from the relevant Trusts and Health Executives who were asked to identify any learning disability services they are aware of within their local area which fell within the research boundary. Information was also extracted from the few existing directory handbooks (*Armagh & Dungannon Trust Directory, Finding a Way Through: A handbook for Parents of Disabled Children in the Foyle Trust and Sperrin Lakeland Areas*) and websites such as *The Confederation of Voluntary Groups* (www.acvg.org), *The Wheel* (www.wheel.ie), *Comhairle* (www.comhairle.ie), *N.I.C.V.A.* (www.nicva.org), *A-Z Care Home Guide* (www.carehome.co.uk) and *Carers UK Directory* (www.carersinfo.net) proved an invaluable source for retrieving information on voluntary and community services.

Compiled lists and relevant maps were disseminated to over 30 health professionals and voluntary service providers across the CAWT region who worked with people with learning disabilities or their carers, and where contacted to ask if any services had been missed or had changed address. The majority of contacts where not aware of all the services in their area and could offer no further information, however five responded with extra contacts to be added to the list.

Information from each of these sources were combined, quality checked (for duplicates and for services no longer in existence) to provide the most up to date contact information, and saved onto an Excel database. The complied list was then sorted into categories and forwarded to Northern Ireland Council for Voluntary Action (N.I.C.V.A) to be mapped. Due to lack of postcodes in the South region, only services within the North could be mapped (appendix 3), however a list of services within the South region has been provided in appendix 4.

Limitations of the Service Mapping

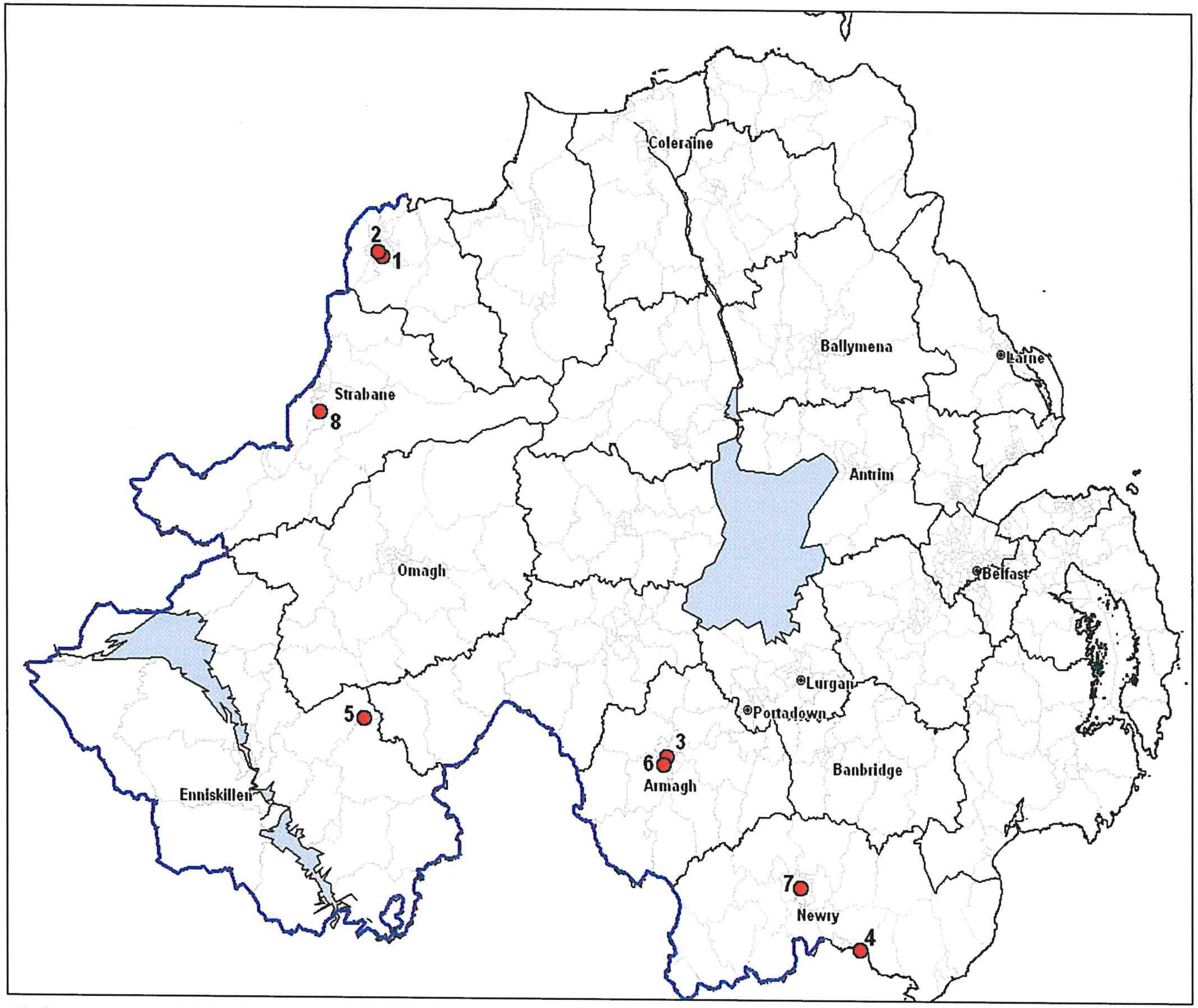
Although great effort was taken to ensure as many services as possible were included, this service list does not claim to be comprehensive.

Compiling the information proved extremely difficult in some areas. Various Trust areas gave a quick response, providing a detailed contact list of statutory, and a small amount of voluntary, services in their area. All voluntary groups for service user or carer support also gave a quick and informative response on services within either NI or the ROI areas. However due to a lack of existing databases and handbook directories, it proved very difficult to gather information from statutory sources regarding services in certain areas. Some were extremely slow in their response (taking up to 5 months to provide a list of statutory services in their area); some neglected to provide any information at all. Furthermore, contact details received from these areas were extremely patchy, with lack of manager details and absent telephone numbers. Statutory bodies often had little or no knowledge regarding any voluntary services in their area, especially carer support groups (all carers support groups were found to be voluntary).

APPENDIX THREE

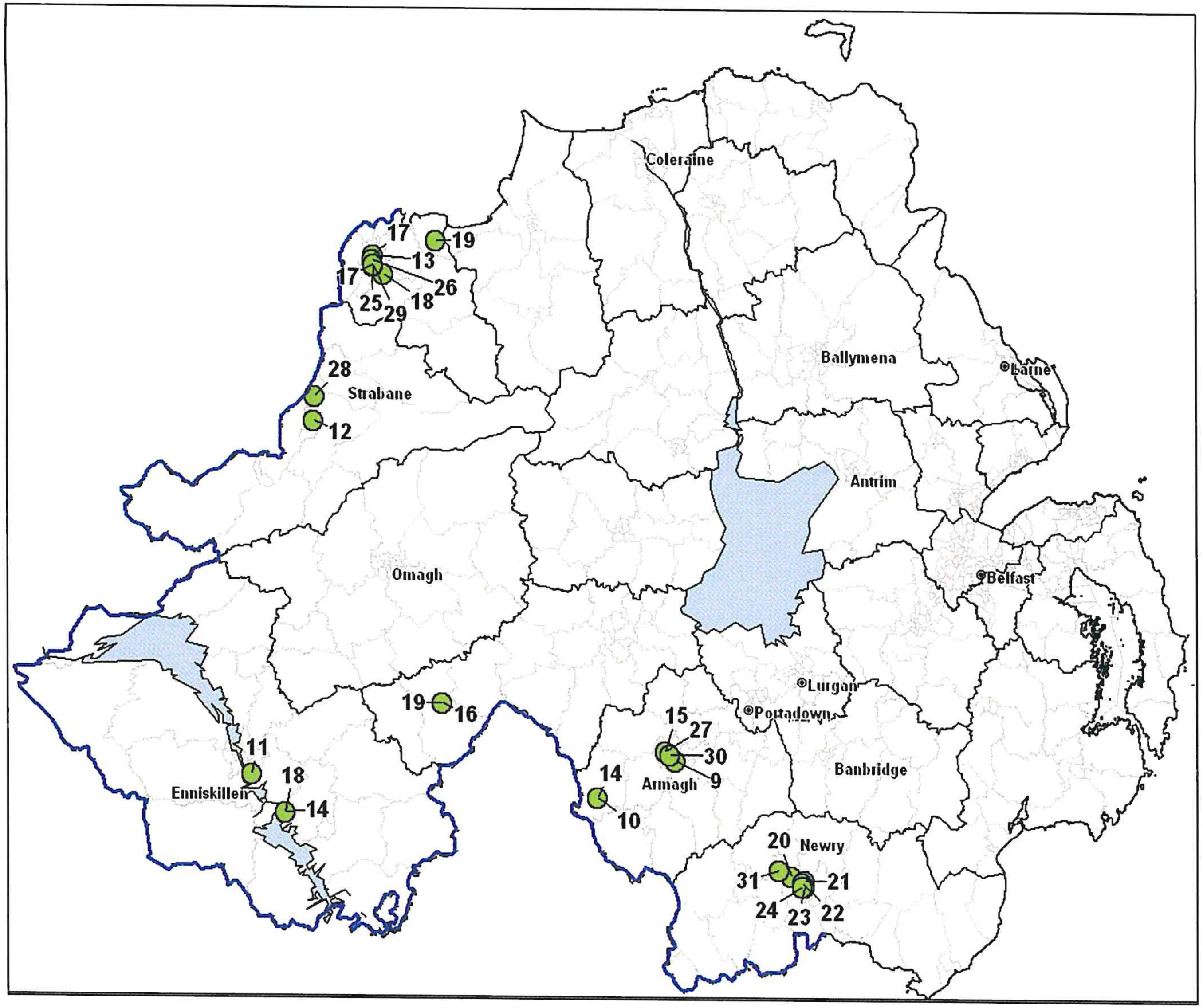
Services within the North

Carers Support Groups for Learning Disability



1	Foyle Downs Syndrome Trust
2	MENCAP (Western Area)
3	MENCAP (Southern Area)
4	PAPA NI (Newry & Mourne Branch)
5	PAPA NI (Fermanagh Branch)
6	PAPA NI (Armagh & Dungannon Branch
7	Positive Futures
8	Western Learning Disability Action Group

General Carers Support Groups



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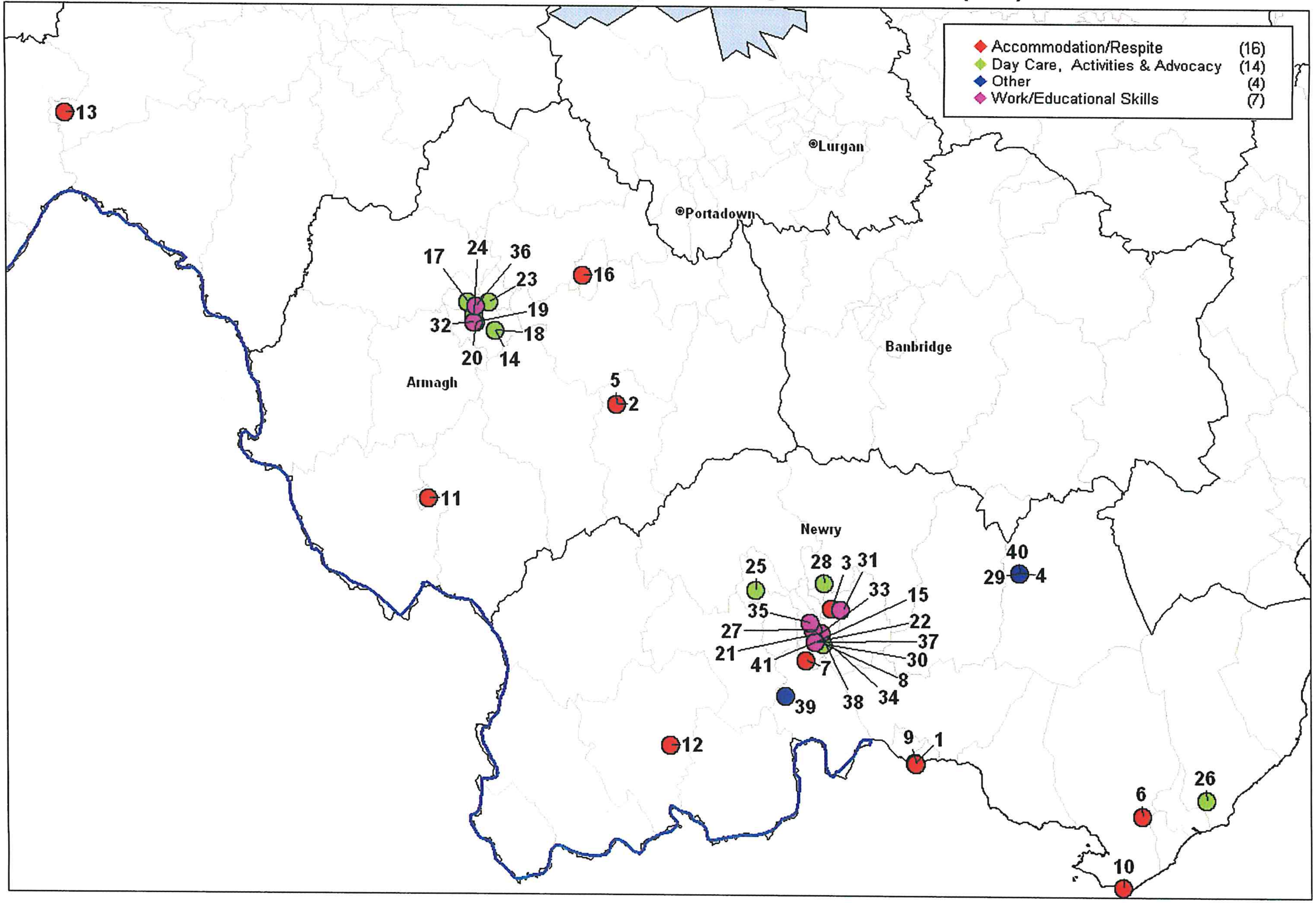
9	Appleby Carers Group
10	Armagh and District Carers Group
11	Care Plus
12	Chairperson Carers Support
13	Chairperson Friends of Stradreagh
14	Armagh and District Carers Group
14	Circles Network
15	Clougher Valley Carers Group
16	Clougher Carers Group
17	Chairperson Friends of Stradreagh
17	Contact a family: Family support worker
18	Circles Network
18	Foyle Parents and Friends
19	Clogher Valley Carers Group
19	Limavady Friends and Family
20	Millview Resource Centre
21	Newry and Mourne Carers Association
22	Newry and Mourne Carers Centre
23	Newry and Mourne Carers Forum
24	Newry and Mourne Carers Association
25	North West Community Network
26	Parents Advice Centre
27	Shared Care Scheme - Armagh
28	Strabane and District Caring Services
29	The Family Information Group
30	Wraparound parents forum
31	Valuing Carers

Services for clients with a Learning Disability – Armagh and Down (NI1)



Services for clients with a Learning Disability – Armagh and Down (NI1)

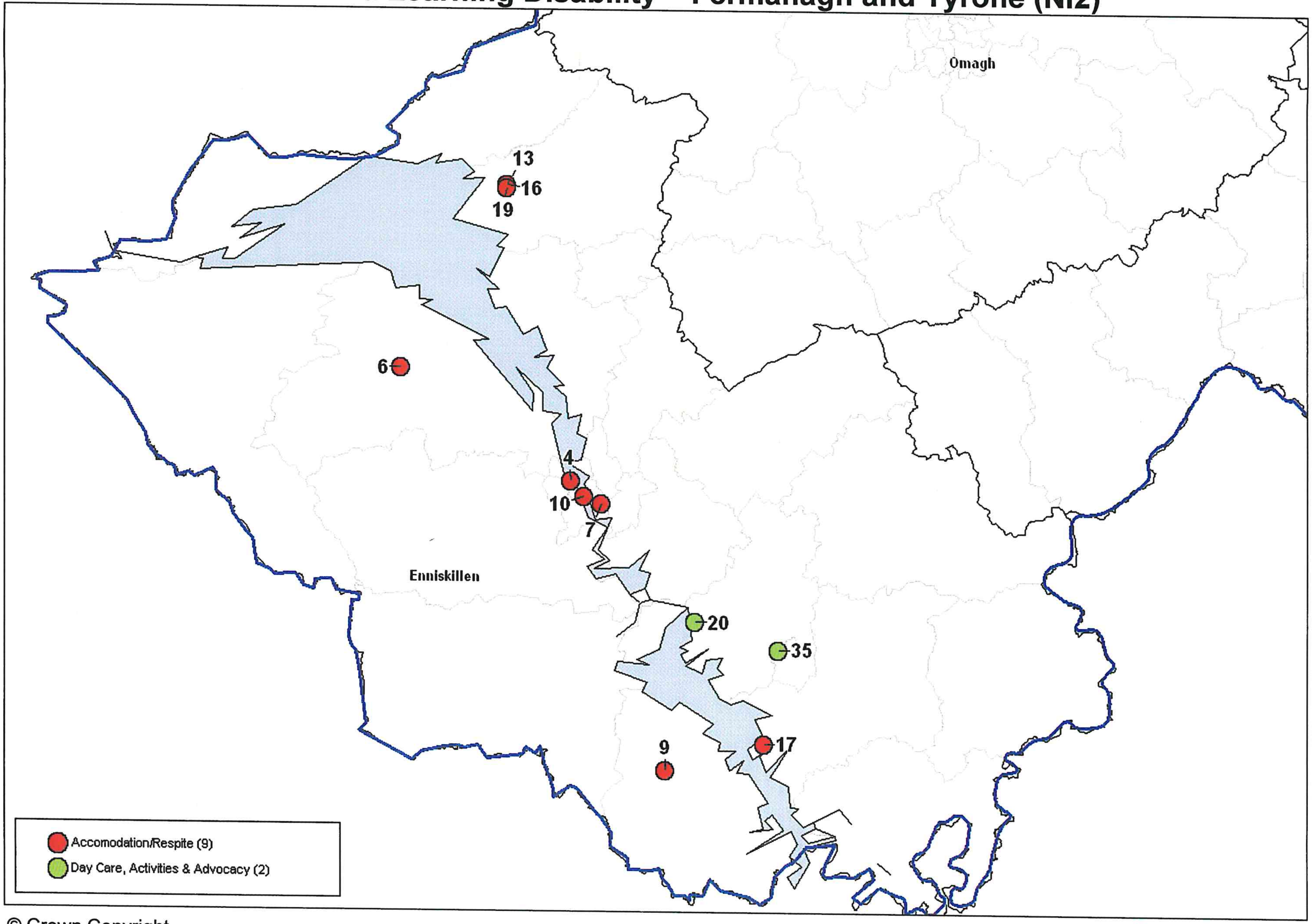
	Accommodation/Respite
1	Arbour House
2	Bawn Cottage
3	Cairn Grove
4	Cairnhill
5	Hebron House
6	Mourne Grange
7	Needham House
8	Orana Respite Care Centre
9	Seafort House
10	Shanlieve
11	Supporting Living Unit MENCAP
12	Teach Sona
13	The Firs
14	The Heathers
15	The Laurels
16	The Meadows

	Day Care, Activities & Advocacy
17	Appleby Careers
18	Appleby Social Education Centre
19	Armagh Senior Gateway Club
20	Armagh Junior Gateway Club
21	Coach House
22	Crossmaglen Day Centre
23	Longtone Riding for the Disabled
24	MENCAP
25	Millview Day Centre
26	Mourne Stimulus Day Care
27	Prospects
28	Riding for the Disabled Association
29	Social Education Centre
30	The Playclub

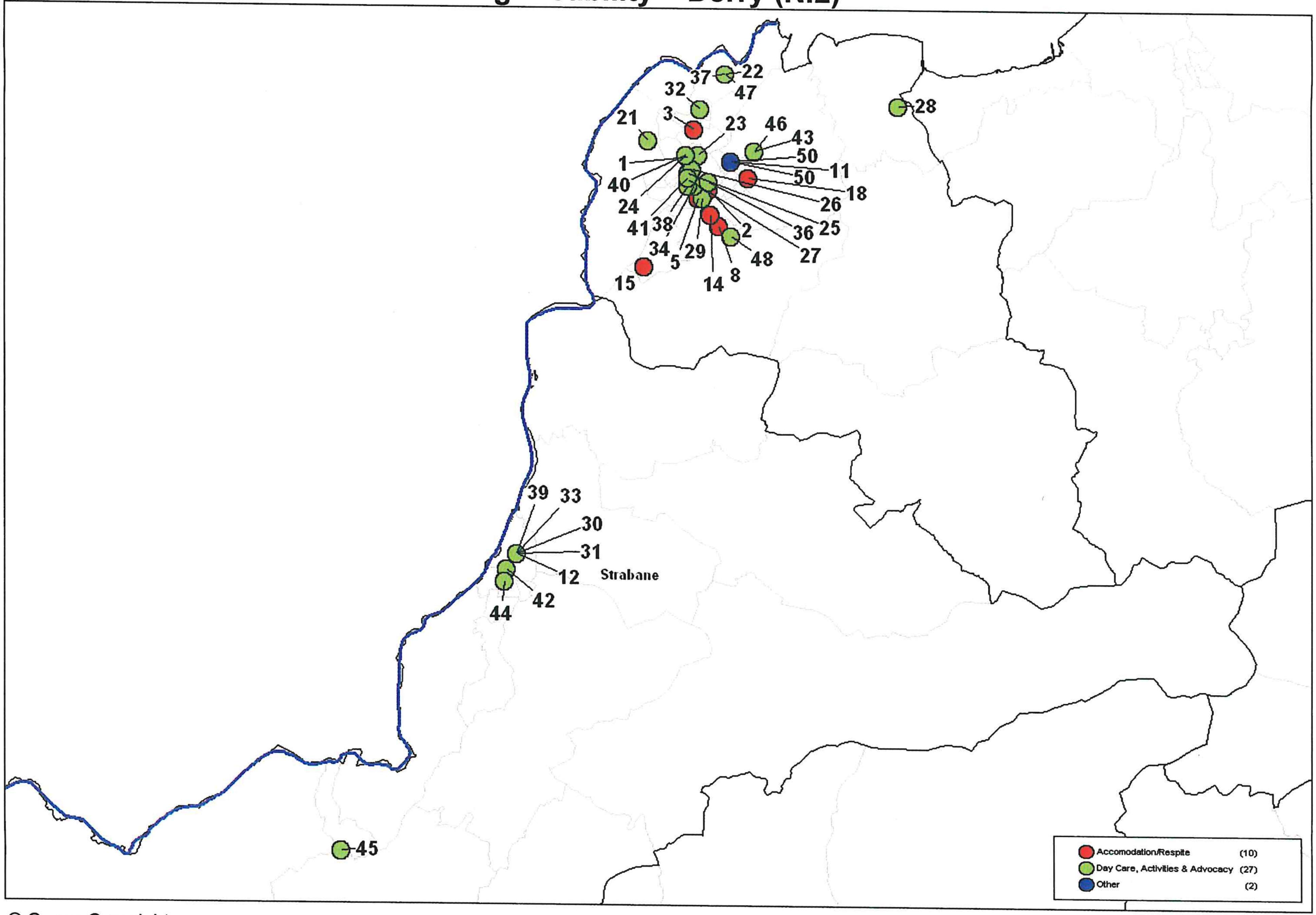
	Work/Educational Skills
31	AMH New Horizons, Newry and Mourne
32	Armagh Out and About Project
33	Coach House Restaurant
34	EGSA Connecting Adults with Learning
35	Institute of Further and Higher Education
36	Lisanally Special School
37	The Laurels

	Other
38	Newry and District Gateway Club
39	Newry Sports Centre
40	Social Education Centre
41	The Laurels Satellite Unit

Services for clients with a Learning Disability – Fermanagh and Tyrone (NI2)



Services for clients with a Learning Disability – Derry (NI2)



Services for clients with a Learning Disability – Fermanagh, Tyrone and Derry (NI2)

	Accommodation/Respite
1	Ardavon House
2	Beechway House
3	Belmont Cottage
4	Castle Lane
5	Craigdene
6	Dromary House
7	Drumclay Care Houses
8	Fairview House
9	Friendship and Caring Trust FACT Barnalee Residential Home
10	Galliagh House
11	Host Family Coordinator
12	Iona House
13	Mantlin Cottage
14	Meadow Bank Care Home
15	Old mill House
16	Praxis Challenge: Kesh Projects
17	Share Holiday Village
18	The Cottages
19	The Creamery House

	Day Care, Activities & Advocacy
20	Circles Network
21	Clients advocate at Community Living Training unit
22	Compass Advocacy Network Ltd
23	DAWN group/NWIFHE
24	Derry Cookie Company
25	Destined
26	Disability Action
27	Evergreen Centre
28	Faughanvale Community Project
29	Foyle Downs Syndrome Trust
30	Glenside Adult Training Centre
31	Glenside Youth Club
32	Greenhaw Day Centre
33	Glenside Self Advocates Group
34	Lilliput Theatre Company
35	Killadeas Day Centre

	Day Care, Activities & Advocacy
36	Maiden City Gateway Club
37	Maybrook Adult Training Centre
38	MENCAP
39	New Horizons Partnership
40	PARCH youth club
41	Rossabbey
42	Riding for the Disabled Association
43	Sow & Grow Horticultural Project
44	Strabane and District Caring Services
45	The Garden Corner
46	The Patients Forum for Lakeview
47	Users Forum (Maybrook)
48	Valley Centre

	Other
50	Evergreen Centre (Transition aid)
50	Assessment and Treatment Centres

Carer Support Groups across North (20 mile corridor region)

Carers Support Groups for Learning Disability

1/ Foyle Downs Syndrome Trust
Spencer House
Spencer Road,
Waterside,
Londonderry
BT47 6AA
Tel: 02871 345991

2/ Mencap
Western Area Office
17-19 Bishop Street,
Londonderry,
BT48 6PR
Tel: 02871 262227

3/ Mencap
Southern Area Office
20 Russell Street,
Armagh
BT1 9AA
Tel: 02837 528767

4/ PAPA NI
Newry and Mourne Branch
Tel: 02830 835670

5/ PAPA NI
Fermanagh Branch
Lackaboy Daycare Centre
Tel: 02889 522391

6/ PAPA NI
Armagh and Dungannon Branch
Tel: 02887 726191

7/ Positive futures
(Southern Office)
8 Savages Terrance
Corry Square
Newry
BT35 6AT
Tel: 02830 267343

8/ Western Learning Disability Action Group
3 Drum Road,
Victoria Bridge
Strabane
Tyrone
BT82 8NS

General Carer Support groups across North –non specific (20 mile corridor region)

9/ Appleby Carers Group
Social Education Centre
43 Ballinahonmore Road
Armagh
BT60 1JD
Tel: 02837 551137

10/ Armagh and District Carers Group
Armagh Confederation of Voluntary Groups
1 College Street
Armagh
BT60 9BT
Tel: 02837 522282

11/ Care Plus
Lackaghboy Industrial Estate
Enniskillen
Fermanagh
BT74 6TR
Tel: 02866 325688

12/ Chairperson Carers Support
3 Drum Road,
Strabane
Londonderry
BT82 8NS
Tel: 02871 382552

13/ Chairperson Friends of Stradreagh
33 Rock Road
Londonderry
BT48 7NE
Tel: 02881 662271

14/ Circles Network
Old School House
Fermanagh
BT94 5HY
Tel: 02866 385067

15/ Clougher Valley Carers Group
Social Services Department
Lisanally Resource Centre,
87 Lisanally Lane
Armagh
BT61 7HW
Tel: 02837 522262

16/ Clougher Carers Group
4 Tullybroom Road
Clougher Valley
Tyrone
BT76 0UW
Tel: 02885 548483

17/ Contact a family:
Family support workers
Londonderry
Tel: 0808 808 3555

18/ Foyle Parents and Friends
8 Gelvin Grange
Londonderry
BT47 2LD
Tel: 02871 347075

19/ Limavady Friends and Family
1 Main Street,
Eglinton
Londonderry
BT37 3AA
Tel: 02871 811684

20/ Millview Resource Centre
Millview Road
Bessbrook
Newry
Bt35 7LP
Tel: 02830 380347

21/ Newry and Mourne Carers Association
1B Erskine Street
Newry
BT35 6BZ
Tel: 02830 267015

22/ Newry and Mourne Carers Centre
6-8 Savages Terrace
Corry Square
Newry
BT35 6AT
Tel: 02830 267015

23/ Newry and Mourne Carers Forum
Newry and Mourne Trust
Community Development Unit,
John Mitchell Place
Newry
BT34 2BU
Tel: 02830 260505

24/ Newry/Mourne Carers Association
Ballybot House
22 Cornmarket
Newry
BT35 8BG
Tel: 02830 267015

25/ North West Community Network
6-8 Pump Street
Londonderry
BT48 6JG
Tel: 02871 279090

26/ Parents Advice Centre
65 Clarendan Street
Londonderry
BT48 7ER
Tel: 02871 372006

27/ Shared Care Scheme – Armagh
Lisanally House
87 Lisanally Lane
Armagh
BT61 7HW
Tel: 02837 522262

28/ Strabane and District Caring Services
32-36 Bridge Street
Strabane
Tyrone
BT82 9AE
Tel: 02871 884986

29/ The Family Information Group
10-12 Bishop Street
Londonderry
BT48 6PW
Tel: 02871 285675

30/ Wraparound Parents Forum
Southern heath and social services board
Torrahill
Armagh
BT61 9DR
Tel: 02887 741466

31/ Valuing Carers
Millview Day Care
Model Village
Bessbrook
Tel: 02830 830347

Services for clients with a Learning Disability across County Armagh and Down

Accommodation / Respite

1/ Arbour House (voluntary)
16 Great Georges Street
Warrenpoint
Newry
BT34 3HR

2/ Bawn Cottage (private)
31a Main Street
Hamiltonsbawn
Armagh
BT60 1PL
Tel: 02838 870666

3/ Cairn Grove (private)
Balmoral Ave
Newry
Armagh
BT34 1JS
Tel: 02830 266442

4/ Cairnhill (private)
39 Rathfriland Road
Newry
Armagh
BT34 5YN
Tel: 02830 268112

5/ Hebron House (private)
84-86 Main Street
Markethill
Armagh
BT60 1PL
Tel: 02837 551357

6/ Mourne Grange (private/voluntary)
Camphill Community
Kilkeel
Newry
BT34 4EX
Tel: 02841 760128

7/ Needham House (statutory)
Kiln Street
Newry
BT35 8QE
Tel: 02830 834200

8/ Orana Respite Care Centre (voluntary)
Orana House
Warrenpoint
Newry
BT34 2PF
Tel: 02837 414564

9/ Seafort House (private)
6 Queen Street
Warrenpoint
Armagh
BT34 3HZ
Tel: 02841 752200

10/ Shanlieve (statutory)
1-3 Randell Heights
Kilkeel
Newry
BT34 4LJ

11/ Supporting Living Unit Mencap
(voluntary)
112/113 Fairgreen park
Keady
Armagh
BT60 3UR

12/ Teach Sona (private)
5 Mullanstown
Mullaghbawn
Newry
BT35 9EX

13/ The Firs (private)
16 Fairgreen
Church Street
Ballygawley
Tyrone
BT70 2LJ

14/ The Heathers (voluntary)
39 Ballnahonemore Road
Armagh
BT60 1JD
Tel: 02837 510058

15/ The Laurels (statutory)
Dromalane Complex
Rathfriland Road
Newry
BT35 8AP
Tel: 02830 261570

16/ The Meadows (private)
Newline
Richill
Armagh
BT61 9QR
Tel: 02838 870005

Day Care, Activities & Advocacy

17/ Appleby Careers (voluntary)
Armagh Business Centre
Loughgall Road
Armagh
BT61 7NH
Tel: 02837 518211

18/ Appleby Social Education Centre
(statutory)
43 Ballynahonemore Road
Ardmore
Armagh
BT60 1JD
Tel: 02837 524335

19/ Armagh Senior Gateway Club
(voluntary)
Dobbin Street Community Centre
Dobbin Street
Armagh

20/ Armagh Junior Gateway Club
(voluntary)
Dobbin Street Community Centre
Dobbin Street
Armagh

21/ Coach House Restaurant, Abbey House
(voluntary)
Abbey Yard
Newry
Down
BT34 2EG
Tel: 02830 268114

22/ Crossmaglen Day Centre
Rathkeeland House
Crossmaglen
Tel: 02830 868185

23/ Longtone Riding for the Disabled
(statutory)
The Stables
Longstone Hospital,
Millinure Lane
Armagh
BT61 7RT
Tel: 02837 528922

24/ Mencap
Southern Area Office
20 Russell Street,
Armagh
BT1 9AA
Tel: 02837 528767

25/ Millview Day Care
Model Village
Bessbrook
Tel: 02830 830347

26/ Mourne Stimulus Day Care
1 Council Road
Kilkeel
Newry
BT34 4NP
Tel: 02841 765897

27/ Prospects (voluntary)
Ballybot House
Cornmarket
Newry
BT35 8BG
Tel: 02830 252501

28/ Riding for the Disabled Association
Newry
Armagh
BT34 1QJ

29/ Social Education Centre (statutory)
Rathfriland Road
Newry
Armagh
BT34 8HU
Tel: 02830 261951

30/ The Playclub
(voluntary)
Orana House
Warrenpoint
Newry
BT34 2PF

Work/Educational Skills

31/ AMH New Horizons,
Newry and Mourne
22A Greenbank Industrial Estate
Rampart Road
Newry
BT34 2BQ

32/ Armagh Out and About Project
(voluntary)
Unit 12
Dobbin Centre
Dobbin Lane
Armagh
BT61 7QL
Tel: 02837 511833

33/ Coach House Restaurant
Abbey Yard
Newry
BT34 2EG

34/ EGSA Connecting Adults with Learning
28 Cornmarket,
Newry
Armagh
BT35 8BG

35/ Institute of Further and Higher Education
Newry Campus
Patrick Street
Newry
Armagh
BT35 8DN

36/ Lisanally Special School
Lisanally Lane
Armagh
BT61 7HF
Tel: 02837 528905

37/ The Laurels Coach House Restaurant
Abbey Yard
Newry
BT34 2EG

Other

38/ Newry and District Gateway Club
20 Kilmorey St
Newry
BT34 2DE

39/ Newry Sports Centre
61 Patrick Street
Newry
BT35 8TR

40/ Satellite Unit (statutory)
Social Education Centre
Crossmaglen
Newry
Tel: 02830 261951

41/ Satellite Unit (statutory)
The Laurels
Crossmaglen
Newry
Tel: 02830 868185

Services for clients with a Learning Disability across County Londonderry, Tyrone and Fermanagh

Accommodation/ Respite

1/ Ardavon House (voluntary)
34 Northland Road
Londonderry
BT48 7NA
Tel: 02871 264428

2/ Beechway House (voluntary)
Shepard's Way,
Dungiven Road,
Waterside
Londonderry
BT47 2AL
Tel: 02871 312627

3/ Belmont Cottage (voluntary)
Racecourse Road
Londonderry
BT48 7RD
Tel: 02871 372350

4/ Castle Lane (Voluntary)
Enniskillen
Co Fermanagh
BT74 5GH

5/ Craigdene
6 Columbia Terrance
Waterside
Londonderry
BT47 1JT
Tel: 02871 342147

6/ Dromary House (Private)
Derrygonnelly
Enniskillen
Fermanagh
BT93 6GA
Tel: 02866 641736

7/ Drumclay Care Houses (Private)
15 Drumclay Road
Enniskillen
Fermanagh
BT74 6HG
Tel: 02866 327255

8/ Fairview House (Private)
24 Trench Road,
Waterside
Londonderry
BT47 3UB
Tel: 02871 345501

9/ Friendship and Caring Trust FACT
(Voluntary)
Barnalee Residential Home
2 Derrylin Road
Lisnaskea Fermanagh
BT92 9LA
Tel: 02866 723233

10/ Galliagh House (Private)
The Brook
Enniskillen
Fermanagh
BT74 7EU
Tel: 02866 328043

11/ Host Family Coordinator (Statutory)
Lakeview
12a Gransha Road
Londonderry
BT47 6WJ

12/ Iona House (voluntary)
Derry Road
Strabane
Londonderry
BT82 8DY
Tel: 02871 383400

13/ Mantlin Cottage (Private)
Mantlin Road
Kesh
Fermanagh
BT93 1TF
Tel: 02686 631976

14/ Meadow Bank Care Home (Private)
11aTrench Road
Londonderry
BT47 2DT
Tel: 02871 347281

15/ Old mill House (Private)
72 Victoria Road
Londonderry
BT47 2RL
Tel: 02871 346199

16/ Praxis Challenge (Voluntary)
36 Main Street
Kesh Projects
Co Fermanagh
BT93 1TF
Tel: 02868 632170

17/ Share Holiday Village
Smithstrand,
Lisnaskea
Enniskillen
Fermanagh
BT92 0EQ
Tel: 02867 722122

18/ The Cottages (Statutory)
Shepard's Way,
Rossdowney Road
Londonderry
BT47 5GW
Tel: 02871 344484

19/ The Creamery House (Private)
38 Main Street,
Kesh
Enniskillen
Fermanagh
BT93 1TE
Tel: 02868 632176

Day Care, Activities & Advocacy

20/ Circles Network (Voluntary)
Old School House,
Fermanagh
BT94 5HY

21/ Clients advocate at Comm. Living Training unit (Statutory)
24 Inchview
Hazelbank
Londonderry
BT48 0QS
Tel: 02871 262921

22/ Compass Advocacy Network Ltd (voluntary)
Can-Can Recycling and The Daisy Chain
The Resource Centre,
Race Course Road
Londonderry
Tel: 07967 758517

23/ DAWN group/NWIFHE (Voluntary)
Patrick Street
Londonderry
BT48 7AL
Tel: 02871 276543

24/ Derry Cookie Company (Voluntary)
Richmond Hall
Eden Terrance
Londonderry
BT48 0DH
Tel: 02871 373400

25/ Destined (Voluntary)
45Great James St
Londonderry
BT48 7DF
Tel: 02871 362824

26 Disability Action (Voluntary)
52 Strand Road
Londonderry
BT48 7AJ
Tel: 02871 360811

27/ Evergreen Centre (Statutory)
Clooney Road
Pilots Row Satellite Units
Stradreagh
Rossville Street
Londonderry
BT48 6LP
Tel: 02871 269418

28/ Faughanvale Community Project (Voluntary)
Unit 8 Benbow Estate
15 Killylane Road
Eglinton
Londonderry
BT47 3DW
Tel: 02871 811615

29/ Foyle Downs Syndrome Trust
(Voluntary)
Spencer House
Spencer Road,
Waters
Londonderry
BT47 6AA
Tel: 02871 343991

30/ Glenside Adult Training Centre
(Statutory)
45a Derry Road
Strabane
Londonderry
BT82 8DY
Tel: 02871 382950

31/ Glenside Youth Club C/o (Voluntary)
Glenside Adult training centre
45a Derry Road
Strabane
Londonderry
BT82 8DY
Tel: 02871 382950

32/ Greenhaw Day Centre (Statutory)
42a Racecourse Road
Londonderry
BT48 8DA
Tel: 02871 358350

33/ Glenside Self Advocates Group
(Voluntary)
C/o Glenside Adult training centre
45a Derry Road Strabane
Londonderry
BT82 8DY
Tel: 02871 382950

34/ Lilliput Theatre Company (Statutory)
The Playhouse
5-7 Artillery St
Londonderry
BT48 6RG
Tel: 02871 368150

35/ Killadeas Day Centre (Voluntary)
Castle Park Centre,
Lisnaskea
Unit , 14-17, 47
Enniskillen Business Centre,
Lackaghboy, Tempo Road
Fermanagh
BT92 0PE
Tel: 02866 342833/02866 320031

36/ Maiden City Gateway Club C/o
Rossdowney House
Glendermott Road
Londonderry
Tel: 02871 314200

37/ Maybrook Adult Training Centre
(Statutory)
Racecourse Road
Londonderry
BT48 8NG
Tel: 02871 353754

38/ Mencap (Voluntary)
17-19 Bishop St
Londonderry
BT48 6PR
Tel: 02871 262227

39/ New Horizons Partnership
(Voluntary)
45c Derry Road
Strabane
Tyrone
BT82 8DY
Tel: 02871 382950

40/ PARCH youth club (Voluntary)
Richmond hall
3 Eden Terrance
Londonderry
BT48 0DH
02871 243213

41/ Rossabbey (Statutory)
98 William Street
Londonderry
BT48 9AD

42/ Riding for the Disabled Association
(Statutory)
Longstone Group
BT61 7RT
Tel: 0845 4507124

43/ Sow & Grow Horticultural Project
(Statutory)
Gransha Park
Clooney Road
Londonderry
BT47 6TF
Tel: 02871 860831

44/ Strabane and District Caring Services
32-36 Bridge Street
Strabane
Tyrone
BT82 9AE
Tel: 02871 884986/ 02871 383760

45/ The Garden Corner Castlederg
Enterprise Centre
Drumquin Road
Castlederg
Londonderry
Tel: 02882 898976

46/ The Patients Forum for Lakeview
(Statutory)
Lakeview Gransha Park
Clooney Road
Londonderry
BT47 6TF
Tel: 02871 865210

47/Users Forum (Maybrook) (Voluntary)
Maybrook Adult Training Centre
Racecourse Road
Londonderry
BT48 8NG
Tel: 02871 353754

48/ Valley Centre (Statutory)
Unit 11 Glendermott Business Park
Tullyalley
Londonderry
BT47 3QR
Tel: 02871 321117

Other

49/ Assessment and Treatment Centres
(Statutory)
Lakeview Hospital
12a Gransha Park
Clooney Road
Londonderry
BT47 6WJ
Tel: 02871 865210

50/ Evergreen Centre (Statutory)
Transition Coordinator
Gransha Park
Clooney Road
Londonderry
BT47 6WJ
Tel: 02871 860261

Information points for County Londonderry, Tyrone and Fermanagh

1/Community Health Care Health Centre
Claudy Health Centre,
38a Irwin Crescent Claudy,
Londonderry,
BT47 4AB

2/ Community Health Care Health Centre
Dungiven Health Centre,
1 Chapel Road, Dungiven,
Londonderry,
BT47 4RS

3/ Community Health Care Health Centre
Great James Street Health Centre,
51-61 Gt James St,
Londonderry,
BT48 7DF

4/ Community Health Care Health Centre
Limavady Health Centre,
Scroggy Road,
Londonderry,
BT49 0NA

5/ Community Health Care Health Centre
Shantallow Health Centre,
Race Course Road,
Londonderry,
BT48 8NL

6/ Community Health Care Health Centre Strabane Health Centre,
Upper Main Street,
Londonderry,
BT82 8AR

7/ Community Health Care Health Centre Waterside Health Centre,
Glendermott Road,
Waterside,
Londonderry,
BT47 1BH

8/ Disabled Persons Badge Scheme,
Department for Regional Development,
Castle Barracks,
Wellington Place,
Enniskillen,
BT74 7HN
Tel: 02866 343700

9/ Fermanagh Citizens Advice Bureau
Belmore Mews,
2 New Street,
Enniskillen,
Tel: 02866 324334

10/ Foyle HSS Trust
(Learning Disability Team)
Riverview House,
Abercorn Road,
Londonderry
BT48 6SB
Tel: 02871 272950
Out of hours: 02871 345171

11/ Foyle HSS Trust
(Domiciliary Care)
Riverview House,
Abercorn Road,
Londonderry
BT48 6SB
Tel: 02871 355000

12/ Foyle HSS Trust
(Home from Home Learning Disability Short Breaks)
Riverview House,
Abercorn Road,
Londonderry
BT48 6SB
Tel: 02871 820261

13/ Foyle HSS Trust
(Sensory Support Services)
Riverview House,
Abercorn Road,
Londonderry
BT48 6SB
Tel: 02871 374619

14/ Foyle HSS Trust
(Speech and Language Therapy)
Riverview House,
Abercorn Road,
Londonderry
BT48 6SB
Tel: 02871864345

15/ Foyle HSS Trust
(Tranisition- Learning Disability)
Riverview House,
Abercorn Road,
Londonderry
BT48 6SB
Tel: 02871 860261

16/ Foyle HSS Trust: Family and Childcare Specialist Services
(Family Intervention East Bank)
Rossdowney House,
Glendermott Road,
Londonderry,
BT48 6BG
Tel: 02871 314200

17/ Foyle HSS Trust: Family and Childcare Specialist Services
(Looked After Services)
Riverview House,
Abercorn Road,
Londonderry,
BT48 6SB
Tel: 02871 266111

18/ Foyle HSS Trust: Family and Childcare Specialist Services
(Duty and Assessment Team)
Whitehill,
106 Irish Street,
Waterside
Londonderry
BT47 2ND

19/ Foyle HSS Trust: Family and Childcare Specialist Services
(Family Services Team)
White Hill,
106 Irish Street,
Waterside,
Londonderry
BT47 2ND
Tel: 02871 314080 (Family Services Team)
Tel: 02871 314099 (Family Worker Service)

20/ Foyle HSS Trust: Family and Childcare Specialist Services
(Family Intervention West Bank)
Shantallow Health Centre,
Race Course Road,
Londonderry
BT48 8NL
Tel: 02871 351350

21/ Foyle HSS Trust: Family and Childcare Specialist Services
(Family Support)
Riverview House,
Abercorn Road,
Londonderry
BT48 6SB
Tel: 02871 266111

22/ Foyle HSS Trust: Family and Childcare Specialist Services
(Fostering and Adoption)
(Family Support)
Riverview House,
Abercorn Road,
Londonderry
BT48 6SB
Tel: 02871 266111

23/ Foyle HSS Trust: Family and Childcare Specialist Services
(Leaving and After Care Team)
Units 14 & 16,
Glendermott Valley Business Park,
Tullyalley,
Londonderry
BT47 7NP
Tel: 02871 321115

24/ Foyle HSS Trust: Family and Childcare Specialist Services
(Residential Child Care)
Abercorn Road,
Riverview House,
Londonderry,
BT48 6SB
Tel: 02871 266111

25/ Foyle HSS Trust: Family and Childcare Specialist Services
(Social Work Manager Early Years Team)
Clooney Hall Centre,
Clooney Terrance,
Waterside
Londonderry
BT47 6AR
Tel: 02871 320950

26/ Foyle HSS Trust: Family and Childcare Specialist Services
(Social Work Manager , The Adoption Team) Rossdowney House,
Glendermott Road,
Waterside,
Londonderry
BT47 6BG
Tel: 02871 345893/02871 314226

27/ Foyle HSS Trust: Residential Childcare (Assessment Unit)
Rossneal,
86 Rossdowney Road,
Waterside,
Londonderry
BT47 1SU
Tel: 02871 314420

28/ Foyle HSS Trust: Residential Childcare (Social Work manager)
103 Chapel Road,
Waterside,
Londonderry
BT47 2BG
Tel: 02871 313381

29/ Foyle HSS Trust: Residential Childcare (Social Work manager)
23 Racecourse Road,
Londonderry
BT48 7RE
Tel: 02871 361224

30/ Foyle HSS Trust: Residential Childcare (Social Work manager)
84 Chapel Road,
Waterside,
Londonderry
BT48 2BG
Tel: 02871 320960

31/ Foyle HSS Trust: Residential Childcare (Social Work manager)
23D Scroggy Road,
Limavady,
Londonderry
BT49 0NA
Tel: 02877 761950

32/ Foyle HSS Trust: Residential Childcare (Social Work manager)
5 Upper Galliagh Road,
Londonderry
BT48 8LW
Tel: 02871 276680

33/ Foyle HSS Trust: Residential Childcare (Social Work manager)
The Cottage,
106 Irish Street,
Waterside
Londonderry
BT47 2ND
Tel: 02871 314480

34/ Northern Ireland Union of Supported Employment
58 Strand Road
Londonderry

35/ Strabane District Council
(Community Services)
Council Offices,
47 Derry Road,
Strabane,
Londonderry
BT82 8DY
Tel: 02871 382204

36/ Western Health and Social Services Board
(Learning Disability Service Manager)
15 Gransha Park,
Clooney Road,
Londonderry
BT47 6FN
Tel: 02871 860086

37/ Sperrin Lakeland HSS Trust
(Senior Social Worker, Community Services Manager)
Strathdene House,
Tyrone and Fermanagh Hospital
Tyrone
BT19 0NS
Tel: 02882 252629
Tel: 02860 344000
Tel out of hours: 02866 382000

38/ Sperrin Lakeland HSS Trust
Community Nursing (Learning Disability)
Strathdene House,
Tyrone and Fermanagh Hospital
Tyrone
BT19 0NS
Tel: 02866 342922

39/ Sperrin Lakeland HSS Trust
(Dental Services)
Strathdene House,
Tyrone and Fermanagh Hospital
Tyrone
BT19 0NS
Tel: 02866 324711

40/ Sperrin Lakeland HSS Trust
(Home Based Services)
Strathdene House,
Tyrone and Fermanagh Hospital
Tyrone
BT19 0NS
Tel: 0286632400

41/ Sperrin Lakeland HSS Trust
(Short Breaks/Time Out)
Strathdene House,
Tyrone and Fermanagh Hospital
Tyrone
BT19 0NS
Tel: 02860 344000

42/ Sperrin Lakeland HSS Trust
(Carers Support Worker)
Community Services Department,
2 Coleshill Road,
Enniskillen,
BT74 7HG
Tel: 02866 344163

Information Points for County Armagh and County Down

1/ Armagh and Dungannon HSS Trust
(Adult Learning Disability Team & Disability Services)
St Lukes Hospital,
Loughgall Road,
Armagh,
BT61 7NQ
Tel: 02837 526302

2/ Armagh and Dungannon HSS Trust
(Care management- Learning Disability)
Trust Headquarters, St Lukes Hospital,
Loughgall Road,
Armagh,
BT61 7NQ
Tel: 02837 522381

3/ Armagh and Dungannon HSS Trust
(Clinical Psychology-Learning Disability)
Trust Headquarters,
St Lukes Hospital,
Loughgall Road,
Armagh,
BT61 7NQ
Tel: 02837 522381 (ext 2375)

4/ Armagh and Dungannon HSS Trust
(Intensive Domiciliary Support Service)
87 Lisanally House,
Lisanally Lane,
Armagh,
BT61 7HW
Tel: 02837 520500 (ext 5589)

5/ Armagh and Dungannon HSS Trust
(Social Work –Children with Learning Disability, Children's Disability Team)
87 Lisanally House, Lisanally Lane,
Armagh,
BT61 7HW
Tel: 02837 522262 (ext 5500)
Tel: 02837 520547

6/ Armagh and Dungannon HSS Trust
Learning Disability Services
Longstone Hospital,
Loughgall Road,
Armagh,
BT61 7NQ
Tel: 02837 522381 (ext 2159)

7/ Armagh and Dungannon HSS Trust
(Physiotherapy Disability Services)
St Lukes Hospital,
Loughgall Road,
Armagh,
BT61 7NQ
Tel: 02837 522381 (ext 2721)

8/ Armagh and Dungannon HSS Trust
(Occupational Therapy Learning Disability)
St Lukes Hospital,
Loughgall Road,
Armagh,
BT61 7NQ
Tel: 02837 522381 (ext 2257)

9/ Armagh City and District Health
(Community services)
The Palace Demense,
Armagh,
BT60 4EL
Tel: 02837 529642

10/ Armagh City and District Health and Social Services
(Community Forum)
39 Foyar Road,
Killylea,
Armagh,
BT60 4NR
Tel: 02837 568218

11/ Armagh Confederation of Voluntary Groups
1 College Street,
Armagh,
BT61 9BT
Tel: 02837 522282

12/ Crossmaglen Community Centre
(Development Team Members)
Crossmaglen,
Newry,
BT35 9AA
Tel: 02830 861949

13/ Department for Employment and Learning Disablement Advisory Service (DAS)
40 Bridge Street,
Newry,
BT35 8AJ
Tel: 02830 254152

14/ Disability Services
10 Victoria Street,
Armagh,
BT61 9DT
Tel: 02837 525989

15/ Newry and Mourne and Social services Trust
(Health Care Team, Physiotherapy Department)
Daisy Hill Hospital,
5 Hospital Road,
Newry,
BT35 8DR
Tel: 02830 835000

16/ Newry and Mourne Community Transport Voucher Scheme (rural areas)
Ballybot House,
28 Cornmarket,
Newry,
BT35 8BG
Tel: 02830 261022

17/ Newry and Mourne District Citizens Advice Bureau
River House,
41C The Mall,
Newry,
BT34 1AN
Tel: 02830 262934

18/ Newry and Mourne District Council
(Area Community Development Officer)
Bessbrook Community Centre,
The Pond Field, Millroad,
Bessbrook,
Newry,
BT35 7BS
Tel: 02830 839666

19/ Newry and Mourne District Council
(Community Services Officer)
Greenback Industrial Estate,
Ramart Road,
Newry,
BT34 2QU
Tel: 02830 313233

20/Newry and Mourne HSS Trust
(Children with disabilities team)
Dromalane House,
Dromalane Road,
Newry,
BT34 2BU
Tel: 02830 825000

21/ Newry and Mourne HSS Trust
(Community Access Officer)
The Conifers,
Dromalane Road,
Newry
BT34 2BU
Tel: 02830 250800

22/ Newry and Mourne HSS Trust
(Community Services Team, Community Development Team)
Community Development Unit,
John Mitchell Place,
Newry,
BT34 2BU
Tel: 02830 834200
Tel: 02830 834281

23/ Newry and Mourne HSS Trust
(Programme manager Learning Disability)
Oakdale House,
Dromalane Road,
Newry,
BT34 2BU
Tel: 02830 825120

24/ Newry District Council Office
Monaghan Row,
Newry**,**
BT35 8DJ
Tel: 02830 313074

25/ Newry Welfare Rights Service
Ballybot House,
28 Cornmarket,
Newry,
BT35 8BG
Tel: 02830 267631

26/ Southern Health and Social Services Board
(Social care department & Community Service manager)
Towerhill,
Armagh,
BT61 9DR
Tel: 02837 410041
Tel: 02837 414612

APPENDIX FOUR

Services within the South

Carer Support Groups across South (20 mile corridor region)

Carers Support Groups for Learning Disability

1/ Down Syndrome
Assocation of Ireland
Donegal Branch
Donegal
Tel: 07491 53170

2/ Down Syndrome Association of Ireland
Leitrim/W Cavan Branch
Leitrim
Tel: 07291 55642

3/ Friends of Sean O Hare
Stranalor
Donegal
Tel: 074 91 31552

4/ P.A.P.A (Parents and Professionals and Autism)
Brid Duane
Rosseylongan, Donegal Town
Donegal
Tel: 07391 23401

5/ Special Needs Special Parents
Dundalk
Co Louth
Tel: 087 6696287

General Carer Support groups across South –non specific (20 mile corridor region)

6/ Cavan and Monaghan Carers
St Marys Hospital
Casteblaney
Co Monaghan
Tel: 087 6832742

7/ Cavan and Monaghan Carers
Killnaesk
Co Cavan
Tel: 087 6832742

8/ Derg Finn Partnership
Glenfinn Street
Ballybofey
Donegal
Tel: 07491 32438

9/ Donegal Carers Association
Ballyraine House
Letterkenny
Donegal
Tel: 07491 21586

10/ Donegal Carers Association
The Heather House
Muckross
Donegal
Tel: 07391 22259

11/ Donegal Carers Association
Tel: 07491 45336

12/ Finn Valley Carers
Dergfinn Centre
Donegal
Tel: 07491 32438

13/ i.C.A.R.E.
7 Ardavan Heights
Buncrana
Co Donegal
Tel: 086 1081200

Services for clients with a Learning Disability across Counties Cavan, Monaghan and Louth

Accommodation / Respite

1/ Annalee View (Statutory)
Cootehill
Cavan
Tel: 049 5552072

2/ Breifne Social Housing (Voluntary)
Breifne Social Housing Assoc, Ireland,
Virginia, Cavan
Tel: 049 8547806

3/ Camphill Community, Robb Farm, (Voluntary)
Corraskea,
Ballybay
Monaghan
Tel: 042 9741939

4/ Carde Activation Unit,
Canal Stores
Clones
Monaghan

5/ Cavan Supported Accommodation Service
Drumalee, Cootehill
Cavan
Tel: 049 433 1161

6/ Cluain Mhuire Group Home (Statutory)
Clonkeencole
Rosleas Road, Clones
Monaghan
Tel: 047 20985

7/ Dartrey Unit (Statutory)
Clougher House Residential Centre
Rooskey
Monaghan
Tel: 047 77411

8/ Domus Servces (Voluntary)
Darro Centre, Norta Road
Drogheda,
Louth
Tel: 041 9873045

9/ Donagh House (Statutory)
Tieraneil
Monaghan
Tel: 087 2624805

10/ Drumlin House (Voluntary)
Cootehill,
Cavan
Tel: 049 5552605

11/ Dundalk Sheltered Accommodation (Voluntary)
Dundalk,
Louth
Tel: 042 932 8766

12/ Farney Unit
Clougher House Residential Centre
Rooskey
Monaghan
Tel: 047 77407

13/ Hilltop Service- St John of God family centre (Voluntary)
Ardee Road,
Dundalk, Louth
Tel: 042 9334663

14/ Iona House
Regional Behaviour Support Service
Castleblaney
Monaghan

15/ Manderley Lodge
Cathedral View
Cavan
Tel: 086 3434302

16/ St Marys (Voluntary)
Drumcar,
Drunleer,
Louth
Tel: 041 6851211

17/ Millbrooke House (Statutory)
Milltown
Monaghan
Tel: 047 84080

18/ Mounthamilton House (Statutory)
Railway Terrance,
Carrick Road, Dundalk
Louth
Tel: 429381400

19/ Order of Malta Regional services (Voluntary)
Malta House
Fairstreet, Drogheda, Louth
Tel: 041 9877240

20/ Ros Na Ri (Statutory)
Cornacassa
Monaghan
Tel: 087 2624805

21/ Supported Accommodation (Voluntary)
Monaghan
Tel: 047 84365

22/ Tonniscoffey House
Tonniscoffey
Dunraymond
Monaghan

23/ 8 Coolshannagh (Statutory)
Monaghan
Tel: 087 6372906

Day Care, Activities & Advocacy

24/ Clones Mental handicap
Altertake
Clones
Monaghan
Tel: 00353 4751146

25/ Ardee Day Care Centre (Voluntary)
Churchill Ardee
Louth
Tel: 041 685 3048

26/ Camphill Community
Clones Road,
Ballybay
Monaghan
Tel: 042 9741939/9742598

27/ Cairde Activation Centre/Clones Day Centre (Voluntary/Community)
Canal Stores
Clones
Monaghan
Tel: 047 20948

28/ Clones Branch of Mentally Hanicapped (Voluntary)
Altertate
Monaghan
Tel: 075 11146

29/ Day Activation Unit
Rooskey
Monaghan
Tel: 047 84768

30/ Disadvantaged Network
Ozanam House, Dundalk
Louth

31/ Dundalk Drama Project
Rehabcare
Dundalk House, Carroll Village
Louth
Tel: 042 932 8766

32/ Dundalk Horticultural Unit
Mounthamilton House
Carrick Road
Louth
Tel: 042 935 7531

33/ Dundalk Resource Centre
Dundalk House. Carroll Village
Church Street, Dundalk
Louth
Tel: 042 932 8766

34/ Errigal Truagh Special Needs (Voluntary)
Errigal,Glenview,
Dundion, Emyvale
Monaghan
Tel: 047 87680

35/ Mounthamilton House
Railway Terrance,
Carrick Road, Dundalk
Louth
Tel: 429381400

36/ National Access for the Disabled Association
52 Main Street,
Carrickmacross,
Monaghan

Appendix Four

Services for clients with a Learning Disability across County Donegal and Leitrim

Accommodation / Respite

1/ Activiation Unit, Resource Centre Ballytivnan
Tel: 071 55100 or 071 55155

2/ Ard Greine Unit (Statutory)
Millndrait
Stranorlar
Co Donegal
Tel: 0749130702

3/ Ballinamore Supported Accommodation (voluntary)
Leitrim
Tel: 071 964 4132

4/ Ballydevitt (Statutory)
Donegal Town
Co Donegal
Tel: 074 97 22316

5/ Bundoran (Statutory)
Co Donegal
Tel: 072 41952

6/ Chapel Road (Statutory)
Dungloe
Co Donegal
Tel: 075 21777

7/ Cill Aoibhinn Group Home (Statutory)
Killymard
Donegal Town
Co Donegal
Tel: 074 97 23031

8/ Drumboe Respite House (Statutory)
Stranorlar
Co Donegal
Tel: 074 91 32274

9/ Glebe Hostel (Statatory)
Stranorlar
Co Donegal
Tel: 074 91 30721

10/ Inbhear na Mara (Statutory)
Bundoran
Co Donegal
Tel: 071 98 41952

11/ James Connolly Memorial Hospital (Statutory)
Carndonagh
Riverwalk House
Co Donegal
Tel: 077 74206

12/ Milltown House (Statutory)
Carndonagh
Co Donegal
Tel: 077 29044

13/ Piermont House (Statutory)
Church Lane
Dungloe
Co Donegal
Tel: 075 22155

14/ Rehabcare Lifford Supported Accommodation (voluntary)
Lifford
Co Donegal
Tel: 074 914 2568

15/ Saimer View (Statutory)
CGH
Ballyshannon
Co Donegal
Tel: 071 98 51696

16/ Sea View Respite House (Statutory)
Dromore
Mountcharles
Co Donegal
Tel: 074 97 35925

17/ Sean O Hare Unit (Statutory)
Stranorlar
Co Donegal
Tel: 074 31552/ 07491 89739

18/ St Martins (Statutory)
Falcarragh
Co Donegal
Tel: 075 65014

Day Care, Activities & Advocacy

19/ Adult Training Centre (Statutory)
Sean O Hare Unit
Co Donegal
Tel: 07491 31552

20/ College Farm Road (Statutory)
Co Donegal
Tel: 074 22389

21/ Cuanannie (Statutory)
Ballyraine
Co Donegal
Tel: 074 25624

22/Downs Syndrome Ireland (Voluntary)
Donegal
Tel: 074 9103527

23/ Downs Syndrome Ireland (Voluntary)
Leitrim/West Cavan
Leitrim
Tel: 071 9855642

24/Rehabcare Ballinamore Resource Centre (Voluntary)
New Golflinks Road,
Ballinamore
Leitrim

25/ St Agnes Day Centre (Statutory)
Donegal Town
Co Donegal
Tel: 07497 21769

26/ Workshop, Resource Centre
Ballytivnan
Tel: 071 55100

Work/Educational Skills

27/ Cashel Na Cor (Voluntary)
Buncrana,Meenagory
Co Donegal
Tel: 07493 21057

28/ Cleary Centre (Statutory)
Donegal Town
Co Donegal
Tel: 07497 22910

29/ Darty Delights (Statutory)
Kinlough
Leitrim
Co Leitrim
Tel: 074 9722910

30/ Inclusion Ireland support groups Coiste (Voluntary)
Cuchulinn
Ballyness
Falcarragh
Donegal
Tel: 074 9135308

31/ Inishowen Learning Disability Network (Voluntary)
Scoil Iosagain
Buncrana
Donegal
Tel: 074 9362450

32/ Rehabcare, Lifford Sheltered Workshop (Voluntary)
Finn Valley Enterprise Park
Lifford
Co Donegal
Tel: 074 9141430

33/ St Nicholas Pre School (Voluntary)
Buncrana
Co Donegal
Tel: 074 93 61486

34/Tullyvarvin Mill Workshop (Statutory)
Buncrana
Co Donegal
Tel: 077 61486

35/ National Training and Development Institute
Letterkenny Road
Lifford
Co Donegal
Tel: 074 41430

36/ Scoil Iosagain
Buncrana
Co Donegal
Tel: 074 9362450

APPENDIX FIVE

References

1.	Acton, G.J. (2002) "Health Promoting self care in family care givers." *Western Journal of Nursing Research* 24 (1): 73-86
2.	Arksey, H & Hirst, M. (2005) 'Unpaid carers' access to and use of primary care services.' *Primary Health Care Research and Development* 6 (2): 101-116
3.	Arskey, H., Jackson, K., Wallace, A., Baldwin, S., Newbronner, E., Hare, P. (2004) *Access to Health Care for carers: Barriers and Interventions* NCCSDO: York
4.	Barron, S & Mulvany, F. (2005) *National Intellectual Disability Database Committee: Annual Report* Health Research Board: Dublin
5.	Bertrand, R. M,.Fredman L. & Saczynski J. (2006) 'Are all caregivers created equal? Stress in Caregivers to Adults with and without dementia.' *Journal of Aging and Health*
6.	Black, L. & Roberts, B. (2006) *Review of Coping strategies for parents and family members of children/adults with learning disabilities* Positive Futures
7.	Bogues, S. (2004) *Focus of Families: Messages from Family Carers* DHSSPS: Belfast
8.	Carers Northern Ireland (2002) *Valuing Carers: Proposals for a strategy for Carers in Northern Ireland* CHI: Belfast
9.	Carers UK (2002) *Without US: Calculating the value of carers support* Carers UK: London
10.	Carers UK (2003) *Missed Opportunities: The impact of new rights for carers* Carers UK: London
11.	Carers UK (2004) *In poor Health: The impact of caring on health* Carers UK: London
12.	Carers UK: (2005) *Back me up- Supporting Carers when they need it most* Carers UK: London
13.	Carmicheal, F., Connell, G. Hulme, C. Sheppard, S. (2005) 'Meeting the needs of carers: Government Policy and social support.' *Management and Management Science Research Institute Working Paper* 208/05 University of Salford: UK
14.	Chambers, M., Ryan, A & Connor, S. (2001) 'Exploring the emotional support needs and coping strategies of family carers.' *Journal of Psychiatric and Mental Health Nursing* 8 pp99-106
15.	CNI & TOPSS (2001) *Training for Carers in Northern Ireland: Issues and*
16.	*Opportunities* Carers Northern Ireland & Training Organisation for the Personal Social Services: Belfast
17.	Cotterill, L, Hayes, L, Flynn, M & Sloper, P. (1997) 'Reviewing Respite Services: some lessons from the literature.' *Disability & Society* 12 (5) 775-788
18.	Department of Health (1995) *Carers (Recognition and Services) Act: 1995* DoH: London
19.	Department of Health (1999) *Caring for Carers: A National Strategy for Carers* DoH: London
20.	Department of Health (2000) *Carers and Disabled Children's Act* DOH: London
21.	Department of Health (2001) *Mental Health of Carers* Office of National Statistics, DoH: London
22.	Department of Health (2001) *Valuing People: A New Strategy for Learning Disability in the 21st Century* DOH: London
23.	Department of Health and Children (2003) *The National Health and Lifestyle Surveys: SLAN & HBSC* Department of Health and Children: Dublin
24.	Department of Health (2005) *Carers (Equal Opportunities) Act) Carers Grant* DoH: London
25.	DHSSPS (2005) *Review of Mental Health and Learning Disability, Equal Lives: Review of Policy and Services for people with a Learning Disability in Northern Ireland* DHSSPS: Belfast
26.	DHSSPS (2001) *Informal Carers Report* DHSSPS: Belfast
27.	DHSSPS (2006) *Caring for Carers: Recognising, Valuing and Support the Caring Role* DHSSPS: Belfast
28.	Doran, T. (2003) Health of young and elderly informal carers: analysis of UK census data *British Medical Journal* 327 p1388
29.	Dunn, M, Burbine, T, Bowers, C & Tantloff-Dunn, S (2001) 'Moderators of stress in Parents of children with Autism' *Community Mental Health Journal* Vol 37, (1) 39-52
30.	Floyd, F (1988) *Survey Research Methods* Sage Publications: London
31.	Fruin, D. (1998) *A Matter of Chance for carers: Inspection of local authority support for carers.* Social Services Inspectorate- DoH: London
32.	Gilleard, C (1998) 'Carers', in *Seminars in Old Age Psychiatrists* Butler, R & B. Pitt (eds) The Royal College of Pychiastrists : London
33.	Goldberg, D. & Williams, P.A. (1988) *A Users guide to the General Health Questionnaire* Nfer-Nelson: Windsor UK
34.	Grant, G & Whittell, B. (2000) 'Differentiated coping strategies in families with children or adults with intellectual disabilities: the relevance of gender, family composition and the life span.' *Journal of Applied Research in Intellectual disabilities.* 13 pps 256-275
35.	Gray, D. (2002) 'Gender and Coping: the parents of children with high functioning autism.' *Social Science and Medicine* 56 pps.631-642
36.	Hartley, L & Wells, J.S.G (2003) 'The meaning of respite care to mothers of children with learning disabilities: two Irish case studies.' *Journal of Psychiatric and Mental Health Nursing*, 10 (3): 335-342
37.	Health Research Board (2001) *The National Intellectual disability database (NIDD): Annual Report* Health Research Board: Dublin

38. Heenan, D. (2000) 'Informal care in farming families in Northern Ireland: some considerations for social work.' *British Journal of Social Work* 30 (6): 855-866
39. Heenan, D. (2006) 'The factors influencing access to health and social care in the farming communities of County Down, Northern Ireland' *Aging & Society*, 26 pp 373-391
40. Central Statistics Office Ireland (2004) *Census 2002: Disability and Carers* CSO: Ireland
41. Kennedy, M.T, McConkey, R. & Roberts, P. (2006) *Interim Evaluation Report on the Lakeland Families Project provided by Positive Futures* Institute of Nursing Research, University of Ulster ans Positive Futures: Belfast
42. Kenny, K & McGilloway, S. (2002) *Caregiver strain and coping in patterns of children with intellectual disabilities in Dublin.* www.frontline-ireland.com/article-65-caregiver-strain.htm
43. Leillot, P., Beevor., A. Hogman, G. Lathlean, J. Ward, M. (2003) 'Carers' and Users' expectations of services- carer version (CUES-C): A new instrument to support the assessment of carers of people with a severe mental illness.' *Journal of mental Health* 12 (2): 143-152
44. Lloyd, L. (2000) 'Caring about Carers: only half the picture?' *Critical Social Policy* 20 (1): 136-150
45. Maher, J. & Green, H. (2002) *Carers 2000: results from the carers module of the General Household Survey* London: The Stationary Office
46. McGarry, J & Arthur, A (2001) 'Informal caring in late life: a qualitative study of the experience of older carers' *Journal of Advanced Nursing* 33 (2) 182- 189
47. McConkey, R & Adams, L (1999) 'Matching short breaks for children with learning disabilities to family needs and preferences.' *Child Care, Health and Development* 26 (5): 429-44
48. N&W HSST (2004) *Supporting Carers: A Strategy for Carers in North & West Belfast* N&W HSST: Belfast
49. National Women's Council of Ireland (2002) *Valuing Care Work* National Women's Council of Ireland: Dublin
50. NI Statistics & Research Agency (1997) *Northern Ireland Health and Well Being Survey* DHSSP: Belfast
51. Nolan, M. (1999a) 'National Strategy for carers: the way forward?' *British Journal of Nursing* 8, p194
52. Nolan, M. & Lundh, U., (1999b) 'Satisfactions and coping strategies of family carers.' *British Journal of Community Nursing* 4, pp 470-475
53. Northern Ireland Statistics Research Agency (2001) *Northern Ireland Census of Population*
54. North Eastern Health Board (2004) *Health Status of People in the North East* NEHB: Kells
55. Office for National Statistics, (2000/1) *General Household Survey* Office for National Statistics: UK
56. Office for National Statistics (2001) *Primary Carers, Identifying and Providing Support to Carers in Primary Care* Census 2001: Northern Ireland
57. Robinson, C. & V. Williams (2002) 'Carers of people with learning disabilities and their experience of the 1995 Carers Act.' *British Journal of Social Work*, 32: 169-183
58. Schwartz, C & Gidron, R (2002) 'Parents of mentally ill adult children living at home: rewards of care giving.' *Health and Social Work* 27, pp145- 154
59. Strang, V, Haughey, M, Gerdner, L, Teel, C, (1999) 'Respite- A Coping Strategy for Family Caregivers' *Western Journal of Nursing Research* 21 (4) 450-471 p450-471
60. Taylor, R., Ford, G. & Dunbar, M. (1995) The effects of Caring on Health: a community based longitudinal study' *Social Science and Medicine* 40 (10): 1407-15
61. The Institute of Public Health in Ireland (2005) *One island- Two systems: A comparison of health status and health and social service use by community- dwelling older people in the Republic of Ireland and Northern Ireland.* HARP: Ireland
62. NIHPS (2001)*The Northern Ireland Household Panel Survey* NIHPS: Belfast
63. The Women's Health Council (2005) *The Women's Health Council: A position paper Ireland Care giving* Women's Health Council: Dublin
64. The Women's Health Council (2002) *Promoting a Gendered approach to policy and service provision* WHC: Dublin
65. Thoits, P. (1995) 'Stress, coping and social support processes: Where are we? What next?' *Journal of Health and Social Behaviour,* p53-79
66. Walker, C & A. Walker (1998) *Uncertain Futures: People with learning difficulties and their aging family carers.* Pavilion Publishing: York
67. Williams, V & C. Robinson (2000) *In their own right: the support needs of family carer's of people with learning disabilities* Bristol: Policy Press
68. www.bmj.bmjjournals.com
69. www.carersni.org
70. www.carersni.org/Information/Helpwithcaring/Carerassessmentguide
71. www.communitycare.co.uk/Articles/2006/02/22/46026/Carers.html
72. www.londonhealth.com,
73. www.positive-futures.net/ld.html

Executive Summary

This research aimed to examine the current health status and support service requirements of unpaid carers of people with a learning disability within a 10 mile corridor either side of the North/South Border. A mapping exercise was also conducted across this area to identify existing carer support groups and all support services for service users. Findings of this study came from 2 main groups of people:

Unpaid carers of people with a learning disability: Attitudes and views were obtained via a postal questionnaire (n=111) and semi structured interviews (n=10)

Health Professionals/Service managers who work within the Learning Disability Field: including area managers and providers of learning disability services, managers of carer support groups, carer development officers and carer support workers. Attitudes and views were taken via a postal questionnaire (n=58) and semi structured interviews (n=16)

Profile of Carer Respondents and their Dependants

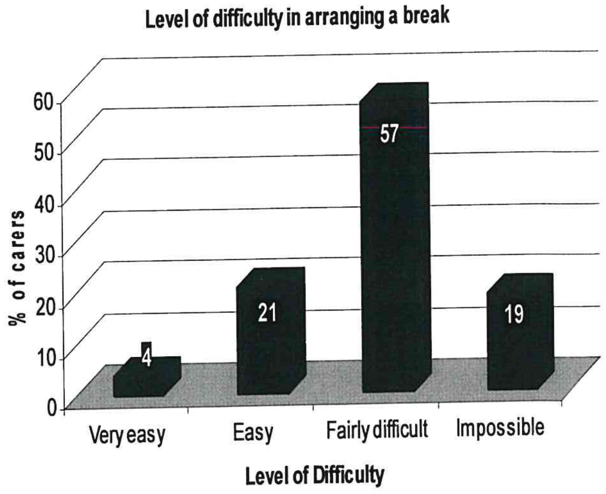
- 83% of carer respondents were over the age of 40 years.
- 95% of carers lived with their dependant, and 87% where caring for their child.
- The majority of carers (80%) were caring for over 100 hours per week.
- 66% of carers had dependants that needed 'a lot' or 'full support'.

Carers' Health

- 64% of carers were in 'fairly good' physical health.
- 45% of carers showed symptoms of poor mental health and 70% of these carers did not feel they received enough support.
- **Carers felt that a greater choice and variety of respite types would ease the burden on their health.**

Service Support

- 86% of carers stated that getting a break from caring was important. Some carers stated that the respite available was not suitable for the one they cared for; others were worried about the standard of care provided by respite staff.



- Carers expressed an interest in a range of respite services being made available including sitting services, leisure schemes and joint holidays.
- The majority of carers found it either difficult or impossible to arrange a break from caring, with 19 % never having had a break since they began caring, the majority of these carers came from rural areas.

Carer Support Groups (CSG)

- 53% of carers did not feel that they received enough support.
- 35% of carers were attending or had attended a Carer Support Group, with a high level of interest if they were made available across the CAWT region.
- The mapping exercise revealed the uneven distribution of general and learning disability specific support groups across the border regions, identifying an absence within many areas.
- CSG were reported as a vital way for carers to get access to information on caring, services available, carers assessment and direct payments and also offer an opportunity to discuss common problems with others in a similar situation.
- Not having anyone to look after their dependant was the main barrier in preventing carers from attending a CSG (29%), Other reasons included feelings of guilt in leaving their caree and being unaware that these types of groups existed.

Cross Border Service Development

- Only 6% of carers were using cross border services. Potential advantages to using a cross border service included reduced travelling time and receiving additional support.
- Whilst 57% of carers were willing to use a cross border service, 35% stated they didn't know.
- Being unaware of available services was the main barrier to using cross border services (83%).
- Health Professionals identified transport, funding and getting the information on services out to carers as the main issues to be addressed in setting up cross border services.

The Positive Side of Caring

- 92% of carers received satisfaction from their caring role. The main sources of satisfaction concerned the person being cared for, such as keeping the dependant happy and well cared for, as well as their love for the caree, milestones achieved by their dependant and the carer's own personal achievements.
- Many found the reciprocal love given by those they cared for helped them to stay positive.

> *"A smile, a hug can make all that difference, you forget all the bad days really…to feel… that you have achieved something if you're getting a friendly face and a smile…Keeping my daughter happy is what keeps me happy".* (Male carer of 25 years)

Carers Assessment

- Only 34% of carers in the North were aware of Carers Assessment
- 31% of Health Professionals rated the assessment as 'poor' and 6% as 'very poor'

Information for Carers

- Carers most wanted information on services that were available to them in their local area.
- The majority of carers did not use internet (57%) and older carers were less likely to use the Internet than younger carers.