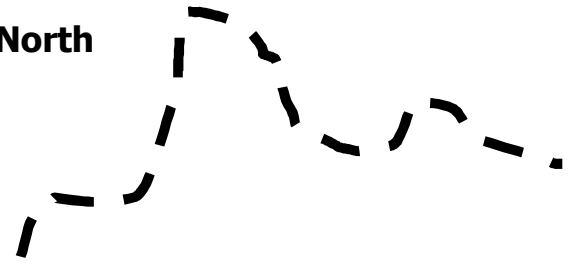


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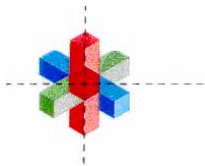


South

# Crossing the Line

## Learning Disability Day Services in 3 Cross Border Areas of Ireland

Exploring the Potential  
for Cross Border Cooperation



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## **Crossing the Line**

Learning Disability Day Services in 3 Cross Border Areas of Ireland – Exploring the Potential for Cross Border Cooperation

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### **Report Edited by**

Ms Sonia Mawhinney

### **Research Conducted by**

Dr. Olwyn Johnston

### **For further information, contact**

Praxis Care Group  
27-31 Lisburn Road  
Belfast  
BT9 7AA  
Tel: (028) 90234555  
[soniamawhinney@praxiscaregroup.org.uk](mailto:soniamawhinney@praxiscaregroup.org.uk)

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### Research Aims

The research aimed to provide recommendations for future development of learning disability day services in 3 cross border areas of Ireland. The research comprised several strands:

- Mapping of currently available day services
- Profile of service users
- Profile of carers
- Interviews with service users, carers, and managers to gather their views on currently available services, the need for service development, and the potential for cross border cooperation.

### Research Areas

The 3 geographical areas investigated each consisted of a 15-mile radius of a midpoint on the border between:

- **Rosslea** (Co. Fermanagh, N. Ireland) and **Clones** (Co. Monaghan, S. Ireland)
- **Garrison** (Co. Fermanagh, N. Ireland) and **Blacklion** (Co. Cavan, S. Ireland)
- **Castledearg** (Co. Tyrone, N. Ireland) and **Castlefinn** (Co. Donegal, S. Ireland).

Maps of the areas are included in Appendix D at the back of the report.

The areas spanned a number of Health Board and Trust areas. They included:

- The North Eastern Health Board (parts of Monaghan/Cavan)
- The North Western Health Board (Sligo/Leitrim, and Donegal)
- The Southern Health and Social Services Board (Armagh and Dungannon Trust)
- The Western Health and Social Services Board (parts of the Sperrin Lakeland Trust and the Foyle Trust).

### Research Method

The research was carried out over a 6-month period, from October 2001 to March 2002. In total, interviews were conducted with 35 service users, 12 carers, and 30 managers of learning disability day services within the 6 areas. Carers were also consulted via a postal survey, which was responded to by 58 individuals. 287 service user profile sheets were completed by service staff, which provided a breakdown of service user characteristics. In addition, professionals working within the learning disability field in the various Health Board and Trust areas were consulted as part of the mapping exercise. For more details on the methodology see Appendix A.

### Mapping

A mapping exercise was conducted to identify all learning disability day services that were being provided within the 6 research areas. Senior social workers and/or learning disability team workers from each of the Health Board and Trust areas were consulted as part of this exercise.

### Service Definition

Training and employment opportunities for adults with learning disabilities were included in the mapping exercise. Cross-disability services were included if more than 15% of individuals who used the service were individuals who had a learning disability (based on the percentage adopted by the DHSS, 1992). Services providing occasional evening and weekend social supports for individuals with learning disabilities were not included in the mapping exercise. There was some overlap between the services, with some individuals using more than 1 service.

Overall, a total of **30** day services were identified across the 6 areas. There were a greater number of services operating within the North of the Island in comparison to the South. Managers from each of these day services were interviewed to obtain detailed information on the nature of the activities provided; sources of funding; management structure; and the number of individuals using the service (see Appendix B). Currently available day services within each area are listed below.

#### **3** day services were identified within the **ROSSLEA** area (north)

- Castlepark Centre, Lisnaskea.
- Day Service at Barnlee Residential Home, Lisnaskea
- Enterprise Centre, Lisnaskea

#### **10** day services were identified within the **CLONES** area (south)

- Cairde Activation Centre, Clones
- Camphill Community Farm Day Service
- Clogher House, Monaghan
- County Monaghan Partnership Supported Employment
- Drumlin House Training Centre, Cootehill
- Errigal Truagh Special Needs Day Service, Emyvale
- Horticultural Training Unit, Monaghan
- Monaghan Training Workshop, Monaghan

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6 day services were identified within the **GARRISON** area (north)

- Buttermarket, Enniskillen
- Lackaboy Centre 1, Enniskillen
- Lackaboy Centre 2, Enniskillen
- Kent Plastics, Enniskillen
- Strule Erne Day Care, Derrygonnelly
- Tir Navar Day Centre, Derrygonnelly

Only 1 day service was identified within the **BLACKLION** area (south)

- North West Supported Employment Partnership Programme

7 services were identified within the **CASTLEDERG** area (north)

- Castlederg Centre (Garden Corner)
- Glenside Adult Training Centre, Strabane
- Gortin Centre, Gortin
- New Horizons
- Pathway Employment Service
- Prospects Day Care, Castlederg
- Strabane Day Centre, Strabane

5 day services were identified within the **CASTLEFINN** area (south)

- New Horizons
- NTDI, Lifford
- Rehab Care, Lifford
- Sean O'Hare Unit, Stranorlar
- North West Supported Employment Partnership Programme

**Evening and Weekend Services**

Although evening and weekend services were not included in the overall research, the mapping exercise identified 3 such services that operated within the research areas. These are:

- FACT Outreach (Rosslea area)
- Faith and Light (Rosslea, Clones, Garrison areas)
- Challenge Befriending (Castlederg area).

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Managers of the 30 services identified within the 6 research areas were provided with anonymous service user profile sheets. These forms were completed for each service user living within the research areas. Profiles were not completed for individuals travelling from outside the research area to use a service within it, or those living within the research area and using a service outside it. Overlap between services was taken into account in order to avoid duplication of data. All geographical areas were well represented, with the exception of the Blacklion area where only 1 service user was identified. The service user profiling exercise is based on the **287** profile sheets returned by service managers.

### Gender and Age

From the information provided, there was a greater percentage of male service users (58%) compared to females (42%). Gender distribution did not differ significantly across the geographical areas. The average age of service users was 36 years, with a range of 17 to 66 years. Overall, males had a slightly lower average age (35 years) compared to females (38 years)<sup>1</sup>. Statistical analysis indicated that service user age differed by geographical area (Table 1), with Clones and Castlefinn reporting the lowest average age (33 yrs) and Castlederg having the highest average age (39 yrs). The proportion of service users aged over 30 years was 62%, supporting the prediction by the DHSS (1992) that by 2002 to 2007, the majority of learning disability day centre users would be over 30 years of age. Although the DHSS projections related only to Northern Ireland day care users, analysis revealed that for the present sample, the proportion of service users aged over 30 years did not vary significantly across the North/South boundaries.

**Table 1: Service User Age**

<b>Clones</b>	33 years
<b>Castlefinn</b>	33 years
<b>Garrison</b>	37 years
<b>Rosslea</b>	38 years
<b>Castlederg</b>	39 years

### Living Situation

The majority of service users (76%) lived with their families; 19% lived in a group home; 3% lived independently (renting or owning their own accommodation); and 1% of individuals lived semi-independently (in a home setting with some supervision). With the exception of Castlefinn, between 60% and 86% of individuals lived with family members. In Castlefinn, just over half (55%) lived with family members and the remainder lived in a group home (23%) or lived independently (23%).

<sup>1</sup> Details of all statistical analysis are noted in Appendix B.

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attending their service 5 days per week, with 12% attending 3-4 days per week and 11% attending 1-2 days per week. Individuals who attended their service 5 days per week varied across the different geographical areas from 59% (Castlefinn) to 86% (Rosslea, Table 2).

**Table 2: Attendance and Transport Across the Areas**

	Rosslea	Garrison	Clones	Castleberg	Castlefinn
<b>Attending 5 days/week</b>	86%	80%	76%	65%	59%
<b>Using Service Bus</b>	96%	72%	84%	91%	50%

### Transport

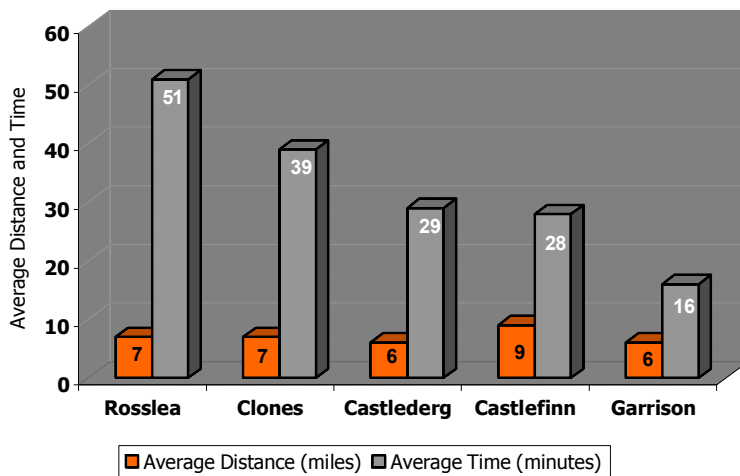
The most common method of transport for individuals to get to and from the service was a bus provided by the service, used by 82% of service users. 7% used a taxi; 6% received transport provided by a carer/ family member; 3% used public transport; and 2% walked to the service from their place of residence. Castlefinn had the lowest percentage of individuals using a bus provided by the service, with only 1 out of 2 individuals using this form of transport (Table 2). Within this area, 21% used public transport and 18% were taken to and from the service by a carer or family member.

### Distance and Time Spent Travelling

The average distance from the service users' place of residence to the service being used (one-way) was 6.4 miles (range 0 to 30 miles). Overall, 82% of individuals lived within 10 miles of the service they attended. The average distance travelled by service users did not vary significantly across the geographical areas (Fig 1), with the average distance ranging from 6 miles (Castleberg and Garrison) to 9 miles (Castlefinn) (Castlefinn).

Although the average distance travelled by service users within each geographical area did not vary significantly, the average time spent travelling from their place of residence to the service (one-way) varied significantly across the

**Fig 1: Average Distance and Time Travelled by Area (One Way)**

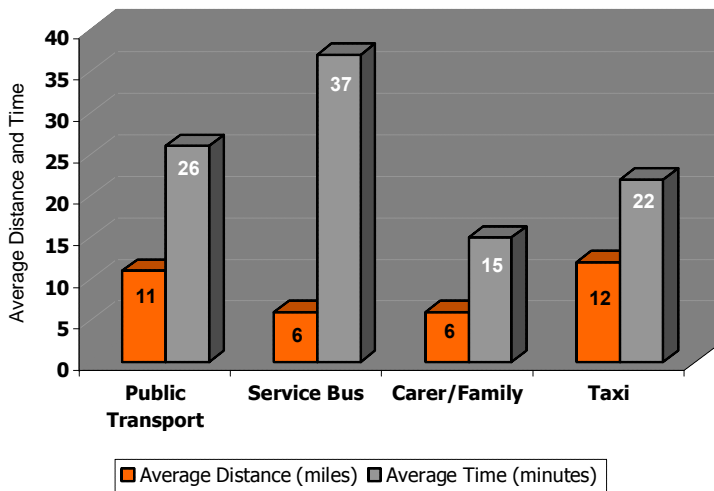




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The average travelling time was 33 minutes, ranging from 2 minutes to 51 minutes. The average travelling time was highest in the Rosslea area (51 minutes) and lowest in the Garrison area (16 minutes). The remaining areas produced intermediate average travelling times: 39 minutes in Clones; 29 minutes in Castledearg; and 28 minutes in Castlefinn. The DHSS (1992 report) recommends that the total daily travelling time to and from day services should not exceed 2 hours. This research estimated that, based upon doubling the one-way travelling times, 18% of service users were exceeding the recommended limit. Almost one third (31%) of those in the Rosslea area exceeded this 2-hour travelling limit. However, it should be noted that total daily travelling time may not always be double the one-way travelling time. For example, in some services those who are picked up by the bus first in the morning will be left off first in the evening, making their morning journey the longest but their evening journey the shortest.

**Fig 2: Distance and Travel Time by Mode of Transport (One Way)**



The type of transport used to get from the service users' place of residence to the service impacts on the length of time spent travelling. As can be seen from Figure 2, although those using a bus provided by the service travelled on average only 6 miles (one-way), they spent the longest

period of time travelling (37 mins). By contrast, individuals who lived the same distance from the service (6 miles) took less than half this time (15 mins) when travelling with a carer/family member. The graph also indicates that individuals who used public transport and taxis lived furthest away from the service (11 and 12 miles respectively).

## Recommendations

This profiling exercise provides an up-to-date description of the characteristics of individuals with learning disabilities using day care services within the 3 cross border areas. It indicates that, in general, the majority of individuals are aged over 30 years, live with family members and attend their service 5 days per week. The majority live within 10 miles of the service

service on a bus provided by the service. A number of  
d on the research findings:

- 62% of service users were aged 30 years and over. This finding supports the suggestion by the DHSS (1992) that by 2002 to 2007, the majority of learning disability day centre users will be over 30 years of age. The increasing age of service users should be taken into account when planning future services. This could involve focusing on specialised day services for older service users, such as the Strule Erne Day Care Centre in Garrison. Having such services would ensure that the specific needs of older people are catered for, and it would also free up places within mainstream day services that are currently being filled by older individuals.
- The DHSS (1992) report recommends that the total daily travelling time to and from day services should not exceed 2 hours. As an estimate based upon doubling one-way travelling times, around one third of individuals in the Rosslea area exceeded this limit. Given that the average travelling distance was not significantly greater in this area compared to the other areas, it is recommended that existing transport provision within the Rosslea area be addressed. Almost all individuals (96%) used the bus provided by the service to travel to and from the service. Offering alternative methods of transport (for example using public transport or supporting family members/carers to provide transport) could be made available to those individuals who travel for an inappropriately large amount of time each day. Another possible solution would be to consider the relocation of some service users who use services in Rosslea to services across the border in Clones, if these services are nearer their place of residence. This possibility will be discussed in the section on the potential for cross border cooperation.

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To date, relatively little information has been available on the carers of individuals with a learning disability who live within the 3 cross border research areas. Therefore, to determine the characteristics of carers, the extent of their caring responsibilities, and the impact of caring on their physical and mental health, carers were asked to complete a postal questionnaire. In total, **58** completed questionnaires were returned. No questionnaires were returned from the Blacklion area, and only 1 was completed from the Castlefinn area. The other areas were well represented: Clones (21); Garrison (14); Rosslea (11); and Castlederg (11). In addition, 12 carers, from across the different areas, participated in a face-to-face interview. Part of the interview aimed to provide more in-depth information about the experience of caring, and the strains and responsibilities associated with being a caregiver.

### Carer Characteristics

Of those carers who completed the postal questionnaire, the majority were female (89%). The age of carers ranged from 24 years to 88 years, with an average age of 57 years. 42% of carers were aged 60 years and over. The largest group of carers described themselves as homemakers (40%), followed by retired individuals (30%), those working full-time (17%), part-time workers (7%), and unemployed individuals (6%). The majority of carers (66%) were married or cohabiting; 23% were widowed; and 11% were single. All carers were related to the individual they were caring for: 74% were a parent to the service user; 17% were the sibling of the person being cared for; and 9% defined themselves as 'other relative'. Looking at carer characteristics across the different geographical areas, carers were most likely to be female and a parent to the service user. Carer age did not differ significantly across the areas.

### Service User Characteristics

Carers were asked to rate on a 4-point scale to what extent the service user was able to care for him/herself and how much supervision the person required. As

**Table 3: Service User Abilities**

	<b>A Lot</b>	<b>A Little</b>	<b>Not Very Much</b>	<b>Not A Lot</b>
<b>Person can care for themselves</b>	21%	42%	17%	19%
<b>Need to supervise person</b>	68%	23%	7%	2%

indicated in Table 3, carers most commonly reported that the person they were helping was able to care for him or herself only 'a little' (42%), and that the person required 'a lot' of supervision (68%).

average, how much time they spent caring for their

relative:

- 1 in 2 carers (50%) stated that they were caring 'all the time, day and night'
- 27% spent a 'moderate' amount of time caring (between 1 and 4 hours most days)
- 14% spent 'a lot' of time caring (4 or more hours daily or almost daily)
- 9% spent 'a little' time carrying out their caring responsibilities (1 hour or less per day)
- In all geographical areas, the most common response was caring 'all the time' (except in Clones where the most common amount of time spent caring was 'moderate').

The carer questionnaire included the Zarit Burden Scale, a scale consisting of 12 questions about the frequency with which respondents experienced various aspects of care-giving burden. Each item is scored on a Likert scale from 0 to 4, with a higher score indicating higher burden. Carers' scores ranged from 0 to 44, with an average score of 10.2. Analysis indicated that carer burden scores did not differ significantly across the geographical areas. A score of 17 and over has been used as a cut-off point to identify individuals experiencing high levels of burden through their caring responsibilities. In this research, 23% of carers reported scores of 17 and above. This is similar to the proportion of carers of older adults with dementia who experienced high burden (Bédard et al., 2001). There was some variation across the geographical areas in the proportion of carers reporting high burden (i.e. scores above the cut-off). Findings confirmed that:

- None of the carers from the Rosslea area reported high levels of burden
- 20% of carers from Castlederg reported high levels of burden
- Around one third of carers in Garrison (33%) and Clones (37%) reported high burden.

During the interviews, carers described caring as producing both a:

- **Physical Strain:** For example, coping with lack of sleep, and physical management of the service user, and a
- **Mental Strain:** For example, the needs of the service user always being at the forefront of one's mind, and trying to manage financially.

Comments from a few carers who described their experience of caring included:

'[my son] had this thing, if he got something that he could wind you up, and he knew what button to press, he pressed it every single minute of the day he got a chance. And he was unbearable. Like,....if Daddy said go right he went left,.....he was like a brat of a teenager really, only that he didn't even understand what he was doing, but he put us through hell'.

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...at problem...And he shouts at the top of his voice all the  
...sometimes the noise gets to me'.

Carers referred to the difficulty of trying to balance caring with other aspects of their lives. One carer stated that caring impaired the extent to which s/he was able to talk to his/her partner. Another described the stress of trying to balance the caring role with work and other family responsibilities:

'I suppose just getting stressed out in terms of trying to balance. I would find when [attending to] other things...feeling guilty because I wasn't at home with my daughter...I did have to go and get some help eventually with my doctor, I knew I wasn't coping, just too many things to do, to be balanced'.

A common strain experienced by carers was that they always 'had to be there' for the service user. Carers stated that this could lead to stress, a lack of time spent alone with one's partner, and a lack of time for oneself. This is reflected in the comments detailed in Table 4.

The purpose of the present research was to identify carer needs in order to improve service provision and as such, the focus is upon those aspects of caring which place carers under strain. However, it should be acknowledged that not all carers viewed their caregiving in terms of strain and burden. Positive aspects of caring were emphasised by a few carers, for example one carer stated:

'We don't feel our daughter to be burdensome. Brings us great joy and happiness'.

A number of carers stated that they did not think of their caring in terms of difficulties as they were 'so used to it', with one carer remarking:

'I don't pass any remarks on it, I am so used to it. I don't pass a bit of remarks on it, I've known no different'.

**Table 4: Strain of Caring**

'My daughter has a certain number of needs that have to be addressed, it doesn't really matter what else is happening, they have got to be addressed'.

'I never really can go away and say, well, I can have a day to myself... it's just like having a child, you've got to be here when [my sister] comes in, you've got to be here when she gets up, it's as simple as that'.

'If we were going out for a meal, he'd want to come...there's times you just can't be bothered to go out, because you're going out for a meal, right, you've to cut up his meat ... because he only can use a fork, he won't, he can't use the knife and fork, and you've to do all that, and by the time you get to your own it's gone cold....and you're still under the pressure and the stress cause he's clumsy, what if he breaks something, what if he drops, you know what I mean'.

'running after him all the time, it's just go,go,go...constant'

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Carers were asked to complete a carer health measure, the SF-36. This is a generic health measure that assesses both physical and mental health. Two scales were selected for inclusion in the present research:

- The '**general health**' scale, which provides an evaluation of personal health and anticipation of future health
- The '**role-physical**' scale, which provides information on the extent to which physical health causes problems with work or other daily activities.

Scores on the general health scale ranged from 5 to 100 (average 67) and scores on the role-physical scale ranged from 0 to 100 (average 79). Higher scores on each of these scales indicate better health. Analysis indicated that neither score differed significantly across the geographical areas. Overall:

- Older carers rated their health as being significantly poorer compared to younger carers
- Carers who reported taking medications improperly (too much, too little, or not at all) in the 3 months prior to completing the questionnaire had a significantly higher average age (71 years) than those who did not report doing so (56 years).

No relationship was evident between the age of the carer and their burden of caring (as measured on the Zarit Burden Scale). However, during the interviews, carers described concerns about their advancing age and the impact this would have on their ability to carry out their caring responsibilities. Aging, in general, was described as having a negative effect upon their ability to care both mentally and physically:

'You're getting older, you're getting tired, you're tired, you're mentally tired as well, which is more so than physically tired. This constant stress and the pressures, the pressure I think is the main thing, you know, you're not as capable of coping with it I think really'.

'I would find as I've got older there's a lot of things now that I'm not doing that I was quite well able to do a few years back, so that in that sense, yes, I would worry about my health...

I think as I've got older I'm not nearly as fit as I was'.

'I do have arthritis in my hands and I would find difficulty now with doing up her clothes and things like that, ... and I would find huge difficulty with her wheelchair, trying to get that in and out of the back of the car,...sometimes it can be very painful and it's awkward trying to do things, I just haven't as good manipulative skills as I would like'.

they engaged in a range of self-care behaviours over the  
ings indicated that:

- Over one third of carers had failed to get enough exercise (43%); did not get enough rest (39%); and put off recreational activities they enjoyed (37%)
- Around one quarter of carers had postponed getting regular medical checkups or examinations (26%); and failed to stay in bed when ill (24%)
- Less commonly, carers reported eating poorly (20%); putting off going to the doctor (18%); taking medications improperly (11%); and cancelling or missing medical appointments (7%)
- Carers in Castlederg had the worst levels of self-care: 50% had postponed regular medical checkups or examinations; 50% had failed to get enough rest; 70% had put off recreational activities they enjoyed; and 80% had failed to get enough exercise.

Analysis indicated that for individuals who had cancelled medical appointments or had put off recreational activities, their carer burden scores were significantly higher compared to those who engaged in these activities. This finding suggests that time pressure leading to a neglect of one's own health and social needs may play a role in the experience of carer burden.

### Carer Concerns

During the interview, carers described various concerns relating to the person they were helping. Carers worried about the service user's limited social life and activities; their health (including inadequate services catering for physical health needs); and their happiness. Carers were also concerned that they were not 'doing enough' for the service user. A common worry expressed by carers was the future care of the person in the event of the carer dying or being unable to cope. Carers said:

'I suppose my other concerns is really, over time, just being able to look after her. Because of her poor mobility and a good appetite she's getting quite heavy and strong, and I would find difficulty sometimes .... she gets really determined about something, just being able to physically manage her.'

'Well at the minute it's just that I get not able, so he'd have to go into a residential home, it's the only thing. It's one of those things, you can't, there's no-one else could look after him when I'd be gone.'

available information on the characteristics and needs of carers for people with learning disabilities within the 3 cross border areas. Based on these findings, a number of recommendations have been proposed.

- Given that 42% of carers were aged 60 years and over, it is recommended that services take into consideration the advancing age of carers in the future planning of services. As the DHSS (1992) point out, the growing proportion of older service users 'living with ageing carers in the community...will have far reaching implications...for...the wider range of family support services that are likely to be needed' (p28). Based on this research, examples of family support services for ageing carers could include:
  - Information and help with arranging future provision for the service user when the carer is no longer able to cope
  - Support targeted at helping the carer cope with poor health (as older carers rated their general health as being poorer)
  - Services to support the aging carer with some of the more physically demanding aspects of caring
  - A campaign targeted at older carers regarding the importance of taking medications properly (as older carers were significantly more likely to take medications improperly).
- Health promotion strategies should be aimed at combating the poor self-care behaviours of carers that can impact upon their health. Efforts should be focused particularly upon promoting exercising, resting, and making time for recreational activities, as over one third of all carers neglected these activities. Health promotion should be concentrated particularly within the Castlederg area, where in the 3 months prior to completing the questionnaire over 50% had neglected basic health care behaviours (such as getting medical check-ups, getting exercise and sufficient rest). These strategies should be complemented by increased and more flexible respite opportunities that would provide more free time for carers to pursue necessary self-care behaviours.
- Initiatives need to be implemented to address the high rates of carer burden within the Garrison and Clones areas, where one third or more of carers reported high burden. Interventions could focus upon alleviating carers' time pressures, supporting carers in the task of balancing caring with other aspects of their lives and providing a flexible support service to enable carers to engage in recreational and medical activities.



## Service Developments

### SERVICE USER VIEWS

35 service users took part in a face-to-face interview to gather their views on the day service they were currently attending. No service users were interviewed from the Blacklion area, mostly due to a small number of services operating within the area. Within Rosslea, only 1 service user was interviewed. This was due to a number of factors, including limited numbers of service users with sufficient communication skills; a lack of interest from service users; and a requirement in this area for carer consent for interviews to take place. However, the Castelderg, Castlefinn, Clones and Garrison areas were well represented.

### Service Activities

Service users were asked to evaluate up to 3 activities which were commonly carried out at, or through, the service they attended. These ratings were averaged to produce an activity rating for each service user. Overall 77% of service users rated the activities as 'good'; 20% rated the activities as 'OK'; and 3% as 'not good'. During the interview service users provided some reasons for their positive ratings of service-organised activities. The social benefits of the activities were frequently highlighted (Table 5). Other reasons for satisfaction were that the activities provided employment (described by some as 'a good job' or 'good work'); offered occupation ('keeps you busy'); fostered a feeling of competence ('It's nice if you can do those things for yourself'); and were 'good fun'. Dissatisfaction with service activities was rare, with only 3% (2 individuals) rating them as 'not good'. These individuals perceived the activities to be 'boring' and lacked sufficient opportunity for social interaction.

**Table 5: Social Benefits**

- 'I love it, you get involved with other people'.
- 'Getting out and meeting people, meeting new faces every day, nice to have a chat with people when you're out'.
- '[I] like being with other people and talking'.

### Transport

Overall, the evaluation of transport to and from services (most commonly a bus provided by the service) was 'good' (81%). This rating remained constant across all areas. Service users reported positive aspects of their transport, such as, reliability, convenience, and social benefits, with one individual stating: '[I] love the bus. Good craic...sing songs'.

Only one service user described negative aspects of their transport:

'It's sometimes fast, sometimes not. It's good when there's no rubbish. There's too many on the bus, the bus is very small, we need a bigger bus, there's too many bags. It's sometimes all mucky, the bus driver has to wash it off. We're not allowed to smoke'.

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Users rated staff members as good, with the remainder stating that staff members were 'OK'. This pattern was similar across all areas. Positive staff qualities included being helpful, kind, not critical, and sociable (Table 6).

### Helpfulness of Service

Of the 33 individuals who responded to this question, all but one felt that the service had helped them (97%). Individuals described how the service had provided social benefits, kept them occupied, and provided a variety of enjoyable activities so that they were not bored (which they stated they had sometimes felt in previous services). In addition, staff members were described as providing help, such as management of finances and coping with bereavement.

### Changes in Current Service

Just over one quarter of individuals (27%) stated they would like to see some changes in the service they were currently receiving. No service users in Rosslea or Clones indicated the need for change, and only 14% of those in Garrison expressed the need for changes. However, 50% of individuals from Castlederg and 60% of those from Castlefinn mentioned areas of the service they felt could be changed or improved. Individuals highlighted 2 main changes namely:

- More time spent away from the centre, for example in supported employment, and/or community facilities
- Greater flexible hours of service provision.

### Service Development

Service user views on the need for service development were further explored by asking participants whether or not they would like to try 'having a job', participate in a course, or avail of more community facilities. Overall, the findings concluded that:

- 70% of individuals stated that they would like to try 'having a job', focusing mostly on the social benefits of working ('I would have more new friends'). Individuals who stated that they would not like to be in a job referred to their own unsuitability for work (e.g. being too old, or not having the necessary abilities); being happy at their current service; and a perceived lack of availability of jobs
- 79% reported that they would like to use more community facilities, citing social benefits; providing an opportunity for a greater range of experiences; weight loss; and being independent

**Table 6: Views of Staff**

'They're good to speak to'  
'The best. Nice people'  
'They're very friendly'  
'They would tell you when you go wrong, but they would be helpful as well'.

they would like to participate in a course (in some cases one they were already completing). Courses mentioned included cookery, computing, literacy, first aid, and employment skills.

### CARER VIEWS ON SERVICES

Carers' views on the service used by the person they were caring for was obtained via the postal survey (completed by 58 individuals) and face-to-face interviews (12 individuals).

#### Services for Person Being Cared For

Carer satisfaction with day services was high, with only a small proportion (5%) reporting that they were dissatisfied with the service the person they cared for was currently receiving. Overall, 61% of carers stated they were 'very satisfied', and 33% were 'quite satisfied' with the service provided. Carers described a range of factors which they felt impacted positively upon their satisfaction:

- Positive staff attributes, including helpfulness; friendliness; support; caring qualities; consideration; efficiency; being straightforward; well trained; and working hard
- Good relationships between staff and service users, and between staff and carers
- The quality of care provided, such as, the service user receiving help with daily living skills; close supervision; safety of the service; accessibility of the service ('you can call in and have a conversation, check on them'); meeting the needs of the service user; providing a variety of activities; a good atmosphere at the service; and the convenience of transport being provided by the service
- Benefits to the service user included enjoyment or happiness; getting out of the house; social contact; and being occupied or kept active. Some carers also mentioned the positive impact of the service in terms of improving learning and communication, and fostering increasing self-esteem and decreased dependence on the carer (Table 7)
- Services were also viewed as providing a break for carers, allowing the carer some free time.

**Table 7: Benefits of Service**

'It has broadened his knowledge of the wider world in a way that nowhere else has'.

'She's there, she's picking up things. She'll never read or write but she knows what you're talking about. I think she knows now more. She'll say wee words. I can see quite a difference in her. Before she wouldn't speak at all, she had her head down all the time, she wouldn't look at anybody'.

'She...is more animated, energised'.

'It gives them a sense of pride, they're proud of it, they get a wage. It's not much, but there's a great show on Friday with the pay packet. It is good for them mentally, they have a place to go, they call it work, they feel good.'

ation with services was high and therefore information on is limited. However, a few factors were mentioned, such as limited staffing; services offering a restricted range of activities; inadequate service venue; and lack of provision for the physical health needs of service users due to poor integration between day services and health services.

### Service Development

Carers were asked to choose from a list of potential services the 3 services that they felt would be most useful in their local area. This was in addition to the service/s the person they were caring for was currently receiving. The most frequently cited service type, as being most needed in the area, was supported employment (49%). This was followed by the use of community facilities (45%) and adult and continuing education (43%). Around one third rated befriending services (36%) and drop-in centres (34%) as the most needed services.

### Services for the Carer

Only 4 carers indicated that they attended services for carers (e.g. carers' associations or parents' meetings, respite and/or domiciliary help). Reasons for not using services aimed at carers themselves included, not being aware of any carer services; being satisfied with current support (e.g. from day service, family, friends); lack of time to attend services; transport difficulties; and feeling that any support provided would be limited (e.g. lack of power of carers' associations, meetings being boring or unhelpful).

### Service Development

65% of carers stated they would like more services to support them in their caregiving role. Demand for carers' services varied across the areas, with 50% of carers in Garrison stating that they would not like more carers' services in their area. However, the majority in the Rosslea, Clones, and Castlederg areas indicated that they would like more services. These individuals identified a range of services that they felt would support them in their role as caregiver, which included:

- Education, information and advice regarding possible caring difficulties and methods of dealing with them (e.g. service user's health problems, handling mood swings, problems arising as service users get older, encouraging service users to fulfil their potential)
- Methods of looking after one's health and coping with stress. It was suggested that this could take the form of an advisory service, nurse visits, or talks from professionals
- More direct professional help with caring (e.g. emergency aid number, immediate respite in emergencies, evening and weekend respite, domiciliary care/home help)
- Contact with other carers (e.g. support groups, social evenings) was mentioned as providing social interaction, support, and an opportunity to discuss and resolve problems.

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highlighted a range of benefits for service users attending day care, which included:

- Achievement of training or employment goals
- Availability of a range of activities catering for individual needs
- Greater independence (e.g. through training, personal development, integration)
- Improved health through physical activity
- Improved quality of life
- Increased confidence and self-esteem
- Positive staff qualities
- Social interaction and community integration.

Day services were also regarded as having knock-on benefits for carers, including respite; peace of mind; and help with the organisation of care (e.g. benefits and medication).

### Service Development

Managers were asked for their views on the development of day services within their general locality and also on any specific issues or developments they could identify within the service they provided. Managers of services, across all 6 areas, identified unmet need in the provision of day services. Some services were described as being oversubscribed, with more service users trying to access the service than were leaving the service. Some service managers, across all 6 areas, stated that they could accept a few more service users. However, in some cases, suitable service users had already been identified, only part-time places were available, or taking on new service users was dependent upon increased funding. Managers in the Rosslea, Clones, Castlederg, Castlefinn, and Garrison areas stated their service had a slow throughput of service users. Reasons for this included, a shortage of appropriate places for the elderly to move on to; a lack of supported employment provision which would enable service users to move out of day care; and a reluctance of service users and carers to progress to a more independent type of service (due to dependence on the service, fears that the service would be unavailable should they want to return, and concerns about benefits being cut if they engaged in employment activities).

With regard to specific developments within the service they were providing, managers highlighted a number of issues:

- **Staff:** A number of managers stated that more staff members were needed in their own service in order to cater for the varied needs evident in the client group.

to the need for increased and more diverse training increased provision of work experience, and supported employment initiatives. They also identified the need for community supports (e.g. drop-in, befriending) to support service users to progress from day centres to training and employment-based initiatives. Liaison with schools and with training and employment agencies was regarded as necessary in order to decrease the focus on day centres as the main form of service provision and reform the current practice of individuals transferring straight from school to day centres.

- **Service Flexibility:** Some managers highlighted the need for increased flexibility in service provision, such as extending evening and weekend service provision opportunities. In addition, managers advocated for flexibility in the required number of hours service users were required to work under supported employment programmes. It was anticipated that this would go some way towards enabling less able individuals to participate in employment initiatives.
- **Transport:** Development of transport facilities was perceived as necessary by a number of managers. This included more buses to shorten travelling times; a bus driver to decrease the necessity for staff to drive buses; and an in-house rather than hired bus to reduce costs and increase flexibility.
- **Venue:** Many managers felt that improvements in their service venue were needed. These included increased size, improved facilities and a change of location. Some managers expressed a desire to move away from busy public places, while others felt that integration would be enhanced by a move into the heart of the community.
- **Specialist Provision:** A few managers identified the need for specialised service provision for the elderly and younger service users. Managers also reported plans to develop person-centred planning; to offer a greater range of activities; to expand the current client base; to address unmet need and increase the service throughput; and to increase the viability of small services.
- **Funding:** The need for greater service budgets in order to implement the required developments was frequently reported by service managers.

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## Recommendations

Overall, there was a high level of satisfaction with day services expressed by service users and their carers. During the interviews, users and carers detailed areas of the service with which they were particularly satisfied and ways in which the service was perceived to be beneficial. Such information forms the basis of identifying areas of good practice that should be promoted within day services. In addition, areas of service development were highlighted.



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## VIEWS ON SERVICES AND SERVICE DEVELOPMENT

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cial benefits of the activities they engaged in, including to and from the service, and their interaction with staff members. Opportunities for service users to interact socially with a range of people should be recognised as a method of good practice and should be actively promoted.

- The provision of services to support carers should be increased to meet the high levels of demand. Only 4 carers reported using carer services, but 65% wanted more services to be available to support them in their caring role. These services should include education, advice, and information on caring; direct professional help with caring; and contact with other carers.
- Ways need to be explored to develop greater opportunities for employment-based activities. Service users, carers and managers highlighted the need for an increase in the provision of work experience and employment initiatives. In addition, managers advocated greater flexibility in the required number of hours service users were required to work under supported employment schemes. It was anticipated that this would enable a greater number of individuals, of lower ability, to experience the associated benefits of working. Service users themselves highlighted a number of benefits of working, such as, increased social networks, being occupied and fostering sense of competence.
- The development of opportunities for training and employment within the community should be complemented by the development of community supports such as befriending and drop-in centres.

## Border Cooperation

### SERVICE USER VIEWS

During the face-to-face interviews, service users were asked 2 questions to find out their views on cooperating with day care services across the border. 33 of the 36 service users

**Table 8: Service users prepared to use a service across the border**

	Yes	No	Don't Mind	Don't know
<b>Castledearg</b>	67%	33%	0	0
<b>Castlefinn</b>	60%	20%	20%	0
<b>Garrison</b>	30%	50%	0	20%
<b>Clones</b>	25%	12%	0	62%

responded to these questions. As detailed in Table 8, the greatest support for using a service across the

border came from service users living within the Castledearg area (67%). A slightly lower percentage of individuals living in Castlefinn (60%) said they would be willing to use a service across the border. Garrison had the highest negative response to cross border cooperation, with 1 in 2 individuals stating they would not be prepared to use a service that was located across the border. The majority of individuals living in Clones were uncertain about using a service across the border, with 62% stating 'don't know'.

Reasons for being willing to attend a service across the border included increased access to facilities such as shops and courses, closer proximity to home, and familiarity with the other side of the border (e.g. knowing someone who lived there). Reasons for not being willing to use such a service generally consisted of being happy with the current service. One service user also mentioned the possible difficulty of the currency difference.

In terms of sharing the service they were currently receiving with service users who lived across the border,

**Table 9: Service users prepared to share a service**

	Yes	No	Don't Mind	Don't know
<b>Castledearg</b>	89%	0	0	11%
<b>Clones</b>	87%	13%	0	0
<b>Garrison</b>	60%	20%	0	20%
<b>Castlefinn</b>	40%	0	60%	0

Castledearg had the highest percentage of individuals supporting this proposal (89%, Table 9). Whereas individuals in Clones

were uncertain about using a service across the border, the majority (87%) stated they were prepared to share their service with individuals who lived on the other side of the border. Within the Garrison area, over half (60%) stated they would be willing to share their service. The majority of individuals from the Castlefinn area were somewhat ambivalent about sharing a service with individuals from across the border, with 60% stating they 'didn't mind'.



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in supporting the individual they were caring for to attend and/or share services across the border. 55 of the 58 carers who completed the postal questionnaire responded to these questions. Overall, there was a mixed response from carers regarding the service user attending a service across the border. Support for such an initiative ranged from a low of 31% in Garrison to 60% in Rosslea (Table 10).

**Table 10: Carers prepared to support cross border service**

	Yes	No	Unsure
<b>Rosslea</b>	60%	20%	20%
<b>Castleberg</b>	45%	36%	18%
<b>Clones</b>	40%	15%	45%
<b>Garrison</b>	31%	31%	38%

Reasons given by carers for supporting the use of a day service across the border included: social benefits for the service user; close proximity of their home to the

border (reducing travelling time to the service); the perception that learning disabled individuals are particularly suited to this type of integration as they have fewer prejudices; facilitating North-South relations; providing a new experience for the service user; and having more options and therefore a greater chance of meeting the service users' needs. Carers who supported using a service across the border mentioned previous successful experiences of cross border or cross-community integration. These included enjoying a holiday across the border, originally living across the border, or engaging in cross border activities carried out by the day service. Other factors which carers stated would encourage them to support the use of a suitable cross border service included convenience (proximity of their home to the border, short travel times, provision of transport) and lack of a similar service being provided closer to their home.

Some carers stated that they would not support the use of a cross border service or that they were unsure about using such a service. Reasons for this included being satisfied with the service the person was currently receiving; facilities being better in their own area; service provision being the responsibility of their own side of the border; fear of cut-backs in their current service due to the development of new services; possible limited availability of places in such a service for people coming from across the border; the distance from their home being too great; the Northern Ireland conflict (for those living in the South); and lack of awareness of facilities across the border.

However, even when people were not willing to use a service across the border, the majority (89%) stated that they would be willing to support the person they were helping to share the service they were using with people from across the border. This ranged from all carers in the Rosslea area stating they would support sharing services to 82% of carers in the

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reasons for supporting the sharing of services replicated the social benefits for the service user; and familiarity with the other side of the border. Additional reasons for supporting the sharing of a service included individuals living on both sides of the border having equal rights to or equal need for

**Table 11: Carers prepared to support sharing a service**

	Yes	No	Unsure
<b>Rosslea</b>	100%	0	0
<b>Clones</b>	90%	0	10%
<b>Garrison</b>	86%	0	14%
<b>Castledearg</b>	82%	9%	9%

services; there being no difference between service users from the North and the South of the border; providing a service to people across the border who may have no

provision; and broadening the horizons of the service user.

### MANAGER VIEWS

During the interviews, managers were asked about their experience of engaging with services across the border and the feasibility of further developing cooperation between services North and South of the border.

### Cross Border Experience

In relation to their experience of cross border integration, managers most frequently mentioned occasional link-ups with services from across the border. 11 managers (from the areas of Castledearg, Castlefinn, Rosslea, and Clones) mentioned having participated in occasional joint activities. These included, social gatherings (e.g. coffee mornings), outings or holidays (e.g. a boat trip, a forthcoming international visit), and joint projects (e.g. in drama, arts, and horticulture). In addition:

- 1 service, from the Clones area, had regular link-ups each week with a day service across the border
- 1 service in the Garrison area had a service user from across the border starting as a regular attendee at the service
- The New Horizons project is available to service users on both sides of the border and also integrates service users from the Castlefinn area with those attending a course in Castledearg.

### Cross Border Feasibility

In terms of the feasibility of cross border integration, 15 managers (representing all 6 areas) stated that they would be supportive of individuals from across the border becoming users of their service. However, they often stipulated that this would be dependent upon funding being provided from across the border for staffing and transport. A few managers stated that they would have no capacity to take on further service users, for example, due to limited

the centre. 12 managers also supported the idea of service using a service across the border.

### Advantages of Cross Border Cooperation

The advantages of cross border integration mentioned by managers included social benefits for service users and staff; increased range of opportunities/resources which might be more effective in meeting the needs of the service users; more convenient, efficient, and cost-effective transport in some cases; increased awareness of services and people on the other side of the border; sharing of expertise and ideas; increased funding opportunities (e.g. international funding, local cross border bodies, and input from Health Boards on the North and the South); and facilitation of North-South and cross-community relations. Comments from managers included:

'You've got 2 authorities and you can combine the benefits of both, combine the good points of both, and you can look at one model against the other model and say this is what's working here, it's working in one region better than the other because of X, Y, and Z, and you can influence policy'.

'The interaction between people with different experiences on both sides of the border is obviously going to be beneficial, everybody brings something different from what they've done, what they've seen'.

Managers also emphasised the increased range of opportunities and increased availability of expertise that could arise from accessing facilities and personnel on both sides of the border.

### Difficulties of Cross Border Cooperation

Although managers were generally supportive of developing links with services across the border, they also highlighted a number of issues that they felt could impede cross border cooperation. The most common issue raised was with regard to finance, with managers referring to the need for necessary funding for transport, activities, and staffing. Funding of the service by local statutory bodies was often cited as a reason for the service not being used by individuals from across the border, and managers stated that funding would have to be sought from the authorities across the border to extend their services in this way. Also, a number of managers noted that learning disabled individuals from the South of Ireland can earn more money before their benefits are affected compared to individuals in the North. This has implications for the cross border development of supported employment services. Transport issues were also mentioned, not only in relation to distance but also in relation to the non-applicability of service transport insurance across the border. Managers also referred

g unmet need on their own side of the border. Other of cross border integration were the early stage of development of their own service in general; different service traditions on either side of the border; lack of awareness of services across the border; possible resentment from services across the border (territorial issues); and taking people out of their own communities.

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## Recommendations

Referring back to the mapping exercise at the start of this report, it is evident that there is an imbalance of service provision between the North and South of the border. Service provision in the Rosslea area (north) is less than that in the Clones area (south). Provision in the Garrison (north) area is greater than that in the Blacklion area (south). Services within Castlederg (north) and Castlefinn (south) were more evenly matched. Eliciting the views of service users, carers and managers on the potential for cross border cooperation is a significant exercise for furthering the debate on sharing services between the North and South of Ireland. Based on these views a number of recommendations have been proposed:

### Rosslea / Clones

- The level of service provision in Rosslea is lower than that in the Clones area. Also, travelling times for service users to and from services was longest in the Rosslea area. Therefore, transferring some individuals using services in Rosslea and those travelling to Lisnaskea to closer services across the border would merit further exploration. Encouragingly, Rosslea had the highest proportion of carers supporting the idea of using a service across the border (60%). Unfortunately, there was a low response from service users in Rosslea area and therefore their views on cross border cooperation were not available. The majority of service users and carers in the Clones area were positive about the possibility of sharing their services with people from across the border. The Activation Centre in Clones, in particular, is active in the promotion of cross border activities, and is the closest service to the border.

### Garrison / Blacklion

- Lack of provision in the Blacklion area points to the need to extend services for individuals living within Blacklion area across the border into the North of Ireland. Currently 1 service user from the Blacklion attends a centre across the border in Derrygonnelly. The majority of service users (60%) and carers (86%) in the Garrison area were positive about sharing their services with people from across the border.

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ent of the cross border cooperation already in operation in the Castleberg/Castleinn area (in the form of a cross border training and employment scheme, and occasional link-ups for one-off projects) would gain support from service users (over 60%). Carers from the Castleberg area were less supportive of the person they were caring for attending a service across the border, but were keen for service users from across the border in the South sharing a service with individuals from the North (82%).

- Overall carers were optimistic about sharing services with other service users from across the border. However, there were more mixed views about the service user they were caring for actually using a service on the other side of the border. To further encourage the sharing and utilisation of cross border services, carers' attention should be drawn to the particularly useful or different aspects of the service across the border in comparison to the service currently being used. Carers mentioned that if the service was shown to provide something in addition to the currently available service, they would be more encouraged to support the individual to use the service. The benefits of such a service to the service user could also be mentioned (e.g. the opportunity to make new friends). Attempts should be made to make use of the service as convenient as possible, as this was an important factor for carers when making their decision about whether or not to support use of a cross border service. Concerns mentioned by carers about, for example, service cutbacks in the local area, and the Northern Ireland conflict, should be acknowledged and addressed.
- Occasional cross border integration of services in the form of shared courses, schemes, or outings are likely to be useful in combating uncertainty. The research indicated that familiarity with the other side of the border, through previously successful cross border experiences (e.g. holidays), and awareness of service provision on the other side of the border tended to be associated with positive responses regarding cross border services. Certainly, the majority of service users and carers were positive about contact with service users from the other side of the border, and therefore might support such one-off events. This type of activity should be developed particularly in those areas where service users or carers expressed high levels of uncertainty about the use of cross border services (namely Clones), or where a significant proportion were against the use of services across the border (e.g. Garrison).
- Overall, managers were mindful of the benefits of cross border cooperation and were often keen to develop such integration. The most frequent type of cooperation



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## POTENTIAL FOR CROSS BORDER COOPERATION

casual link-ups with services across the border, but of the cross border use of services on a more permanent basis. This type of development has the potential to alleviate unmet need and over subscription to some services and should be pursued. However, managers identified a number of practical and logistical difficulties that would need to be addressed in order for the cross border integration of services to be successful. Such issues need to be further explored.

This was an ambitious piece of research in terms of conducting a mapping exercise of day services within 3 cross border areas, determining the characteristics of service users and their carers, and eliciting the views of a number of stakeholders regarding the potential for cross border cooperation, all within a 6 month research period. However, over this relatively short period of time a wealth of detailed information has been collated.

- The research has provided up-to-date information on the range of day services that are currently being provided within the cross border areas and has highlighted areas where there is an imbalance in support services north and south of the border. It has provided information on the management and funding of services, the activities carried out at services, the numbers of individuals attending such services, and their staffing quotient.
- The research has detailed the characteristics of individuals using day services, providing relevant information on the increasing age of service users, the distance and time taken to travel to the service they use, and the method of transport used.
- The research has filled a gap in information regarding the carers who support service users attending the day services. The findings from the research point to a group of carers who are mostly aged over 60 years old, and who have genuine concerns over how they will cope with caring as they grow older and how the service user will be provided for. Many of the carers experienced a high level of carer burden and reported poor self-care behaviours. Carers expressed the difficulty they faced in trying to balance the demands of caring with other aspects of their lives.
- The research found that overall both users and carers were very positive about the service they (or the person they cared for) received. With regard to service development, service users, carers and managers highlighted the need for an increase in the provision of work experience and employment initiatives.

The information provided by this research is timely, particularly in relation to assessing user, carer and manager's views on the potential for cross border cooperation, given the growing momentum for developing cross border integration. The research points to the conclusion that service development should not be restricted by the boundaries of buildings or borders. Rather attempts should be made to access all useful opportunities in the community on either side of the border. The research has indicated that initiatives aimed at 'crossing the line' between the North and the South, would receive support from managers, carers, and service users.

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### **Service User Questionnaire**

Service user views were elicited by means of a face-to-face interview using a semi-structured questionnaire. Research findings to date have offered conflicting evidence as to whether open or closed questions are most useful for eliciting responses from learning disabled individuals (see Rikberg Smyly, 1997; Sigelman et al., 1983; Sigelman et al., 1982). Therefore, a combination of question types such as those used by McVilly (1995) were employed. These included open questions ('Tell me about...'; 'Why...?'), yes/no questions, opinion based questions ('What do/don't you like?'), and evaluative questions (participants asked to provide an evaluative rating on a Likert scale (ranging from good/OK/not good/don't know). Where Likert scales were used, visual aids displaying happy, sad, or neutral faces were shown when necessary. Although this method has not always been found to be useful by previous researchers (McVilly, 1995), in the present research the aids did prove valuable and responses selected by the service users tended to be corroborated by comments made later in the interview. The use of follow-up questions and asking for examples also served to check the reliability of evaluations made by service users. This qualitative data increases the credibility of the high levels of satisfaction reported by service users, and decreases the likelihood that these ratings were due to acquiescence or attempts to provide a socially desirable response. Attempts were made to relate questions to personal and concrete events or situations in the service users' lives as it was felt that more abstract questions would decrease response rates.

### **Procedure: Service User Interviews**

Service managers were provided with information leaflets to distribute amongst service users. The leaflet provided information on the research and how the service user could be involved. The leaflets and consent forms were designed to be accessible to learning disabled individuals, following guidelines from Bashford et al. (1995). The service users to be interviewed were chosen by managers on the basis of their ability and willingness to take part in an interview. Consultation with service users with more profound levels of learning disability was therefore limited, although general service evaluations were obtained from a few such individuals. Prior to each interview a service user consent form was read to the service user, who gave their written or verbal consent to take part in the research. The form was co-signed by a member of staff (or, in the case of the service user interviewed at home, his informal carer). Some managers suggested that service user participation in an interview should be subject not only to the consent of the service user but also to the consent of their carer. In such cases a question concerning permission for the service user to take part in an interview was included in the carer survey. If carers were willing for the person they cared

... were asked to provide contact details to the researcher for the user interview.

The majority of service user interviews were conducted on a one-to-one basis. 2 individuals were interviewed together. All but one was interviewed at the service they were using. A member of staff was occasionally present during the interview. Each interview lasted for approximately 20 minutes, although interview length ranged from 5 minutes (in the case of the more profoundly learning disabled) to 30 minutes.

### Carer Survey

The carer postal survey consisted of 1 questionnaire (a short version of the Zarit Burden Interview: Bédard et al., 2001) and a number of smaller scales or questions drawn from the SF-36 (Ware et al., 1993) and the Caregiver Health Survey (Boise, 1999). In addition, the survey included a number of socio-demographic questions, and questions exploring carers' views on learning disability services, carers' services, and cross border cooperation.

The Zarit Burden Interview was originally developed for use with individuals caring for relatives with senile dementia (Zarit et al., 1980), but is easily transferable to other caregiving settings. A number of different versions of the scale have been used since it was originally developed. A short version of the scale developed by Bédard et al. (2001) was chosen in order to reduce demand on participants. This version of the scale was developed with carers of older adults with dementia, but as with the original scale is transferable to those caring for people with learning disabilities. The scale contains 12 questions about the frequency with which respondents experience various aspects of caregiving burden. Each item is scored on a Likert scale from 0 to 4, with a higher score indicating higher burden.

The SF-36 is a generic health measure which measures 8 health concepts, covering both physical and mental health. The 2 scales selected for inclusion in the present survey related to physical health: the 'general health' and 'role-physical' scales. The general health scale provides an evaluation of personal health and anticipation of future health, and the role-physical scale provides information on the extent to which physical health causes problems with work or other daily activities. A higher score on each scale indicates better health.

The items drawn from the Caregiver Health Survey were concerned with the amount of time spent caring, and whether or not carers had neglected a variety of self-care behaviours in the 3 months prior to completing the questionnaire (for example, if they cancelled or missed medical appointments, or failed to get enough rest).

## Interviews

to managers of learning disability day services falling within the research areas. A copy of the map was also provided, and managers were asked to send the survey only to those who lived within the research area. The survey packs contained a prepaid envelope (or stamped envelope for those carers living in the South of Ireland) for return of the survey to the researcher. The survey included a question on whether or not the respondent would be willing to take part in an interview on similar topics. If the carer was willing to take part in an interview, they were asked to provide their contact details so that the researcher could contact them to arrange the interview.

The carer interview covered issues such as caring responsibilities, worries, and concerns; service evaluation; views on the development of services for the person being cared for and the carer themselves; and views on cross border cooperation in learning disability day services. The majority of carer interviews took place in the carer's home, with 1 taking place at the carer's place of work. Each interview lasted for approximately 30 minutes, although the length of interviews ranged from 10 minutes to 1 hour and 15 minutes.

### Manager Interviews

For each of the services identified, a service manager was interviewed for approximately 1 hour to explore issues such as, the activities offered by the services, aims of the service, service size and overlap with other services, and the manager's views on the need for service development and the potential for cross border cooperation of services in the area. For a few services more than one person was included in a manager interview, where that person had substantial input into the running of the service. In a few cases, 1 manager was interviewed in relation to a number of services for which they had direct managerial responsibility.

total of **30** day services were identified across the 6  
ter number of services operating within the North of the  
island in comparison to the South. Managers from each of these day services were  
interviewed to obtain detailed information on the nature of the activities provided; sources of  
funding; management structure; and the number of individuals using the service. The  
following provides a synopsis of each identified service.

**ROSSLEA:** Overall, **3** day services were identified within the Rosslea area.

- **Castlepark Centre, Lisnaskea.**

**Funding:** The service is funded and managed by Sperrin Lakeland Trust, and is provided through Killadeas Day Care.

**Activities:** Activities include physical exercise, voluntary community work, desktop activities, learning skills, college courses, and the use of community facilities. Some individuals are in supported employment, with support provided by a supported employment officer.

**Service Users:** The service caters for 33 service users.

**Staffing:** A day care worker (manager) and 2 care assistants staff the centre.

- **Day Service at Barnlee Residential Home, Lisnaskea**

**Funding:** This service is funded by Sperrin Lakeland Trust, and is managed by a voluntary organisation (Friendship and Caring Trust), which runs the residential home.

**Activities:** Service users take part in the group programmes organised within or through the residential home. These include social activities, use of a therapeutic kitchen and multisensory room, use of community facilities, adult and continuing education, and events organised outside day service hours.

**Service Users:** At the time of the research, 2 individuals were using this day service.

**Staffing:** Staffing ranges between 3 and 4 senior staff and care staff. This depends on the number of individuals in the home on a particular day, and the needs of those individuals.

- **Enterprise Centre, Lisnaskea**

**Funding:** The service is funded and managed by Sperrin Lakeland Trust, and is provided through the Killadeas Day Care.

**Activities:** Activities include physical exercise, voluntary community work, desktop activities, learning skills, college courses, and use of community facilities. Some individuals are in supported employment, with support provided by a supported employment officer.

**Service Users:** The centre caters for 19 service users of lower ability.

**Staffing:** Includes 3 care assistants, 1 day care worker, and 1 senior day care worker.

services were identified within the Clones area.

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- **Cairde Activation Centre, Clones**

**Funding:** The Clones Branch of the Mentally Handicapped Association of Ireland, a voluntary organisation, provides this service in partnership with the North Eastern Health Board. FAS<sup>2</sup> provides the majority of the funding for the service staff.

**Activities:** Activities include arts and crafts (e.g. knitting, finishing off wooden products such as stools made by the centre carpenter, flower arranging, painting, making candles and jewellery); physical exercise (e.g. training for the Special Olympics); adult education; computing; using local community facilities; involvement in community activities such as the Clones festival; and supported employment.

**Service Users:** 15 individuals currently use the service.

**Staffing:** The centre has 6 staff members.

- **Camphill Community Farm Day Service**

**Funding:** Camphill is a voluntary organisation and receives funding from the North Eastern Health Board.

**Activities:** This is a working community, producing goods from the garden, farm, and workshops. Workshop activities include weaving, food processing and candle making. Social outings include visiting craft sales and plant nurseries. Although the focus is upon work, leisure activities are also provided. Day service individuals are invited to evening activities on the farm, such as concerts.

**Service Users:** The farm is primarily residential (with 15 residents). It also offers a day service to 2 local individuals.

**Staffing:** The farm is run by 4 long-term co-workers and up to 11 short-term co-workers. The short-term co-workers generally work at the farm for approximately 1 year.

- **Clogher House, Monaghan**

**Funding:** This centre is funded and managed by the North Eastern Health Board.

**Activities:** The centre provides a range of activities including arts and crafts, tabletop activities, numeracy and literacy, computer skills, swimming, and use of community facilities. A number of service users are in supported employment (e.g. in hotels and department stores). The service users also avail of services at the Monaghan Training Workshop and Horticultural Training Unit. There is a multisensory room and a special care room, which is used for one-to-one care and specific care programmes for those with more severe needs.

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<sup>2</sup> FAS - An Foras Aiseanna Saothair; a government training and employment organisation responsible for the allocation of funding to training agencies involved with people with disabilities.

the service.  
f members (4 nurses and 9 care staff). Additional staff  
work at the centre on a sessional basis (e.g. art teacher).

- **County Monaghan Partnership Supported Employment**

**Funding:** This is a government-funded scheme which is run by the Monaghan Partnership (a limited company set up in 1996 to work on the local development programme, helping the socially excluded develop to their full potential).

**Activities:** The scheme is cross-disability supporting people in work, or in pre-employment activities, such as CV preparation and interview skills. Other individuals are involved in training, and some work on a community employment scheme.

**Service Users:** The scheme has 101 service users on its books, of which 63 are currently involved in the programme.

**Staffing:** An acting team leader and 2 job coaches staff the service.

- **Drumlin House Training Centre, Cootehill**

**Funding:** The centre is run by a voluntary organisation, and receives most of its funding from the North Eastern Health Board. The centre also receives a Department of Education allowance to pay for instructors.

**Activities:** This service provides time-limited foundation training and sheltered work for individuals with learning disability after school and before progression to further training/employment. The rehabilitative training programme lasts for 3-4 years. The centre runs a Training Opportunities Programme covering personal and practical skills designed to take trainees through the transition phase from school to adult life. A fully equipped house beside the centre is used to teach independent living skills. The centre also includes a printing workshop, a craft room, a garden centre, and a kitchen for training in catering. A remedial teacher comes to the centre to teach numeracy and literacy. In addition, supported employment is organised for some trainees. Trainees regularly make use of local community facilities and the service organises day trips and short breaks.

**Service Users:** 31 trainees currently attend the centre. Trainees are usually aged 18 years and over (although a few start aged 16 – 17 years).

**Staffing:** 16 staff members work at the centre, including the centre manager, administrator, driver, caretaker, 5 instructors, catering assistant, and care assistants.

- **Errigal Truagh Special Needs Day Service, Emyvale**

**Funding:** The North Eastern Health Board funds the service. A voluntary committee also undertakes fundraising initiatives to support the service.

ing skills, social integration, computing, literacy and  
and drama, horticulture, physical exercise, sign language,  
relaxation therapy, and aromatherapy. The service also aims to host a social evening and  
weekend activity each week.

**Service Users:** 10 service users currently use the service.

**Staffing:** The service has 2 full-time staff members, a manager and a nurse. The service  
also employs 2 part-time individuals on a community employment scheme (through FAS), and  
hires tutors.

- **Horticultural Training Unit, Monaghan**

**Funding:** The service is funded and managed by the North Eastern Health Board.

**Activities:** Activities include outings to a forest park to collect materials, sowing seeds and  
bedding, making up window boxes, planting flowers, growing vegetables, and producing  
Christmas wreaths. Members of the public visit the unit to collect horticultural materials.

**Service Users:** At present there are 12 service users, with 6 service users attending the unit  
exclusively (others also attend Clogher House day activation unit).

**Staffing:** The unit has 1 manager, 2 care staff and 1 care staff on a FAS social employment  
scheme. Students from the horticultural college provide voluntary staffing.

- **Monaghan Training Workshop, Monaghan**

**Funding:** This service is funded and managed by the North Eastern Health Board.

**Activities:** The service provides sheltered employment to adults with a learning disability.  
This takes the form of 2 catering operations, contract cleaning for the Local Healthcare Unit,  
and Horticultural Grounds Maintenance which is based in the community. The workshop runs  
a computer class and movement to music sessions. A drama project is currently being  
organised in conjunction with a locally based theatre group.

**Service Users:** There are 4 service users based at the workshop. Up to 15 other individuals,  
who are based elsewhere, use the workshop facilities each week.

**Staffing:** The unit has a manager, 3 care staff, and 1 FAS community employment worker.

- **NTDI, Monaghan**

**Funding:** Both the National Training and Development Institute (NTDI) and Rehab Care (see  
below) are part of the Rehab Group. These are cross-disability services catering for client  
groups with different levels of ability. The Rehab group is a private, not for profit  
organisation whose services are 'bought in' by the North Western Health Board.

**Activities:** NTDI is the education and training division of the Rehab Group. The service runs  
3 programmes: Company based training (which focuses on vocational outcomes, such as

level training); Fresh Start (primarily for people who have had a setback); and the Access Programme (a roundabout programme which focuses on personal development). This programme involves IT skills, work sampling in the community, leisure activities, in-house training, overseas trips, compensatory education, psychological support, and crisis intervention.

**Service Users:** 35 service users (15 with learning disabilities) currently attend NTDI.

**Staffing:** 10 staff members work at the centre, a manager, secretary, and a course instructor for every course. Psychologists, remedial resource teachers, and IT tutors are also employed on a sessional basis.

- **Rehab Care, Monaghan**

**Funding:** The rehab organisation runs the service with financial support from the North Eastern Health Board.

**Activities:** This is a sheltered workshop which carries out contract work for industry (e.g. packaging, upholstery). The service also provides in-house literacy and numeracy, computing, swimming, use of community facilities, and short breaks.

**Service Users:** The service currently caters for 40 service users, 90-95% of whom are individuals with learning disabilities.

**Staffing:** Staffing includes a supervisor, an assistant supervisor, and a canteen worker. Students occasionally volunteer with the service on a job scheme during the summer months.

<b>GARRISON:</b> Overall, <u>6</u> services were identified within the Garrison area.
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- **Buttermarket, Enniskillen**

This unit is situated within a small craft centre and is run by a day care worker (managed from Lackaboy 1, see below). 11 service users currently attend the unit.

- **Lackaboy Centre 1, Enniskillen**

**Funding:** The service is funded and managed by Sperrin Lakeland Trust.

**Activities:** The centre incorporates 2 separate units. The activities are aimed at developing individuals' social skills, independent living skills, and educational skills. Activities include outings into the town centre, leisure activities, supported employment, and teaching in Fermanagh College (e.g. woodwork, art, pottery, and health and safety, with NVQ qualifications available). Occasional evening activities are also organised. Service users at the other 3 Enniskillen centres also carry out these activities.

**Service Users:** 17 individuals use the centre.

**Staffing:** A senior day care worker manages this centre, the Buttermarket, and Kent Plastics. In addition, there is 1 day care worker and 2 care assistants.



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en managed by Sperrin Lakeland Trust.

**Activities:** This is the core unit for all of the Killadeas Units within County Fermanagh. Activities carried out are the same as those mentioned above in Centre 1.

**Service Users:** The service caters for 11 service users with more profound disabilities.

**Staffing:** The unit is staffed by 1 manager, 1 senior day care worker, 1 day care worker, 2 care staff, 2 catering staff, and 1 day care worker who is responsible for supported employment. A secretary on site provides secretarial services for all the Killadeas services.

- **Kent Plastics, Enniskillen**

The service provides sheltered work in the Kent Plastics factory for 10 service users. The scheme is supervised by a care assistant under the supervision of the senior day care worker who is attached to the Lackaboy 1 Centre (see above).

- **Strule Erne Day Care, Derrygonnelly**

**Funding:** This service is funded and managed by Sperrin Lakeland Trust.

**Activities:** The service offers a variety of activities, including, art therapy, drama, beauty therapy, hairdressing, aromatherapy, reminiscing, craft, flower arranging, discussion groups, use of community facilities, and talks on road safety and crime prevention.

**Service Users:** The service is designed for adults aged over 60 years who have a learning disability. It currently caters for 6 service users.

**Staffing:** The service is staffed by 2 day care workers, and is managed by the 2 managers of the Drumary House residential home in Derrygonnelly.

- **Tir Navar Day Centre, Derrygonnelly**

**Funding:** The service is funded and managed by Sperrin Lakeland Trust, and is provided through the Killadeas Day Care.

**Activities:** A range of activities is offered including a recreational programme, supported employment (e.g. playgroup assistant, ironing for a local residential home), college courses (e.g. beauty therapy, computing, civics, catering), and a social programme.

**Service Users:** This centre caters for 16 service users of mixed ability.

**Staffing:** The centre is staffed by 1 senior day care worker (who manages the centre), 1 day care worker, and 1 care assistant.

service was identified within the Blacklion area.

- **North West Supported Employment Partnership Programme**

**Funding:** This is a cross-disability programme which is run by a consortium, consisting of the North Western Health Board, Donegal Supported Employment Service, Leitrim Partnership Board, and Leitrim Association of People with Disabilities. Funding is provided from FAS.

**Activities:** A vocational profile is created through consultation with the individual and support is given to enable the individual to obtain employment. Individuals who find employment have an employment contract and receive the minimum wage. To be involved in the programme potential employers must adhere to a set of criteria. For example, employers need to have adequate insurance and a safety statement; they have to take part in monitoring; and must be willing to allow job coaches on site.

**Service Users:** Prospective service users must be interested in, and capable of, working for a minimum of 15 hours per week. The service currently has 24 learning disabled individuals.

**Staffing:** Staffing comprises 1 coordinator, 9 job coaches, and 1 project officer (part time).

**CASTLEDERG:** Overall, **7** services were identified within the Castlederg area.

- **Castlederg Centre (Garden Corner)**

**Funding:** The centre is funded and managed by Sperrin Lakeland Trust.

**Activities:** This satellite, or outreach centre offers a range of activities including, social training, recreational activities, a vocational programme (offering supported employment such as tidying and packing shelves in local shops), numeracy and literacy skills, and participating in arts, crafts and computing at a local College.

**Service Users:** The service caters for 17 service users (3 part-time and 14 full-time).

**Staffing:** 1 manager and 2 care assistants staff the centre, with occasional assistance from voluntary staff.

- **Glenside Adult Training Centre, Strabane**

**Funding:** The centre is funded and managed by the Foyle Health and Social Services Trust.

**Activities:** Courses on woodwork, catering, social skills, and computing are made available to service users through the local College. Social training is also provided through supporting individuals to use local community and leisure facilities. Individuals are also supported to participate in the Special Olympics. Some individuals are in supported employment organised by the centre, or are engaged in programmes offered by Pathway and New Horizons.

**Service Users:** This day centre caters for 83 service users.

staff members, including 1 manager, 1 senior day care assistants, and a clerical officer. Occasionally voluntary staff members also work at the centre.

- **Gortin Centre, Gortin**

**Funding:** The service is funded and managed by Sperrin Lakeland Trust.

**Activities:** Some service users are in supported employment organised by the centre (e.g. caretaking in a community centre) and others work in the Garden Corner shop at which the service is based. Activities include recreation; courses on topics such as art and cookery at Omagh College; ASDAN (Award Scheme Development and Accreditation Network); NVQ level training where appropriate; making hanging baskets; computer skills; writing; visiting shops, cafes and the library. Occasional day trips are also organised by the service.

**Service Users:** At present 9 service users attend the centre,

**Staffing:** 1 day care worker and 1 care assistant staff the service. Occasionally technical college students have voluntary work placements at the centre.

- **New Horizons**

**Funding:** New Horizons is largely funded by European monies (including Interreg) and is investigating sustainability strategies for when this funding is no longer available. For example, the Foyle Trust now funds 10 places, and resource materials have been developed and marketed to other organisations in order to generate income.

**Activities:** The is a cross border training, supported employment, and enterprise partnership between the Foyle Trust, North Western Health Board, National Rehabilitation Board, Disability Action, and Ashbrook Organic Farm. The 3 aspects of the service are viewed as developmental stages along which service users can progress. These are combined in a catering project which involves training on food hygiene, independent travel, and appropriate work behaviour. The catering project is provided in partnership with the Orchardville Society and North West Institute for Further and Higher Education. New Horizon offers accredited qualifications in horticulture, conservation, and catering. In addition, supported employment is provided in retail, catering, playgroups, factories, administration, and libraries.

**Service Users:** New Horizons is aimed at a variety of groups such as the long-term unemployed and individuals with mental health difficulties. However, at present, the majority are learning disabled individuals. The number of individuals using the service varies each month due to people moving between courses, but ranges between 40 and 60 per month.

**Staffing:** Core staffing consists of 6 people, with an additional 3 to 4 seconded staff.

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Project between Pathway and the North West Institute of Further and Higher Education. The service is managed by Mencap (a voluntary organisation) and is funded by the Foyle Trust, the Training and Employment Agency, and the European Social Fund.

**Activities:** Pathway is an employment placement service with the aim of providing service users with paid employment or long-term voluntary employment. Training is provided on work skills and travelling. Job sampling is also arranged, which includes work in retail, catering, horticulture, administration, and domestic work. The work placements are voluntary, with payment only being possible when individuals come off their benefits. Pathway encourages employers to pay travel expenses, but will pay these if necessary. Support and monitoring of work placements is provided until no longer needed. The Pathway service runs other programmes including, getting school leavers into employment and NVQ courses in partnership with the North West Institute for Further and Higher Education. Mencap has also recently become a provider of the Job Brokering Service (through the New Deal for Disabled People programme), which is a nationwide scheme aimed at individuals with a higher level of ability than those in Pathway. The scheme provides support with job search skills, creating CVs, help with applications and interviews, and support at work.

**Service Users:** The service is for people living in the Foyle Trust area who are interested in working and capable of developing work skills. This service has a total of 41 individuals.

**Staffing:** 1 employment officer and 1 assistant employment officer staff the service.

- **Prospects Day Care, Castlederg**

**Funding:** Mourne Community Care manages the service, and it is funded by Sperrin Lakeland Trust.

**Activities:** This day centre was initially set up to cater for a mental health client group. In 2000 the service was extended to provide a service 1 day per week for individuals with a learning disability. The centre offers service users craftwork and social activities. In addition, carers of individuals have an opportunity to participate in activities and to receive support and advice from statutory workers visiting the centre.

**Service Users:** At the time of the research, the service was catering for 5 service users.

**Staffing:** 1 project manager and 1 project worker are employed at the centre.

- **Strabane Day Centre, Strabane**

**Funding:** This cross-disability centre (including mental health, dementia, and elderly individuals) is funded and managed by the Foyle Health and Social Services Trust.

**Activities:** The centre offers a programme of activities such as healthy eating, first aid, cookery, gardening, self-care, exercise, quizzes, music therapy, theme evenings, social skills

on, shopping, and arts and crafts. Evening outings are  
are engaged in supported employment through the  
Pathway project and in courses at a technical college.

**Service Users:** 14 individuals currently attend the centre.

**Staffing:** The centre is staffed by 1 manager, 1 senior day care worker, 5 care assistants, and 1 voluntary bus driver.

<b>CASTLEFINN:</b> Overall, <b>5</b> services were identified within the Castlefinn area.
---

- **New Horizons**

Detailed above under the Castledearg heading.

- **NTDI, Lifford**

**Funding:** The Department of Health and FAS fund this training centre.

**Activities:** The centre runs 3 training programmes: Skills Foundation, Employer Based Training (EBT), and Distance Learning (DL). The Skills Foundation is a centre-based course, which is funded by the Department of Health. It offers remedial teaching on topics such as health and safety, numeracy and literacy, and also offers skills sampling through work experience. The course runs for 30 hours per week and lasts for approximately 2 years. Completion of this course informs selection for more vocationally focused training. The EBT and DL programmes are based in the community and are funded by FAS. Within the EBT programme, individuals are based in a variety of employment settings for between 6 to 16 months. All individuals attend the centre once per week to participate in activities such as, computing, relaxation, drama, and art and design (with some opportunities for certification).

**Service Users:** Individuals must be approved as suitable for training by the appropriate funding and monitoring body. There are currently 7 trainees on the Skills Foundation course, 24 individuals on the EBT programme and 24 individuals are on the DL course.

**Staffing:** 3 part-time staff members run the Skills Foundation course and 2 instructors provide the EBT programme.

- **Rehab Care, Lifford**

**Activities:** Most individuals are involved in sheltered employment within a small commercial unit (e.g. sewing, packing). As a recent development, a few individuals are in supported work in the community (e.g. cleaning in a nursing home, packing shelves in a shop). The service is currently undergoing a conversion into a cooperative workshop. This will result in participation being optional, as it will be less target-driven than the current commercial workshop, and any profits will be made available to the individuals. Other activities are offered, for example, assisting individuals with hygiene, and finance management.



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...tly learning disabled) currently use the service.  
...members, 1 Community Service Manager and 1 Assistant  
Supervisor. There are plans to recruit 2 more staff members. Voluntary help is available  
through a government-run summer student scheme, where students are employed in the  
centre and the service is reimbursed for their salaries.

- **Sean O'Hare Unit, Stranorlar**

**Funding:** This centre is funded and managed by the North Western Health Board.

**Activities:** The centre runs a variety of activities including numeracy and literacy; drama  
therapy; horticulture; beauty therapy; swimming and horse riding; supported employment;  
visiting local shops; hill walking; arts and crafts; and performing in an annual pantomime.

**Service Users:** The unit currently caters for 38 service users.

**Staffing:** The centre employs 5 members of staff. A small number of additional staff work  
part-time through the FAS scheme.

- **North West Supported Employment Partnership Programme**

Detailed above under the Blacklion heading.

## Analysis

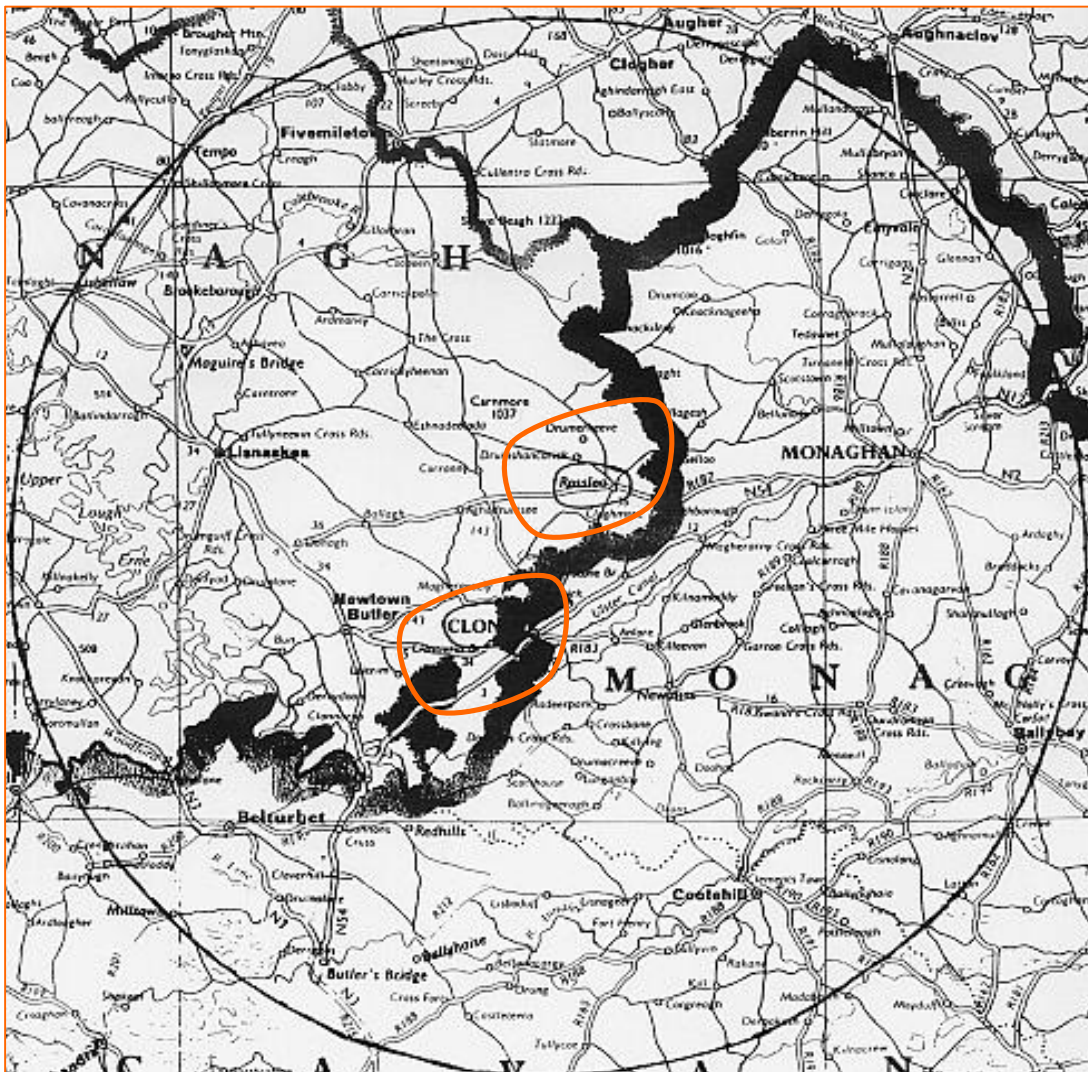
- Service user age differed significantly by area (Chi-square = 11.3;  $p < .05$ ).
- Average time spent travelling from place of residence to the service (one-way) varied significantly across the geographical areas (Chi-square = 28.5;  $p < 0.5$ ).
- Carer general health as assessed by the SF-36 was significantly related to age ( $\rho = -.346$ ;  $p < .05$ ).
- The average age of those who reported taking medications improperly in the 3 months prior to completing the questionnaire was higher than those who did not report doing so ( $z = 1.979$ ,  $p < .05$ ).
- Those who had failed to stay in bed when ill scored significantly lower on both general health ( $z = 2.237$ ,  $p < .05$ ) and role-physical ( $z = 2.384$ ,  $p < .05$ ), as did those who had eaten poorly ( $z = 2.678$  and  $z = 3.625$  respectively,  $p < .05$ ), and those who had put off recreational activities they enjoyed ( $z = 4.308$  and  $z = 3.956$  respectively,  $p < .05$ ).
- Significantly lower role-physical scores were produced by those who stated that they had put off going to the doctor ( $z = 3.413$ ,  $p < .05$ ), and by those who had postponed getting regular medical checkups or examinations ( $z = 2.846$ ,  $p < .05$ ), failed to get enough rest ( $z = 2.322$ ,  $p < .05$ ), had taken medications improperly ( $z = 2.119$ ,  $p < .05$ ), and had failed to get enough exercise ( $z = 2.186$ ,  $p < .05$ ).
- Data analysis revealed that carer burden scores were significantly higher for those who had cancelled medical appointments ( $z = 2.008$ ,  $p < .05$ ) and those who had put off recreational activities ( $z = 2.111$ ,  $p < .05$ ).

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## Areas

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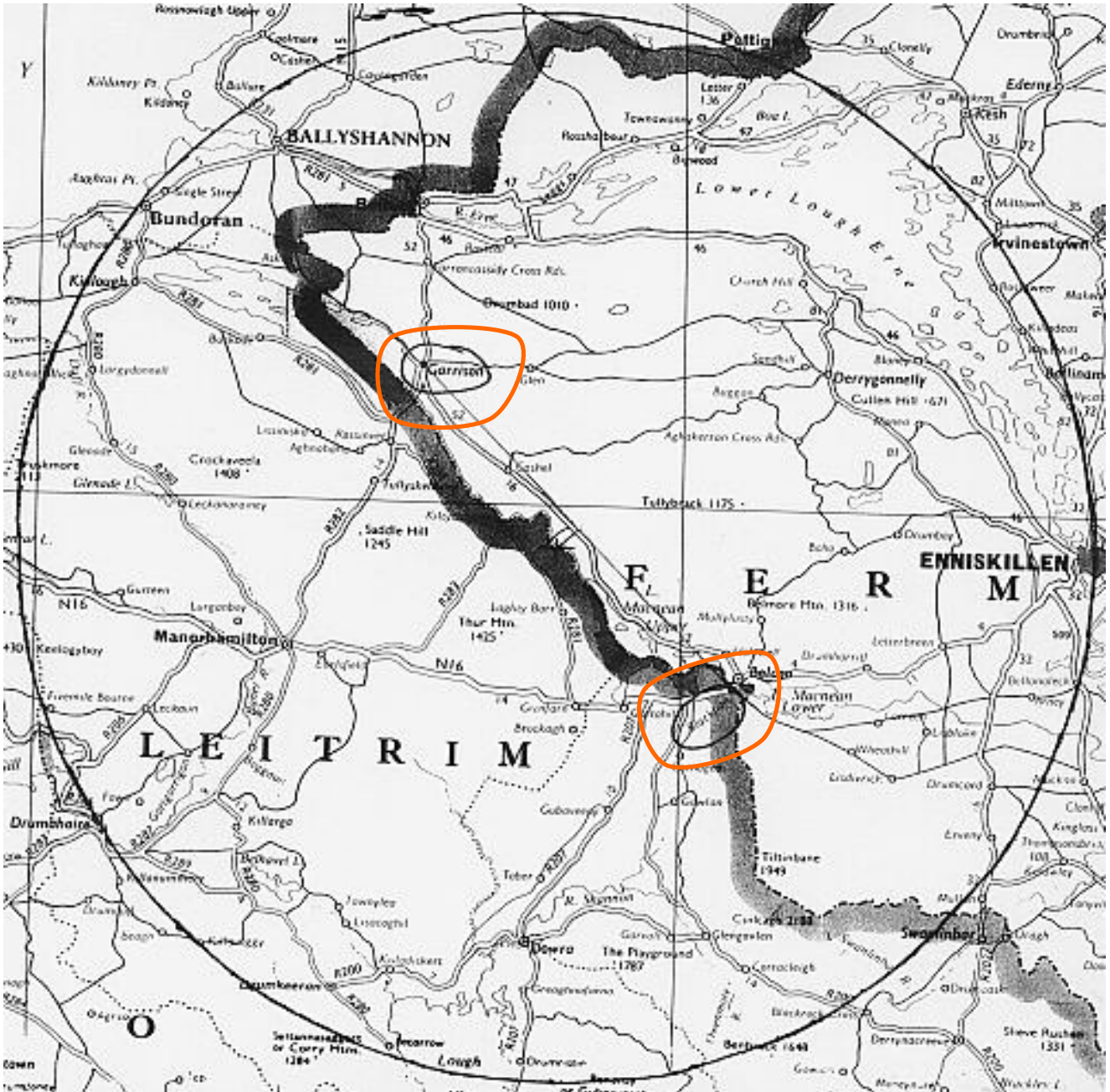
Map of **Rosslea** (Co. Fermanagh, N. Ireland) and **Clones** (Co. Monaghan, S. Ireland),  
outlining the 15 mile radius.





... (Co. Wick, S. Ireland) and **Blacklion** (Co. Cavan, S. Ireland),

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Ireland) and **Castlefinn** (Co. Donegal, S. Ireland),

