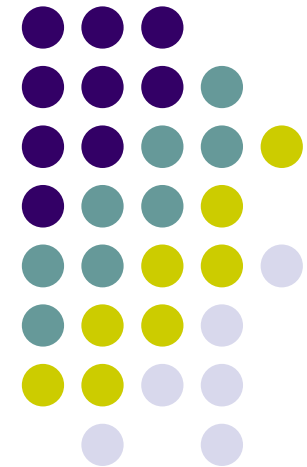


Traumatic Brain Injury Service Development Project 2001 - 2002

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Occupational Therapist



Discussion Points



- Purpose
- Process
- Results
- Conclusions
- Key Issues
- Recommendations

Aim of the Study



To Highlight Local Service Needs By:

- Identifying the existing services available to clients with traumatic brain injury and their carers
- Surveying these services with a view to identifying any gaps
- Consulting with interested clients and carers living in the South Lanarkshire Council Area

Proportion of Staff Interviewed



Total Number of Services **24**

Total Number of Staff Members **98**

40% Specialist

25% Local Office

16% Community Mental Health Teams

8% Day Centre Staff

8% Young Physical Disability Teams were interviewed.

Admissions to NHS from South Lanarkshire Council Outcomes According to Age : Figures Quoted Per Annum



Age	Under17	17-25	26-35	36-45	46-55	Over 55	Total
Actual Incidence	195	108	95	77	71	183	731
*Severe	5	3	3	2	2	5	20
*Moderate	12	6	6	5	5	11	45
*Mild	163-195	90-108	79-95	64-77	56-71	152-183	604-731

*Estimated according to Headway National Statistics

Figures according to information received from; ISD Scotland, Hospital & Community Information Unit using the World Health Organization's International Classification of Diseases 10th Revision (ICD10) for period April 1997 and March 2000.

Common Causes



National & Local percentages generally matched

- RTA being most common at 47%
- Domestic and Industrial injury at 30%
- Higher Percentage of Assaults and a
- Lower Percentage of Sports Injuries were reported locally

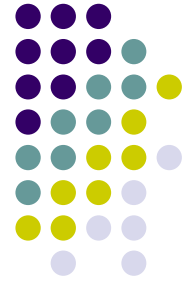
Local Age Ranges



Compared with ICD (10) figures:

- Significantly few under 17's
- Lower percentage of under 25's
- Higher percentage of 26 to 55 years
- Similar percentage of over 55's

Local Population Incidences

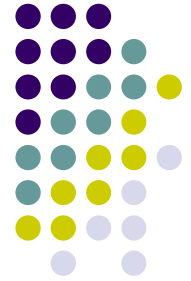


Total Population of SLC: 307,400

Total Population of known clients: 159

- Clydesdale seems to have a higher than expected incidence
- East Kilbride a lower than expected incidence

Response Rate



Participants were sought through existing Services, Health Boards, Hospitals, GP Practices, Local Press, Adverts & Poster Campaign.

Total Number of Information Sheets Sent 1039
(Requested 139)

Total Number of Completed Interviews 103 (74% of those requested)

Total Number of Completed Interviews 103

57 Client Interviews

46 Carer Interviews

Ratio 5 men to 1 women

Carers



- Spouses/partners (50%) and
- Sons/Daughters (41%) were main carers
- 43.5% reported having other dependants
- 61% were lone carers
- Half were over 55 years

Length of Time Providing Care & Hours Spent Caring per Week



- Most have Cared for between 1 to 5 and 11 to 20 years
- Over Half Care for over 35 hours per week
- With 70% inclusive Caring for over 21 hours

Caring for someone with a brain injury is described in literature as stressful, challenging and long term.

Type of Difficulties Reported



- Cognitive

concentration, decision making, memory, planning

- Mood

depression, anxiety, panic, anger, irritability

- Behaviour

inappropriate, impulsive, childish, passive, aggressive

Support Provided by Carers



Practical Assistance with:

- Cooking
- Shopping & Housework
- Budgeting
- Travel

Prompting

Advocating

Assistance with Socialising

The family have been widely cited in literature as the principle support system for clients.



Home Care

Services highlighted that Home Care:

- Provided mainly housework
- Needed to change to offer social support
- Needed to adopt an enabling role

Private Home Care was described as:

- Financially motivated
- Lacking in staff consistency, supervision and training

Clients Social Circle



- The Majority of clients (70%) reported having a close friend.
- Most (60%) socialise Alone or with Family
- 84% of Clients highlighted that their ability to socialise is limited
- 66% of services identified client isolation

Clients Living Situation



- Majority previously stayed with Parents
- Now the majority stay alone
- Slightly less stayed with spouses/partners
- Less stayed with spouses/partners and children

Previous studies identified that marriages were under considerable strain due to brain injury

Carers Well Being



- Approx 80% reported experiencing a range of negative emotions to an irregular extent
- Services (46%) also highlighted carer strain
- Just less than half reported a diagnosed disability
- Just over half felt that their health had deteriorated due to the caring role

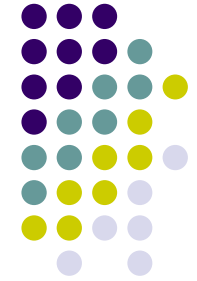
Carer strain is widely recognised in literature



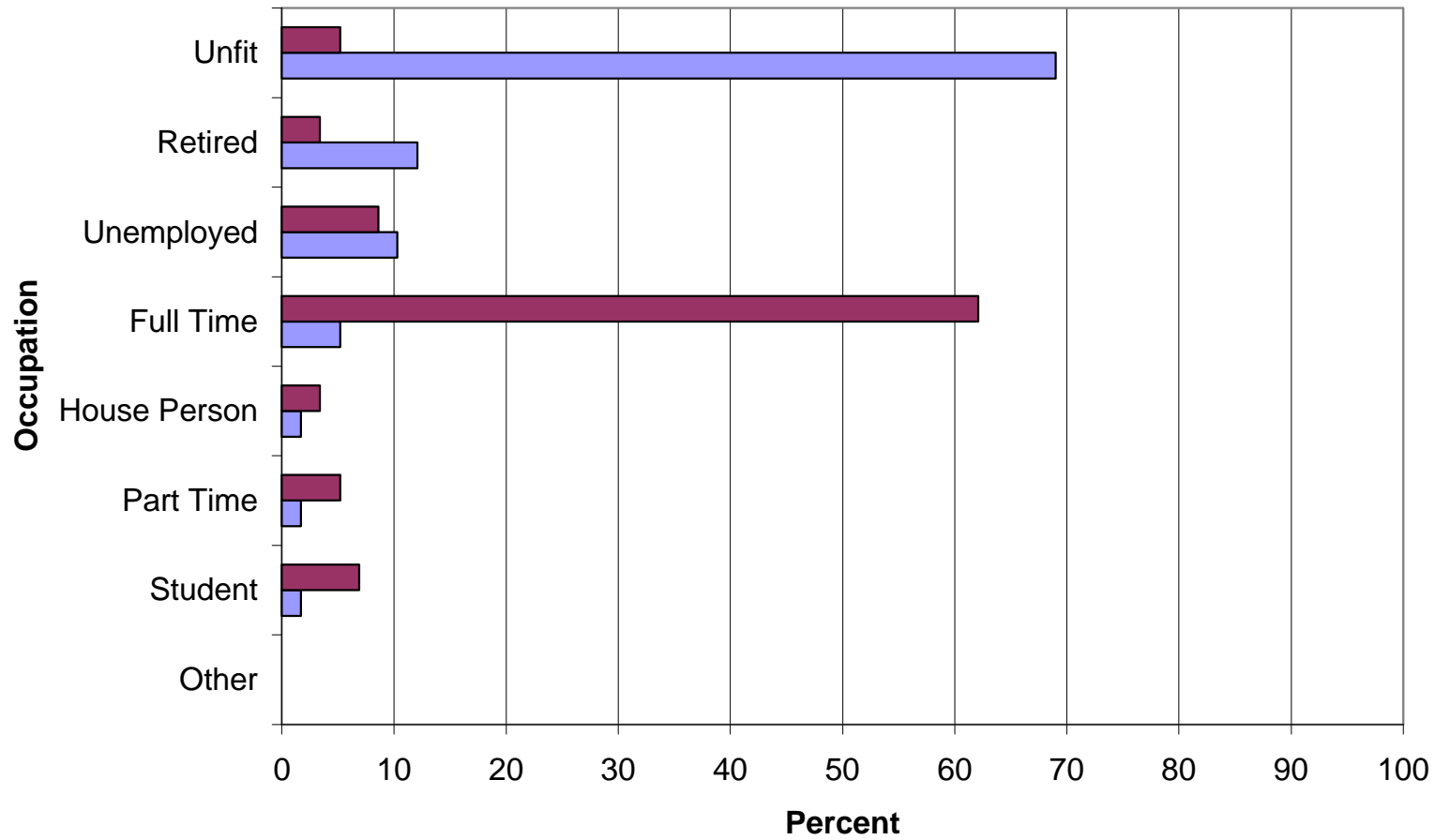
Client Occupations

- Significant decrease in those in Full Time Employment
- Significant increase in those now unfit for work
- 71% felt that their job prospects were severely affected by the injury
- The vast majority would like to return to varying types of work

Clients Occupations



Clients Occupation



Benefits



- Services at just less than 50% identified that finance was a major difficulty for clients
- 21% highlighted that clients had difficulties attaining benefits as brain injury is considered temporary & is largely unseen
- Carers (67%) also highly rated the need for assistance with benefits

The complexity of brain injury is little understood within the current benefits system

Carer Occupations



- Only half of those in full time before remain in full time employment
- Decrease in those in part time employment
- Most now describe themselves as housewives/husbands or retired

Carer Prospects

- Equal percentages (40%) considered their job prospects were severely affected as not affected
- Majority requested no opportunities but some requested volunteer, study, full and part time

Hospital Services



- A large percentage of clients and carers did not receive services at inpatient stage
- This decreased markedly at outpatient stage

The most frequently requested services at this stage were:

- Social Work
- Psychology
- Occupational Therapy
- Counselling

Hospital Services



The most frequently received services at this stage were:

- Neurology at 60%

Access to multidisciplinary assessment was poor

- Approx 45% received Physiotherapy
- Less than 29% gained access to any other member of the team
- 5% received Psychology & Counselling

Teasdale et al also found that despite the majority of his study having mental sequelae PT was the most frequently offered service

Hospital Services



- Over half clients and carers were not given information on brain injury
- 3 clients & 5 carers were given leaflets on brain injury
- Few (17%) were aware of a discharge plan
- Fewer (12%) were involved in the discharge plan
- Fewer (9%) were advised of support services after discharge

Hospital Services



Hospital Social Work

- 80% of clients and carers were not contacted by social work after injury
- Just over 80% did not receive a social work assessment at this stage.
- 93.5% of carers have not received a carers assessment

Hospital Services



Literature identifies that:

- Rehab is medically effective, cost effective & lacking
- Neuropsychological management & multidisciplinary assessment are rare although essential
- Clients are often discharged without sufficient rehab

Stages of Recovery



- The majority of specialist staff felt that clients/carers had difficulty accessing services at all stages of recovery
- The majority of non-specialist staff felt that clients/carers had difficulty accessing services once in the community
- All agreed that clients/carers had most difficulty once living in the community for a few years

Community Services



Altogether few clients have received many community services.
Local Services were utilised regardless of appropriateness

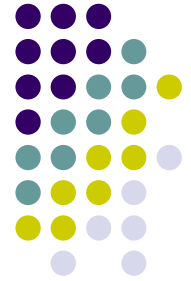
The most frequently received services were:

- Community Occupational Therapy at around 40%
- Social Work at just less than 40% and
- Residential Rehabilitation at around 30%.

22% of clients and 15% of carers reported currently receiving social work input

A recent Glasgow based study found that 15% had social work contact

Community Services



The most frequently requested services by clients and carers at this stage were:

- Headway
- Social Work
- Job Retraining
- Befriending

Carers also highlighted a need for

- Counselling
- Community reintegration

Community Services



Support groups and befrienders were infrequently highlighted as a need by interviewed services (20%).

However most services identified the need for:

- Structured Daily Activity
- Improved Rehabilitation
- Specialist Service
- Localised Services

Community Services



Literature widely supports the lack of service provision highlighting:

- General service provision
- Clear policies
- Early rehabilitation
- Community integration
- Long Term support
- Rehabilitation as and when required
- Inappropriate placement
- Access to respite
- Funding

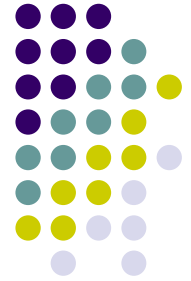
Community Services



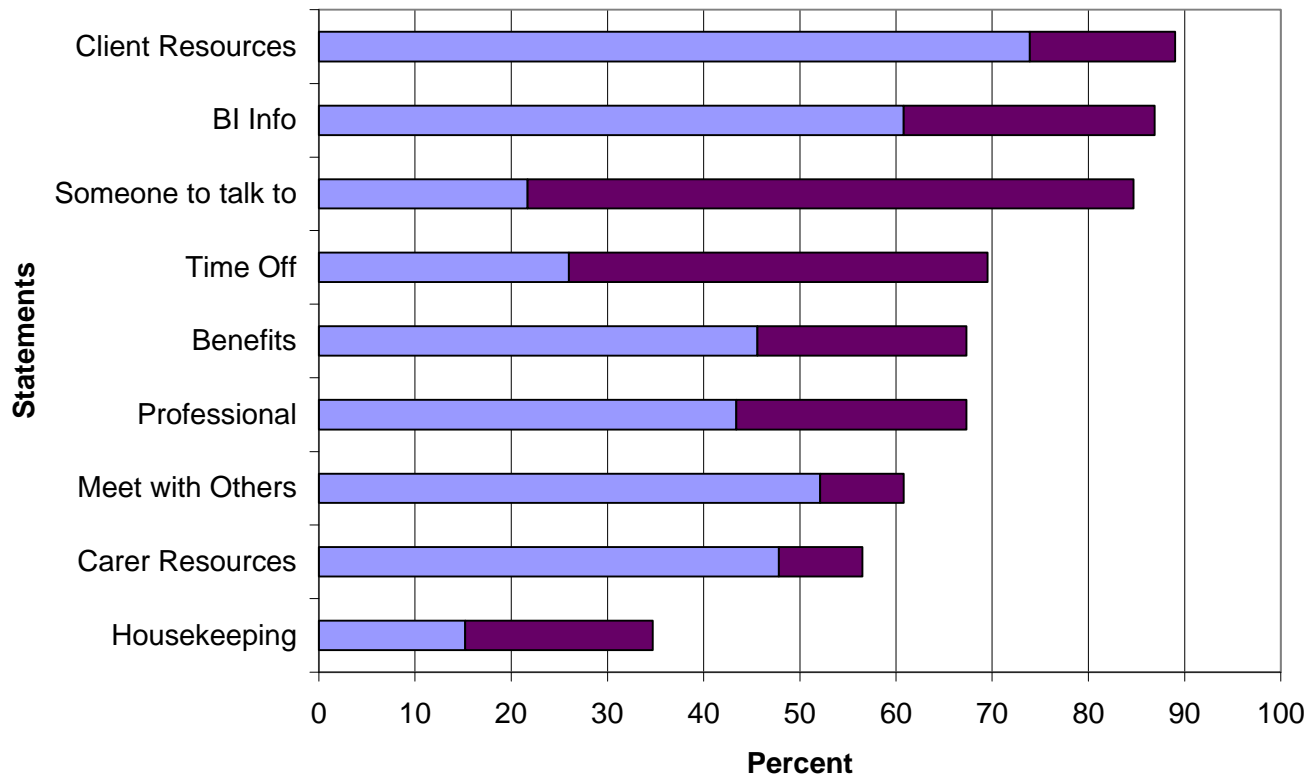
Recommendations from Literature include:

- Specialist multidisciplinary outreach teams
- Localised ABI services
- Regional specialist advisors

Carers Important Statements



'Important' Statements Met & Not Met





Joint Working

75% of interviewed services identified the need for improved joint working

Local Offices (83%) reported that joint working improves:

- Education
- Discharge planning
- Social Work involvement

Majority of Local Office's (67%) felt that clients:

- Accept the need for medical & physical interventions (NHS)
- Are reluctant to accept the need for social, emotional & psychological support (SW)

Joint Working



Specialist services (45%) reported that Social Work were inadequate raising:

- Time taken to respond
- Being rarely involved
- Resource led assessment

All Local Office's expressed ignorance on the part of colleagues in health regarding the benefits of social work involvement.

Client & Carer Suggestions



- Coordinators
- Separate client/carer groups
- Specialist ward staff
- Social clubs
- Information packages

Lack of communication was extensively highlighted in literature. Coordinators and advocates are recommended.



Conclusions

There is extensive agreement between literature, services, clients and carers on:

- General lack of services & resources
- Lack of coordination & communication
- Unseen cognitive, mood and behavioural difficulties being most common
- Most often extensively, practically and emotionally supported by family
- Long term & stressful

Key Issues



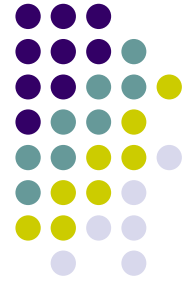
- 242 potential service users identified; 160 potential clients & 54 carers
- Completed interviews represented 67 (42%) of known clients
- 15 – 22% currently have social work input
- Potential increase of identified clients if care pathways are improved. Possibly 461 people annually with long term moderate/severe disability.

NHS



1. Specialist management by consultant & experienced ward staff
2. Multidisciplinary assessment with early access to; social work, psychology, occupational therapy and counselling
3. Coordinator identified early
4. Access to residential rehabilitation
5. Outpatient multidisciplinary assessment & treatment
6. GP training in brain injury and effects

Joint NHS & Social Work



1. Clearly defined care pathways
2. Headway leaflets
3. Information leaflets on resources
4. Consultant led regular multidisciplinary clinic meetings

Social Work



- Case coordination managed locally
- Specialist workers *
- Home care to provide social support
- Use of Rehab Scot work related programmes
- Specialist training of welfare rights officers
- Further reviews of; residential and children's needs

Specialist Workers



- Keep database of clients & carers
- Attend hospital clinics
- Provide information, advise & support
- Training
- Create & update information pack/ resources
- Work jointly with Volunteer agencies in developing & supporting new local groups *
- Facilitate volunteer service
- Specialist Occupational Therapy service
- Advertise new service
- Produce & run library of information