

## THE SOCIAL NETWORKS OF OLDER PEOPLE WITH LEARNING DISABILITIES LIVING IN STAFFED COMMUNITY BASED HOMES

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### Introduction

There have been a number of attempts to conceptualise and measure social relationships for people with learning disabilities. For example, Newton *et al.* (1994) suggest that a person's social life may be described on four dimensions: their personal or social network, their pattern of social interactions, the stability of relationships and the social support offered within these relationships. The interactions within a social network can be examined on several dimensions; for example their size, frequency of contact, function, context and durability (Storey, 1993). Studies have described networks for particular groups of people with learning disabilities. For example, adolescents (Siperstein and Bak, 1989), people living in British community homes (e.g. Seed, 1990), people living with their natural families (Krauss *et al.*, 1992) and people in competitive employment (Knox and Parmenter, 1993). Several studies have

highlighted that improving and maintaining relationships for people who have recently left hospital is particularly difficult (e.g. Dagnan *et al.*, 1995; Atkinson, 1986). However, maintaining relationships is important from both a normalisation perspective (e.g. O'Brien and Lyle, 1987) and because a range of positive outcomes, such as the moderation of the impact of severe life events on psychological and physical health have been associated with social support (e.g. Gollay *et al.* 1978; Ganster and Victor, 1988; Cobb, 1977; O'Connor, 1983).

Increased longevity had lead to a growing number of older people with learning disabilities (Hogg and Moss, 1993; Hogg *et al.*, 1988; Day and Jancar, 1994). There have been several studies of the physical and mental health of older people with learning disabilities (e.g. Day and Jancar, 1994), however, there have been fewer studies of their social networks (Seltzer, 1985). Hogg and Moss (1993) carried out a survey of the characteristics of 122 people with learning

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disabilities with a mean age of 63.5 years living in Oldham in Great Britain. They report the informal social networks of this group in the two categories of family and friends. They found that, although few people had living parents, 67.5% of people living in the community had contact with family members as did 62.1% of people living in hospitals. Contact with family did not differ significantly according to age, functional ability or home type. Between 41.9% and 85.7% of people living in different types of community homes had contact with people without learning disabilities, although only 10.3% of people living in hospital had such contacts. Functional ability was related to contact with people without learning disabilities although this was difficult to separate from the effect for home type. Krauss and Erickson (1988) studied the informal social networks of 49 people with learning disabilities who were all over 40 years old, had at least one monthly contact with a family member and could provide information in a brief interview. They compared features of networks for people living with family, in staffed community homes or institutions. They found that people living in these home types had contact with a mean of 5.7, 9.3 and 9.2 respectively. Krauss and Erickson (1988) categorised support as either personal/emotional (e.g. listening to problems, giving advice, giving emotional support), recreation (e.g. spending leisure time together) and formal (e.g. helping the person in their contacts with services). They found that for people living in all home types the family provided most support of each type. They found that some features of social networks differed considerably between

people living with their family and those living in staffed homes. In particular they noted that those people who lived at home had fewer people in their networks and spent more time in activities with members of the family than did people living in staffed houses or institutions.

Other studies have examined factors that influence the nature of social networks for people with learning disabilities. For example, Kennedy *et al.* (1990) studied 20 people with severe learning disabilities with a mean age of 39 years. They found that the size of networks and the number of family members was highly associated with the number and variety of activities within and outside the home. Krauss *et al.* (1992) studied 418 adults with learning disabilities with a mean age of 33.6 years who lived with their families. They found that they had a mean of 7.1 people in their social networks, these were mainly made up of family members. They also found that people who had severe or profound learning disabilities had fewer people in their social networks and that men had fewer friends and fewer same sex friends than did women with learning disabilities.

Here, we report on the social networks of 52 older people with learning disabilities living in community-based residential homes for three or four people in Solihull. The description of social networks for older people with learning disabilities who have recently left hospital is of particular interest. It is likely that the family of such people will be older and that relationships will have been harder to maintain over the years they have been in hospital. The participants have a mean age of over 60 and are all

ex-residents of hospitals for people with learning disabilities. In this paper we describe the frequency of contact and nature of support offered within social networks. In particular we describe data on the support offered in leisure activities as these have been identified as important for older people with learning disabilities (Hogg, 1994). Where possible, data are presented that allow comparison with previous studies of social networks of older people with learning disabilities.

## Method

### *Participants*

The participants were 52 people with learning disabilities living in small staffed homes in Solihull. The group is made up of 40 (78%) men and 12 (23%) women, with an average age of 63.6 years (SD = 12.6). Six (11.5%) of the group were aged between 40 and 49 years; 20 (38.5%) between 50 and 59; 9 (17.3%) between 60 and 69 and 17 (32.7%) were over 70 years old. All had previously lived in hospitals for people with learning disabilities. At the time of the study they had been living in their present homes for a mean of 3.3 (SD = 1.2) years. The group were assessed using the Wessex Scale (Kushlick *et al.*, 1973), which is a brief disability rating scale. TABLE I shows the characteristics of the group in categories derived from this scale.

### *The Home*

The participants lived in 15 three and four bedroom staffed houses in Solihull

in the West Midlands. The homes are traditional family houses, where necessary adaptations have been carried out to provide facilities for people with physical disabilities. The homes always have one member of staff on duty and the residents receive a home-based community oriented day service. This service supports residents in activities within and outside the home according to their preferences (McEvoy *et al.*, 1993). People living in these homes have been shown to have a high quality of life, measured using the *Questionnaire on Quality of Life* (Cragg and Harrison, 1986) and participate in a range of activities in the local community (Dagnan *et al.*, 1995). Solihull is a metropolitan borough on the outskirts of Birmingham, UK. It has a population of 220,000 people.

### *The Social Network Questionnaire*

The questionnaire was an adaptation of the measure used by Krauss and Erickson (1988) and covered the following areas.

1. The number of family members, co-residents or co-workers, friends with learning disability who are not co-residents or co-workers, and others (e.g. advocates, friends without learning disabilities) with whom the person with learning disabilities has contact.
2. The number of contacts a year with members of a person's network. Contact was coded as by letters, phone calls and visits.
3. The type of support received from each person. This was coded, following Krauss and Erickson (1988) as personal/emotional (e.g. listening to

**TABLE I**  
**Characteristics of Participants Using Categories Derived from the Wessex Scale (1973)**

Category	Number	Percent
<b>Incontinent</b>		
Severely incontinent		
Mildly incontinent	19	36.5
Continent	33	63.5
<b>Mobility</b>		
Non-ambulant	4	7.7
Partly ambulant	14	26.9
Fully mobile	34	65.4
<b>Self-help</b>		
Not able	6	11.5
Partly able	27	51.9
Able	19	36.5
<b>Literacy</b>		
Not literate	44	84.6
Partly literate	4	7.7
Literate	4	7.7
<b>Speech</b>		
Not verbal	8	15.4
Some verbal disability	17	32.7
No verbal disability	27	51.9
<b>Sensory Impairment</b>		
Some sensory impairment	23	44.2
No sensory impairment	29	55.8
<b>Challenging behaviour</b>		
Severely challenging	3	5.8
Mildly challenging	13	25.0
Not challenging	36	69.2

problems, giving advice, giving emotional support and helping with personal care), recreational/leisure (e.g. celebrating birthdays, visiting places in the community, doing tasks) and formal (e.g. managing financial and legal affairs, representing the person at meetings). All responses were coded by the two authors.

4. The person who accompanied the study participant most during leisure activities within and outside the home. The activities used in this part

of the questionnaire were those for which participation is recorded in the *Questionnaire on Quality of Life* (Cragg and Harrison, 1986; Dagnan *et al.*, 1994; Dagnan *et al.*, 1995).

#### *Procedure*

The social network questionnaire was completed between April 1994 and June 1994. Where possible the questionnaires were completed in one session for each person. Questionnaires were

completed in a group interview with key residential staff, day service staff and, where possible, the participants themselves.

## Results

In total there were 48 (92%) people with learning disabilities with at least

one person in their social network. The mean number of people in a social network was 3.1 (SD = 2.1). TABLE II presents the characteristics of the social networks. Twenty-seven (52%) people with learning disabilities have some form of contact with family or co-residents. Fifteen people (29%) have contact with people without learning disabilities; of these 6 people (12%) have

**TABLE II**  
Details of Contact within Social Networks

	Mean	SD	Range	People with at least one such contact	
				Number	%
<b>Family</b>					
Number of people	1.2	1.4	0 - 5	27	52
Annual number of contacts					
by phone	22.7	44.0	0 - 208	18	35
by letter	6.0	14.5	0 - 72	20	38
in person	18.0	35.5	0 - 156	24	46
<b>Co-resident</b>					
Number of people	0.7	0.8	0 - 3	27	52
Annual number of contacts					
by phone					
by letter					
in person	235.4	279.8	0 - 1095	27	52
<b>Friends with a learning disability</b>					
Number of people	0.9	1.3	0 - 4	22	42
Annual number of contacts					
by phone	3.4	11.4	0 - 52	5	10
by letter	1.5	7.4	0 - 52	5	10
in person	45.7	124.0	0 - 736	22	42
<b>Other people without a learning disability</b>					
Number of people	0.3	0.5	0 - 2	15	29
Total number of contacts					
by phone	3.1	10.7	0 - 52	6	12
by letter	0.3	1.2	0 - 8	4	8
in person	16.4	54.7	0 - 365	15	29
<b>Total Network</b>					
Number of people	3.1	2.1	0 - 8	48	92
by phone	20.1	27.9	0 - 104	29	56
by letter	5.5	11.7	0 - 55	28	54
in person	264.3	262.0	0 - 1203	48	92

**TABLE III**  
**Number of Participants Receiving Support from within Social Network**

	Personal Support		Formal Support		Recreational Support	
	Number	%	Number	%	Number	%
Family	19	37	7	13	10	19
Co-residents	27	52	1	2	7	13
Friends with a learning disability	20	38	2	4	12	23
Others	11	21	4	8	5	10
Total	45	87	12	23	25	48

**TABLE IV**  
**People who Take Part in Leisure Activities with Participants**

Activities	Family		Co-residents		Friends with learning disability		Others without learning disability	
	n	%	n	%	n	%	n	%
Public House	3	6	17	33	5	10		
Bingo			4	8				
Cinema	1	2	10	19				
Church	1	2	11	21			1	2
Holiday			18	35	4	8		
Walking			16	31	1	2		
Club/Societies			6	12				
Adult Education			4	8	2	4		
Watching Sports			7	13				
Playing Sports			2	4				
Visiting Others	9	17	6	12	1	2		
General Outings	2	4	19	37	4	8	1	2
Dances			19	37	4	8		
Swimming			1	2				
Playing records			8	15	2	4		
Table Games			11	21	1	2		
Hobbies			5	10	5	10	1	2
Entertaining Guests	1	2	9	17	2	4		
Gardening			3	6			2	4

contacts with advocates. The mean annual number of written, phone and face-to-face contacts with family is 46.7 (SD = 79.7), with co-residents is 235.4 (SD = 279.8), with friends with a learning disability is 50.5 (SD = 125.0) and with others is 19.8 (SD = 56.6). More residents

receive visitors than receive phone calls or letters. TABLE II also shows the average number of times a year members of social networks write, telephone and visit.

TABLE III shows the type of support participants received from members of

their social networks. The most common type of support is personal and emotional. The number of residents who engage in the leisure activities listed in the *Questionnaire on Quality of Life* (Cragg and Harrison, 1986) with members of their social networks is shown in TABLE IV. Most people take part in activities with co-residents; fewest take part in activities with people without learning disabilities.

### Further Analysis

A series of t-tests was carried out to compare the total number of contacts experienced by participants in the year in each of the network categories across gender and two composite variables, derived from the Wessex Scale. One variable was created that divided the group into 19 (37%) people with full self-help skills and 33 (63%) people who do not have full self-help skills; this variable is referred to as ABLE following Kushlick *et al.* (1973). The second variable divided created two groups, one of 45 (87%) people who do not have a major disability in incontinence, mobility or challenging behaviour and one of 7 (13%) people who do have such disability; this variable is referred to as CAN following Kushlick *et al.* (1973). These data are shown in TABLE V; there are no significant differences in any of these comparisons. The age of participants was also correlated with the number of contacts made with people in each of the network categories. Pearson's  $r$  for the correlation of age with the total number of contacts with co-residents was 0.11 (ns), for the correlation of age with the total number of contacts with friends

with learning disabilities it was -0.01 (ns) and for the correlation of age with the total number of contacts with others it was -0.01 (ns). The only significant result was a negative correlation between age and the total number of contacts with family (Pearson's  $r = -0.37, p < 0.01$ ).

## Discussion

This paper has described the social networks of 52 older people with learning disabilities living in small community-based staffed homes in Solihull. We have identified both the size of social networks and types of contact. These data can be compared with those from other studies. Krauss and Erickson (1988) selected people with a lower age limit of 40 years, who had at least monthly contact with families and who could communicate in a brief interview. Given the selection criteria, it is likely that the data presented in their paper are not representative of older adults with learning disabilities living in community homes in Britain. The data here can be compared better to those on contact with family and friends presented by Hogg and Moss (1993). The two studies show a similar level of contact with family but the participants in the present study have less contact with people without learning disabilities and more contact with co-residents. These differences are due to a number of factors. The participants in the present study had previously lived in hospital and so have not had opportunities to form relationships in the community. Many participants did not originate from the area in which they now lived and this will affect the ease by which family

**TABLE V**  
**Comparisons of Total Number of Contacts in Each Social Network Group for Gender, and two Dichotomous Variables Based upon the**  
**Wasssex Scale**

	Gender				ABLE				CAN								
	Men		Women		Full Self-help skills		Not full Self-help skills		No Disability		Major Disability						
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD					
Family	41.1	70.8	65.3	195.7	-0.70		49.4	89.3	45.2	75.0	0.18		49.3	84.4	29.9	37.3	0.60
Co-residents	227.8	280.1	260.7	289.9	-0.22		318.3	328.8	187.7	239.9	1.65		231.5	283.3	260.7	275.9	-0.25
Friends with a learning disability	49.5	130.4	54.0	110.1	0.06		85.0	181.2	30.8	72.9	1.53		54.7	132.4	24.0	58.4	0.60
Others	22.7	62.3	10.7	30.2	0.81		5.1	28.2	22.6	68.0	-0.46		19.6	59.7	22.0	31.6	-0.11

contacts can be maintained. Contact with friends with learning disabilities who were not co-residents often represents the maintenance of relationships formed in hospital. In the houses studied a particular effort had been made to maintain such relationships.

Particular attention has been paid to participation in leisure activities with members of the social network. Most participants took part in the listed leisure activities with other people who lived in their homes. The next most frequent groups with whom participants took part in leisure activities were other people with learning disabilities followed by family members. Few people took part in leisure activities with people who did not have learning disabilities. It has been suggested that for older people with learning disabilities leisure is one aspect of their lives in which there can be a sense of continuity (e.g. Hogg, 1994). In addition, it has been suggested that, as they get older, people's needs for social contact will increasingly be met in leisure activity (Kelly, 1983). In the present study 87% of people have relationships fulfilling an emotional support function and 47% have relationships fulfilling a leisure support function. These functions may be seen as particularly important for older people (Kelly, 1983). Very few residents have advocates or friends without learning disabilities. It is important that ways of offering the opportunity to develop such relationships are considered (e.g. Richardson and Riche, 1989; Firth and Rapley, 1990). Although not included in this analysis it was often reported that close relationships had been formed with staff members. It is important to acknowledge that many staff members in small

community homes provide support for residents beyond their defined role, such as taking part in activities with residents in their own time. However, it was difficult to reliably define where the professional role ended and the personal relationship began. Therefore, only relationships with other than paid staff have been considered in this paper. It is important not to assume that larger social networks and greater levels of contact are better for all residents. The quality of a person's social life will be influenced by their preferences for activity and contact. The person's satisfaction with elements of their social network is considered in some measures. For example, Power *et al.* (1988) present the Significant Others Scale which measures both actual and preferred levels of support from significant people in the person's social network. This perspective on social networks has not been researched for people with learning disabilities. The degree of choice that people had over activity and social contacts will be explored in future papers.

This paper has provided information relating to the size, structure, functions and support offered in leisure activity of the social networks of older people with learning disabilities who have previously been hospital residents. The data suggest that relationships with family and friends who have learning disabilities can be developed and maintained in community services when older people leave hospital and that variables such as the level of disability need not have an effect upon relationships. However, the development of relationships offering emotional and recreational support from people without learning disabilities has happened slowly. Further information

about how relationships between older people with learning disabilities and others are developed and maintained and their role in enabling leisure activity would be useful in making recommendations about how best to improve the quality of social networks.

## Summary

This paper reports a study of the social networks of 52 older people with learning disabilities living in small community-based, staffed homes. We report the number of people in the networks, who they are and the frequency and type of support they offer with particular emphasis upon support in leisure activities. The relationship of age, sex and disability with number of contacts with people in the social network was explored. The only significant relationship indicates that older people have fewer contacts with their families.

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