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Friendship Activities of Adults with Intellectual Disabilities in Supported Accommodation in Northern England

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Background Despite there being considerable evidence to suggest that friendships are central to health and well-being, relatively little attention had been paid to the friendships of people with intellectual disabilities.
Methods Friendship activities involving people with and without intellectual disabilities were measured over the preceding month in a sample of 1542 adults with intellectual disabilities receiving supported accommodation in nine geographical localities in Northern England.
Results The results of the study indicate: (1) low levels of friendship activities among people with intellectual disabilities in supported accommodation; (2) people with intellectual disabilities are more likely to be involved in activities with friends who also have intellectual disabilities than with friends who do not have intellectual disabilities; (3) most friendship activities take place in the public domain rather than in more private settings (e.g. at home); (4) the setting in which a person lives is a more significant determinant of the form and content of activities with their friends than the characteristics of participants.
Conclusions Further attention needs to be given to research and practice initiatives aimed at increasing the levels of friendship activities of people with intellectual disabilities.

Keywords: friendships, relationships, social networks, supported accommodation

Introduction

Apart from the enjoyment and opportunities provided by friendships, regular contact with friends has also been recognized as an important determinant of positive physical and psychological health (Brunner 1997; Sarason *et al*. 1997; Department of Health 1998; Marmot & Wilkinson 1999; World Health Organization 2001).

Somewhat surprisingly, however, the friendship needs and aspirations of people with an intellectual disability have attracted relatively little attention in either research or policy and practice (Felce 1988; Amado 1993; Llewellyn 1995; Prescosolido 2001). As Bayley (1997) suggests 'Friendships for people with learning difficulties often appear to count for little in the estimation of those who control their lives. In some cases, administrative neatness seems to count for more…' (p. 94). The apparent discounting by researchers and professionals of the importance of friendships stands in marked contrast to the expressed concerns of people with intellectual disabilities, who consistently report that making friends and participating in activities with their friends are among the most important issues of concern to them (Racino 1999; Knox & Hickson 2001; Read 2002; Cummins & Lau 2003; McVilly K., Parmenter T., Stancliffe R. & Burton-Smith R., unpublished data). For example, Froese *et al*. (1999) reported that 81% of their participants with an intellectual disability wanted to have more friends and 65% indicated they wanted the opportunity to develop a 'best friend' relationship.

There is some evidence, however, from recent policy initiatives to suggest that the importance of friendships is becoming increasingly recognized. Recent English policy, for example, has concluded that 'people with learning disabilities are often socially isolated. Helping people sustain friendships is consistently shown as being one of the greatest challenges faced by learning disability services. Good services will help people with learning disabilities develop opportunities to form relationships' (Department of Health 2001a, p. 81).

The available evidence suggests that for many people with an intellectual disability the opportunity to make friends and spend time with friends appears limited (Berkson & Romer 1980; de Kock *et al.* 1988; Lowe & de Pavia 1991). For example, Bulm *et al.* (1991) reported for that, while over 70% of respondents with developmental disability expressed a desire to marry, only 7% of respondents reported having an opportunity to maintain a 'steady relationship' with a best friend. Robertson *et al.* (2001) reported that the median size of participants' friendship networks (excluding staff) to be just two people. These findings are consistent with those of earlier studies. Finally, the Australian National Consumer Satisfaction Survey (Steering Committee for the Review of Commonwealth/State Service Provision & National Disability Administrators 2000) reported that up to 32% of persons living in larger accommodation services indicated they had no friends. Across all service types approximately 40% of participants indicated that they either did not have friends or only had friends 'sometimes'. Of those participants reporting to have a friend, only 24% reported having a friend who was neither a family member nor a paid worker.

If services are to more effectively support the friendship needs and aspirations of people with an intellectual disability, there is a need to understand the key factors influencing the formation and maintenance of friendships. In particular, what aspects of people's lives facilitate or hinder friendship and participation in activities with friends? The current study builds upon earlier work examining the social ecology of adults with an intellectual disability (Landesman-Dwyer *et al.* 1979; Berkson & Romer 1980; Berkson 1981) that have sought to investigate both the individual characteristics of participants and the environmental features of support services that have the potential to influence participants' interpersonal affiliations.

Method

Sampling

The data were collected between 2000 and 2002 across 10 geographical localities in Northern England in the context of audit-based reviews of the quality of supported accommodation (Bliss *et al.* 1999). Supported accommodation included all forms of support provided to enable people with intellectual disabilities to live outside their family home. It included examples of supported living, group homes, hostels and cluster housing. Of the nine areas, six fell within the 20% most socially deprived districts in England, two within the 21–40% most deprived and two within the 41–60% most deprived (Department for the Environment, Transport and the Regions, 2000). Within each area, sampling strategies were determined by local managers. These included sampling all people with intellectual disabilities receiving supported accommodation from a particular provider organization and a variety of random and non-random sampling strategies. Information was collected on a total of 1542 adults with intellectual disabilities. The number of participants per locality ranged from 42 to 373. Given sampling was undertaken by local organizations in the context of service audit, it was not possible to determine response rate.

Measures

The 'North West Audit of Quality in Residential Supports' (Bliss *et al.* 1999) involves the collection of basic information from a key informant (e.g. keyworker, first-line manager) on the characteristics of people with intellectual disabilities and the nature of the residential support they receive prior to a visit by an external audit team. Areas covered in the audit were determined following a range of focus groups of key stakeholders: people with intellectual disabilities, support staff, professional staff and managers (Bliss *et al.* 1999). Specific items were selected by a steering group comprising of researchers, people with intellectual disabilities, family carers, professional staff and managers. The pre-visit information includes: demographic information, measures of the structural characteristics of the person's home, the 'Index of Community Involvement' (ICI: Raynes *et al.* 1987, 1994;) and the 'Learning Disability Casemix Scale' (LDCS: Pendaries 1997).

The ICI measures the frequency of use within the preceding 4 weeks of a variety of community resources. It has been shown to possess acceptable internal consistency (Cronbach's alpha = 0.70; Raynes *et al.* 1994) and to discriminate between activity patterns shown by the residents of institutional and community-based provision (cf. Emerson & Hatton 1996a). The ICI was extended for the present study by including six questions related to specific friendship activities (having a friend to stay over in your home, staying over with a friend in their home, having a friend around for a meal, going out for a meal with friends, going out on a day trip with friends, being visited at home by friends). For each of these items, information was collected separately for friends who themselves had learning disability and friends who did not have Learning Disability giving a

Table 1 Characteristics of participants and settings

	n	*Percentage*
Age (mean age = 49.3 years, SD = 15.5)		
18–24	72	5
25–34	199	13
35–44	337	23
45–54	328	22
55–64	298	20
65–74	164	11
75+	93	6
Gender		
Men	824	54
Women	693	46
Ethnicity		
White	1485	98
S Asian	9	1
Black	10	1
Other	10	1
Adaptive behaviour		
Most able	504	36
Moderately able	443	32
Least able	441	32
Challenging behaviour		
No/little	646	55
Moderate	377	32
Severe	143	12
Sensory impairment		
Yes	221	18
Epilepsy		
Yes	434	29
Size of setting (number of co-residents)		
1	66	5
2–3	494	35
4–6	743	52
7–9	57	4
10+	74	5
Type of setting		
Participant home owner	5	<1
Participant holds tenancy	835	61
Small residential home	102	8
Larger home (4+ residents)	270	20
Nursing home	53	4
NHS provision	42	3
Adult placement	52	4
Dispersal/location		
Dispersed in community	1211	86
Campus/cluster housing	194	14
Type of prior residence		
Residential child setting	49	3
Family	304	20
Group home	178	12
Hostel	124	12
Residential/village community	114	8
Institution	491	33
Other	191	13

total of twelve items. These additional 12 items demonstrated acceptable levels of internal consistency (corrected alpha = 0.64).

The LDCS is a simple 23-item behaviour-rating scale of adaptive behaviour and challenging behaviour. The scale has acceptable psychometric properties including good convergent validity with the 'AAMR Adaptive Behavior Scale' (Nihira *et al.* 1993) and acceptable levels of inter-informant and test–retest reliability (Comas-Herrera *et al.* 1999).

Participants

Information on the characteristics of the participants and the nature of the residential support they received is presented in Table 1.

Results

Friendship activities

Table 2 presents summary data on friendship activities across the full sample, over a 4-week period. The median number of occurrences of all friendship activities with friends with intellectual disabilities was 2. The median number of occurrences of friendship activities with friends without intellectual disabilities was 0.

There were no statistically significant differences between the number of times participants stayed over with friends with or without intellectual disabilities. For all other categories of friendship activities, reported number of occurrences was greater with friends who

Table 2 Percentage of participants engaging in types of friendship activities in the preceding 4 weeks

Item	*Friends with intellectual disabilities*	*Friends who do not have intellectual disabilities*
Having a friend to stay over*	1.8	0.5
Staying over with a friend	1.4	1.6
Having a friend round for a meal*	15.8	4.1
Going out for a meal with a friend*	44.8	14.1
Having a day trip out with friends*	44.8	11.1
Being visited at home by friends*	22.6	12.6
Any of the above	65.3	25.3

*Mean number of occurrences reported as significantly greater ($P < 0.001$) for friends with intellectual disabilities, than for friends without intellectual disabilities.

had intellectual disabilities when compared with friends who did not have intellectual disabilities (having a friend to stay over in your home: Wilcoxon's $z = 4.17$, $P < 0.001$; having a friend around for a meal: Wilcoxon's $z = 9.94$, $P < 0.001$; going out for a meal with friends: Wilcoxon's $z = 16.12$, $P < 0.001$; going out on a day trip with friends: Wilcoxon's $z = 17.78$, $P < 0.001$; being visited at home by friends: Wilcoxon's $z = 7.62$, $P < 0.001$; total activities Wilcoxon's $z = 19.66$, $P < 0.001$).

Binary logistic regression (forward conditional variable entry, $P_{entry} < 0.05$, $P_{exit} < 0.1$) was used to identify variables associated with presence in the preceding 4 weeks of (1) friendship activities with friends with intellectual disabilities and (2) friendship activities with friends without intellectual disabilities. Candidate predictor variables are listed in Table 3. Results of the analyses are presented in Table 4.

Corrected odds ratios (ORs) given an indication of the extent to which positive categorization on a particular predictor variable is associated with positive categorisation on the dependent variable, when the effect of all other variables is taken into account. Thus, for example, the results in Table 4, once the effects of other variables are taken into account, participants supported by organizations in locality B were 70% more likely to have participated in friendship activities than participants supported in other localities. Nagelkerke 'pseudo' r^2 is in index, similar to r^2 in multiple regression, of the extent to which the predictor variables 'account' for variation in the dependent variable.

As can be seen, the identified variables were only weakly or moderately related (individually corrected OR <2 and overall, Nagelkerke 'pseudo' r^2 <0.1) to friendship activities. However, three points are worthy of note. First, in both analyses setting characteristics were more strongly related to outcomes than participant characteristics (combined OR of 3.8 and 1.3 for activities with friends with intellectual disabilities, 5.2 and 1.6 for activities with friends without intellectual disabilities, respectively). Second, only one variable (greater levels of adaptive behaviour) was associated with increased probability of participating in activities with friends who did and did not have intellectual disabilities. Finally, while the overall model accounted for little 'variance' in group membership, all individual variables were associated with at least a 20% increase in the chances of participating in friendship activities.

Table 3 Candidate predictor variables

Participant characteristics
Age (18–24, 25–34, 35–44, 45–54, 55–64, 65–74, 75+)
Gender (male, female)
Ethnicity (White, South Asian, Black, Other)
Epilepsy (yes/no)
Adaptive behaviour (LDCS) (most able, moderately able, least able)
Challenging behaviour (LDCS) (no/little, moderate, severe)
Reported mental health problem (yes/no)
Sensory impairment (yes/no)
Type of previous accommodation (family home, group home, hostel, institution)
Setting characteristics
Supporting local authority
Number of hours per week attending day/work programme
Whether attends segregated day programme for adults with intellectual disabilities
Housing and support provided by different organizations
Staffing ratio within home
Registration status of home (small home $n < 4$; registered care home $n > 4$; nursing home)
Participant has legal tenancy
Number of co-tenants
Crude annual staff turnover
Housing provided as part of cluster
Reported staff role (friend, advocate, teacher, crisis manager, social co-ordinator, transport provider)
Participant has individual plan

Table 4 Variables associated with presence of friendship activities within preceding 4 weeks

Variable	*Corrected odds ratio*	P-*value*
Friends with intellectual disabilities*		
Supported by organizations in locality B	1.70	0.003
Not living in Registered Nursing Home	1.58	0.034
Staff role of advocate	1.40	0.002
More able	1.25	0.004
Friends without intellectual disabilities†		
Staff role not being transport provider	1.52	0.027
Previous type of accommodation was a hostel	1.49	0.019
Staff role of crisis manager	1.40	0.006
Participant holds tenancy	1.37	<0.001
Not having severe challenging behaviour	1.26	0.004
More able	1.25	0.006
Lower levels of staff turnover	1.22	0.013

*$n = 815$; model $\chi^2 = 42.8$; d.f. $= 4$; $P < 0.001$; Nagelkerke $r^2 = 0.076$.

†$n = 883$; model $\chi^2 = 61.3$; d.f. $= 7$; $P < 0.001$; Nagelkerke $r^2 = 0.097$.

Discussion

The results of the study indicate: (1) what may be considered to be low levels of friendship activities among people with intellectual disabilities in supported accommodation; (2) people with intellectual disabilities are more likely to be involved in activities with friends who also have intellectual disabilities than with friends who do not have intellectual disabilities; (3) most friendship activities take place in the public domain rather than in more private settings (e.g. at home); (4) the setting in which a person lives is a more significant determinant of the form and content of activities with their friends than the characteristics of participants.

These results do, however, need to be treated with a degree of caution. First, while the sample size is relatively large, due to the sampling procedure it cannot be assumed to be representative of all adults with intellectual disability receiving supported accommodation in England. Comparison with available national data suggests that study participants: were marginally older (mean age 49.3 years in the present study, 45.4 years in the UK 1991 Census: Emerson & Hatton 1996b); contained a representative proportion of men (54% in the present study, 55% in the UK 1991 Census: Emerson & Hatton 1996b); were living in slightly smaller units (mean size 4.5 in the present study, 6.1 in England in 2001: Department of Health 2001b). No national information is available to judge the extent to which our sample was representative with regard to ethnicity. The representativeness of samples is, of course, a major problem faced by virtually all research undertaken in the field of intellectual disability.

Second, while the data collection utilized several instruments with acceptable psychometric properties, the additional friendship items had only a marginally acceptable internal consistency. As noted, items were selected by a steering group comprising of researchers, people with intellectual disabilities, family carers, professional staff and managers. There were, however, no further checks on the extent to which these items reflected the friendship activities or aspiration of people with intellectual disabilities. In addition, no normative data is available on these items. No within-study check was made on the reliability or validity of data collection.

Third, the category 'friend' was self-defined by individual participants. As such, it is likely that there were potentially significant inter-informant variations with regard to who was included in this category. Finally, we were only able to examine associations between a restricted range of predictor variables and friendship activity.

Nevertheless, the results are generally consistent with the existing literature with regard to what may be considered the limited number of friendship activities (e.g. Robertson *et al*. 2001) and the relative importance of setting factors (as opposed to personal characteristics) in accounting for variation in level of friendship activities (e.g. Romer & Berkson 1980; Robertson *et al*. 2001). The latter point suggests that intervention at a systems level would appear critical to the promotion and support of friendship for people with intellectual disabilities, rather than simply to focus on the development of social skills of individuals (Goldstein 1999).

Two and a half decade ago, Gershon Berkson drew attention to the need to consider friendships when developing and evaluating services: 'We tend to emphasize size of facility, hours spent in programming, staff to client ratio and other easily countable variables on the assumption that we are at least defining the necessary conditions for a decent standard of life. There seems to be no objection to doing that. But, I am concerned that we have become so involved with these issues that we have sometimes failed focus on some of the things we all know to be important' (Berkson 1980, p. 4). More recently, in reflecting on the development of services and what it means to foster an inclusive society, Reinders (2002) has proposed, 'ultimately, it is not citizenship, but friendship that matters' (p. 5). It is evident that if we are to promote an inclusive society and enhance the quality of life for people with intellectual disabilities, further research is needed to better understand and more effectively support people's aspirations for, and experiences of friendship.

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References

Amado A. (1993) *Friendships and Community Connections between People with and without Developmental Disability*. Paul H. Brookes, Baltimore, MD.

Bayley M. (1997) *What Price Friendship: Encouraging the Relationships of People with Learning Difficulties*. Hexagon Publishing, Wootton Courtenay, UK.

Berkson G. (1980) A final word on social behaviour of mentally disabled people in supervised communal facilities. Conference paper presented at the Gatlinburg Conference on Research in Mental Retardation & Developmental Disability. Gatlinberg, TN, 14 March 1980.

Berkson G. (1981) Social ecology of supervised communal facilities for mentally disabled adults: V. residence as a predictor of social and work adjustment. *American Journal of Mental Deficiency* **86**, 39–42.

Berkson G. & Romer D. (1980) Social ecology of supervised communal facilities for mentally disabled adults: 1 – Introduction. *American Journal of Mental Deficiency* **85**, 219–228.

Bliss V., Emerson E., Quinn H. & Thomas D. (1999) *NW Audit of Quality in Residential Supports*. Hester Adrian Research Centre, Manchester.

Brunner E. (1997) Socioeconomic determinates of health: stress and the biology of inequality. *British Medical Journal*, **314**, 1472–1476.

Bulm R., Resnick M., Nelson R. & Germaine A. (1991) Family and peer issues among adolescents with spina bifida and cerebral palsy. *Paediatrics* **88**, 280–285.

Comas-Herrera A., Knapp M., Beecham J., Pendaries C. & Carthew R. (1999) *Development of Benefit Groups and Resource Groups for Adults with Learning Disabilities in Residential Accommodation*. PSSRU, London School of Economics, London.

Cummins R. & Lau A. (2003) Community integration or community exposure? A review and discussion in relation to people with a learning disability. *Journal of Applied Research in Learning Disabilities*, **16**, 145–157.

Department of Health (1998) *Independent Inquiry into Inequalities in Health*. HMSO, London.

Department of Health (2001a) *Valuing People: A New Strategy for Learning Disability for the 21st Century*. Department of Health, London.

Department of Health (2001b) *Community Care Statistics 2001: Residential Personal Social Services for Adults, England*. Department of Health, London.

Department of the Environment, Transport & the Regions (2000) *Indices of Deprivation 2000*. Department of the Environment, Transport & the Regions, London.

Emerson E. & Hatton C. (1996a) Deinstitutionalization in the UK: outcomes for service users. *Journal of Intellectual and Developmental Disability* **21**, 17–37.

Emerson E. & Hatton C. (1996b) *Residential Provision for People with Learning Disabilities: An Analysis of the 1991 Census*. Hester Adrian Research Centre, University of Manchester, Manchester.

Felce D. (1988) Evaluating the extent of community integration following the provision of staffed residential alternative to institutional care. *Irish Journal of Psychology* **9**, 346–360.

Froese P., Richardson M., Romer L. & Swank M. (1999) Comparing opinions of people with developmental disabilities and significant persons in their lives using the Individual Supports Identification System (ISIS). *Disability and Society* **14**, 831–843.

Goldstein A. (1999) *The Prepare Curriculum: Teaching Prosocial Competencies*, Revised Edition. Research Press, Champaign, IL.

Knox M. & Hickson F. (2001) The meanings of close friendship: the views of four people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* **14**, 276–291.

de Kock U., Saxby H., Thomas M. & Felce D. (1988) Community and family contact: an evaluation of small community homes for severely and profoundly mentally handicapped adults. *Mental Handicap Research* **1**, 127–140.

Landesman-Dwyer S., Berkson G. & Romer D. (1979) Affiliation and friendship of mentally retarded persons in group homes. *American Journal of Mental Deficiency* **83**, 571–580.

Llewellyn G. (1995) Relationships and social support: views of parents with mental retardation. *Mental Retardation* **33**, 349–363.

Lowe K. & de Pavia S. (1991) *NIMROD: An Overview*. HMSO, London.

Marmot M. & Wilkinson R. (1999) *Social Determinants of Health*. Oxford University Press, Oxford.

Nihira K., Leland H. & Lambert N. (1993) *Adaptive Behaviour Scale – Residential and Community*, 2nd edn. Pro-Ed, Austin, TX.

Pendaries C. (1997) Pilot study on the development of the learning disability Healthcare Resource Groups. *British Journal of Learning Disabilities* **25**, 122–126.

Prescosolido B. (2001) The role of social networks in the lives of persons with disabilities. In: *Handbook of Disability Studies* (eds G. Albrecht, K. Seelman and M. Bury), pp. 468–489. Sage Publications, Thousand Oaks, CA.

Racino J. (1999) 'People want the same things we all do': the story of the Area Agency in Dover, New Hampshire. In: *Policy, Programme Evaluation and Research in Disability: Community Support for All* (ed. J.A. Racino), pp. 119–137. The Hayworth Press, Binghamton, NY.

Raynes N., Sumpton R. C., & Flynn M.C. (1987) *Homes for Mentally Handicapped People*. Tavistock, London.

Raynes N., Wright K., Shiell A. & Pettipher C. (1994) *The Cost and Quality of Community Residential Care: An Evaluation of the Services for Adults with Learning Disabilities*. David Fulton Publishers, London.

Read G. (2002) Issues arising from 43 Quality Network Reviews. In: *'The Quality Network'*. The British Institute of Learning Disabilities (BILD), Kidderminister, UK.

Reinders J. (2002) The good life for citizens with intellectual disabilities. *Journal of Intellectual Disability Research* **46**, 1–5.

Robertson J., Emerson E., Gregory N., Hatton C., Kessissoglou S., Hallam A. & Linehan C. (2001) Social networks of people with mental retardation in residential settings. *Mental Retardation* **39**, 201–214.

Romer D. & Berkson G. (1980) Social ecology of supervised communal facilities for mentally disabled adults: ii – predictors of affiliation. *American Journal on Mental Deficiency* **85**, 229–242.

Sarason B., Sarason I. & Gurung R. (1997) Close personal relationships and health outcomes: a key to the role of social support. In: *Handbook of Personal Relationships*, 2nd edn (ed. S. Duck). Chichester, John Wiley and Sons, pp. 547–573, UK.

Steering Committee for the Review of Commonwealth / State Service Provision & National Disability Administrators (2000) *Consultancy Report - National Satisfaction Survey of Client of Disability Services*. Commonwealth of Australia, Canberra, ACT.

World Health Organization (2001) *International Classification of Functioning, Disability and Health*, 10th edn. World Health Organization, Geneva.