

Friendship Matters? The significance of friendship in the lives of adults with profound and multiple learning disabilities

Subject of inquiry

Friendship is commonly identified as one of the human ‘goods’; those aspects of human existence which contribute to what we often call ‘quality of life’. We tend to think of people with lots of friends as likely to be happy and those without any as unfortunate (Allan, 1989). Accordingly, it might be argued, supporting people with profound and multiple learning disabilities (PMLD)¹ to develop friendships should be a priority for those concerned with their well-being.

This argument is increasingly to be found in Government policy documents. For example, the new national learning disability strategy *Valuing People Now* (Department of Health, 2009), commits central and local government departments to working together to build and sustain new relationships, specifically including friendships. This attention to friendships and relationships is interesting, because Government policy has previously been criticised for its reliance upon rights and citizenship as a way of conceptualising our relations with people with learning disabilities, to the exclusion of alternative or supplementary frameworks (e.g. Reinders, 2008). Alternative conceptual frameworks which have been suggested include care (e.g. Kittay, 2005) and my subject of inquiry: friendship.

Most prominent amongst the advocates of friendship have been Christian thinkers and theologians (e.g. Reinders, 2008; Vanier, 1999). The claims they make for friendship go well beyond the ‘quality of life’ argument. They contend that friendship is not simply one of many good things in life, but actually the ultimate good: the point of human existence. Friendship with people who have PMLD is said by them to be a means to discover our own humanity and to affirm theirs. This affirmation is believed to be important because people with PMLD lack (or are seen to lack) the self-awareness, autonomy and rationality central to Western notions of what it means to be a person.

¹ People with PMLD are people who, since childhood, have had an impairment of intellectual functioning so profound, that it is not measurable using the available psychometric tests. They also have severe communication impairments and physical or sensory impairments.

However, there seems to be a disjuncture here. For the lack of these characteristics would surely also preclude reciprocity, which, along with choice, is commonly recognised as a defining characteristic of friendship (Pahl, 2000). Thus, friendship with people who have PMLD appears to be a contradiction-in-terms.

This observation leads to a number of questions: does friendship with people with PMLD exist beyond the normative discourse of policy and theology? To put this another way: is it present in the local contexts in which people with PMLD live their lives (for example, family homes, day centres and residential care settings)? Surprisingly, the existing literature does not provide a clear answer. In general, empirical studies of people with PMLD have focused on the achievement of intersubjectivity, rather than the social phenomenon of friendship, whilst studies of friendship have dealt mainly with people with mild and moderate learning disabilities.

If friendship *is* a feature of the local contexts in which people with PMLD live: what is its salience, how is it achieved in talk and interaction, and what kind of normative claims are made for it there? Where does friendship stand with respect to the alternative relational discourses (for example, care or citizenship), as a means of framing ethical relations with people with PMLD?

Methods

Using a 'constructionist ethnographic' approach (Holstein and Gubrium, 2008), I am spending time with a number of adults with PMLD, with people identified as their friends and with their families and care workers (about a month per 'case'). I am following up friendship wherever my participants suggest it is to be found, including among people with PMLD and between people with PMLD and 'non-disabled' people. I am accompanying the participants with PMLD going about their ordinary activities (using video on occasion to record interactions), interviewing their friends, family members and care workers and looking at some of their personal records, including photo albums and care plans. I am also interviewing the managers of the organisations which provide the participants with PMLD with services and reviewing organisational policies. The data generation part of the project is running until the end of 2010. The analysis of the data generated will be informed by some of the principles of discourse analysis (Potter and Wetherell, 1987), ethnomethodology (Garfinkel, 1967) and conversation analysis (Sacks, 1992).

Contribution of the study to knowledge, policy and practice

Direct benefits for participants: I hope that the study will directly benefit participants (people with PMLD and others including their families, friends, carers, and advocates) by giving them the chance to reflect upon the relationships which the participating person with PMLD currently has, and consider the relationships which they could or should have.

Profound and multiple learning disabilities: The number of adults with PMLD appears to be increasing as a proportion of the general population of people with learning disabilities, due to the increased survival of children with PMLD (Parrott et al, 2008; Department of Health, 2008). Consequently, the question of how we relate ethically to people with PMLD, which has always been present, has acquired greater salience and urgency. Due to the historic marginality of people with PMLD, there has been very little research into their lives and no consensus as to how we should conduct such research effectively and ethically. It is my belief that detailed study of what people do and say in local contexts may have considerable value and I hope to test this proposition through my study.

Friendship: Friendship has been referred to as the defining relationship of our time (Vernon, 2007). I hope that this study may contribute something to the growing body of sociological work on friendship (e.g. Spencer and Pahl, 2006).

Acknowledgments

This project is supervised by Dr Marcus Redley and Dr Howard Ring (Cambridge Intellectual and Developmental Disabilities Research Group) and funded by the Foundation for the Sociology of Health and Illness, the Health Foundation and the NIHR CLAHRC for Cambridgeshire and Peterborough.

References

- ALLAN, G. (1989) *Friendship : developing a sociological perspective*, Boulder, Westview Press.
- DEPARTMENT OF HEALTH (2008) *Valuing People Now*. London. The Stationery Office.
- GARFINKEL, H. (1967) *Studies in Ethnomethodology*. Englewood Cliffs, NJ. Prentice-Hall.
- HOLSTEIN, J. AND GUBRIUM, J. (2008) *Handbook of Constructionist Research*. New York. Guilford Press.
- KITTAY, E.F. (2005) Dependency, Difference and the Global Ethic of Longterm Care (with Bruce Jennings and Angela A. Wasunna). *Journal of Political Philosophy*. 13 (4): 443-69.

- PAHL, R. E. (2000) *On friendship*, Cambridge [u.a.], Polity Press.
- PARROTT, R., WOLSTENHOLME, J. & TILLEY, N. (2008) Changes in demography and demand for services from people with complex needs and profound and multiple learning disabilities. *Tizard Learning Disability Review*, 13, 26-37.
- POTTER, J. & WETHERELL, M. (1987) *Discourse and social psychology : beyond attitudes and behaviour*, London; Newbury Park, Calif., Sage Publications.
- REINDERS, H. S. (2008) *Receiving the gift of friendship : profound disability, theological anthropology, and ethics*, Grand Rapids, Mich., William B. Eerdmans Publishing.
- SACKS, H. (1992) *Lectures on Conversation*. Oxford. Basil Blackwell.
- SPENCER, L. & PAHL, R. E. (2006) *Rethinking friendship : hidden solidarities today*, Princeton, N.J., Princeton University Press.
- VANIER, J. (1998) *Becoming human*, New York, Paulist Press.
- VERNON, M. (2006) *The philosophy of friendship*, Basingstoke, Palgrave Macmillan.