Social Relationships and Disabled People:
The impact of direct payments

Disabled people increasingly employ personal assistants (P.A.s) via direct payments rather than receive support from workers contracted by local authorities. This research by Sarah Woodin is the first detailed study into relationships with and between disabled employers, P.A.s, family and friends in the UK. Selected findings are that:

- Where family members had previously provided assistance to disabled relatives, interpersonal relationships often improved substantially. Although family members continued to help disabled people with some aspects of daily living this was predominantly by common agreement, and help was usually reciprocal.

- Friendship and employment characterised relationships between disabled employers and personal assistants. However disabled employers expressed preferences for one or the other form of relationship and working patterns reflected this.

- Employers who exercised more autonomy in the home than others (often men, whether living with a partner or without, and women living on their own) preferred a friendship rather than employment relationship style with P.A.s where possible because it offered more flexibility.

- Disabled parents, especially lone mothers with young children, often employed friends they had known socially before or family members. Concerns about the security of their position as a parent influenced their decisions.

- Relationships between employers and P.A.s were influenced by a wide range of structural and contextual factors that pushed both towards employment and towards friendship. For example, outside the home, employers presented personal assistants as friends to strangers and as employees to professionals.

- While local authorities emphasised the responsibilities of disabled people as employers, these employers often wanted to discuss their experiences of the more complex interpersonal aspects of employing P.A.s with one another.

Relationships with P.A.s

There is a received wisdom that a disabled person's relationship with personal assistants should be that of an employer with employee (Vasey, 1996). The implication has been that forming a friendship is a sign of weakness or loneliness (Marfisi, 2002) and the disabled people's movement has emphasised the importance of choice and control over support arrangements.

Likewise the 1996 Community Care (Direct Payments) Act states that employers should be 'willing and able' to manage direct payments, implying that formal managerial responsibility is important.

However, almost all employers and P.A.s characterised their relationships as having elements of employment and friendship. This dichotomy arose because P.A.s are contracted to do work, but they are based in the employer's home: a private place for living.

'You're invading somebody's personal space…but it's your job.' (personal assistant)

In the home, most employers preferred to adopt one style or the other overall: they were purposeful about their choice of 'paid friendship' or employment as a model for P.A. arrangements.

'They are an employee, first and foremost. (It's important) that she can understand why you do things in a certain way.' (employer)
Or:
'You need to have a friendship. It's intimate in one way because of the nature of the job. You've got to get on or else it won't work.' (employer)

'Paid Friendship'

There were several reasons for emphasising 'paid friendship'. Some tasks, such as help with bathing, were more comfortable when an informal relationship existed. Secondly, where employers received assistance for many hours a week, there would have been very little sense of home life if P.A.s were not incorporated into it. Thirdly, 'paid friendship' also arose from an instrumental need for favours: some employers simply did not receive enough assistance hours. Several made

arrangements with P.A.s for favours (e.g. driving or other help) outside of working time, and because favours were often returned (e.g. helping P.A.'s children with homework), friendships developed.

Family Relationships

Many family members had provided assistance to disabled people prior to direct payments and many still did. The difference was that family members no longer felt obligated to help. They did so because they felt they chose to. Disabled employers and their relatives said that they now felt they were a 'proper' family member. They could be confident of other people spending time with them because they wanted to, not because they had to.

'I'm not as snappy….When I'm spending time with my mum, I'm spending time *with* me *mum*.' (family member)

In many instances disabled employers spent less actual time with family members but the quality of relationships improved.

P.A.s and Family / Friends

'Paid friendship' that characterised some employer-P.A. relationships differed from 'social friendship'. It rested on the assumption that jobs would get done (but see the section on 'Disabled Parents', below).

Apart from a few who needed 24 hour assistance, most employers preferred to keep social friends and P.A.s separate from one another:

'I see my time with that circle (social friends) as being *my* time, on my own.' (employer)

P.A.s kept in the background when friends or family were visiting, or employers scheduled P.A.s and visitors at different times. Those who had tried to build closer relationships changed back: too much contact between P.A.s and social friends could cause discomfort.

Disabled Parents

Parents who were part of a traditional partnership, who had older children, or whose custody of their children was not subject to potential challenge, recruited

P.A.s in much the same way as other employers: through informal networks or formal advertisements.

Lone parents often recruited social friends or family members. They did so because they needed to maintain a sense of the house as a home rather than work place, especially as many used personal assistance to help with caring for children. However, equally importantly they felt that in these circumstances the P.A. would not question their position as a parent. Several lone parents felt that their children might be taken away and recruited people known to be allies.

Employing social friends and family created problems however. Many disabled parents found it difficult to re-configure the relationship in order to make sure that jobs got done, and some made compromises because they were unwilling to lose the valued social support that these social friends provided.

'So we've been sat here for 4 hours talking, and nothing's got done.' (employer)

Lone parents had the least social support and needed most help with practical tasks. With a more secure position, it may be that disabled parents will feel less need to rely on recruiting these 'safe' personal assistants, who actually posed unexpected difficulties for them.

Gender and Households

More women than men received direct payments. This was because they often provided unpaid help to other family members and were less likely to receive help themselves. They could not take it for granted that they would be seen as the main employer by spouses. For example:

'In the end it's to give me respite.' (husband)

In some instances P.A.s' partners challenged the employer's wishes, especially if they were used to telling their (P.A.) wives what to do.

'We had her husband round here saying 'don't shout at my wife' and really it wasn't a thing to do with him.' (employer)

One P.A.'s husband refused to allow his wife to support her employer on a singles dating evening, for example, and another persuaded his wife (a P.A.) to return her employer's pension book to the post office without consultation.

Women living with others were over-represented among employers opting for an employer-employee arrangement (with the exception of some lone parents, discussed above). They placed more emphasis on making sure that the basic personal assistance tasks were completed than on the flexibility involved in a 'paid friendship'.

Intimacy

Many employers would not have been able to meet potential partners and go on dates without assistance. However the presence of a P.A. was intrusive and could put off new partners.

Some P.A.s resented the appearance of a new partner, although others supported and encouraged sexual relationships. Both employers and P.A.s did what they could to minimise the intrusion but for some employers and their partners the degree of intrusion experienced jeopardised relationships. Where employers lived with partners and spouses, efforts to keep them separate were usual.

Men were more likely to view P.A.s as potential partners: three men had formed personal relationships in the past, but no women. Relationships also formed between P.A.s and family members in some instances, and where these ended it could cause friction in working arrangements with the employer.

Public Relationships

Employers did make choices about how they wanted to work with personal assistants, albeit within the constraints of sometimes unequal relationships with family members and friends. They had rather less freedom in other contexts, discussed below.

Local Authority Professionals
Assessors had the power to grant or retain payments and to stipulate what funding might be used for. They often tried to offload responsibility while retaining a measure of control. Employers were very aware of the need to present an appropriate

employer-employee face in meetings with professionals, even where they adopted a friendship stance in other settings. Trusted P.A.s often colluded with this.

The General Public
Despite some instances where people had been helpful and friendly, all employers reported instances of being abused and insulted by strangers.

Strangers did not understand what personal assistance was, and could not be relied upon to support the idea of independent living. More importantly, an intimation that the P.A. was working led to an assumption that the employer was a receiver of 'care', implying lack of competence and ability.

'They will think that I need a carer with me - that I need care.' (employer)

Also problematic for employers was the notion that a personal assistant might be a servant, something that is not generally acceptable to many due to class connotations. Employers presented P.A.s as friends or said nothing (leaving others to draw their own conclusions) to get around these problems.

Conversely, personal assistants preferred that others were told that they were in fact employed. If this was not done, they explained to their families and friends when the employer was not present. One exception, a male P.A., preferred to be identified as a friend. Several participants noted the stigma attached to men working as personal assistants and being identified as 'working in care'.

Employers could not avoid professionals or the general public, and these encounters demanded very different portrayals of employer-personal assistance relationships. This questions the common notion that relationships *ought* to take a certain form. Participants often had not much choice in the matter, if they were to be treated reasonably well in each situation. Public situations often called for relationships that were different from those in the home.

Conclusion

Employing personal assistants is highly complex. Home and work life overlap in inextricable ways and employers, family members, friends and personal assistants make sense of these circumstances by balancing a myriad of considerations. Employers developed competence over time. Trying out alternative ways of 'doing' personal assistance was an important part of the process.

References

Marfisi, C. (2002). Personally Speaking: a critical reflection of factors which blur the original vision of personal assistance services. *Disability Studies Quarterly, 22*(1), 25-31.
Vasey, S. (1996). The Experience of Care. In G. Hales (Ed.), *Beyond Disability: towards an enabling society.* London: Sage.

About the Study

50 people took part. In 2003-2004, 30 disabled employers living in north west and central England were interviewed, corresponding to 9 local authority areas. Employers' ages ranged from 24 to 77: 19 women and 11 men. 4 identified as from a minority ethnic group. 10 employers each nominated a family member or friend and a personal assistant, who were subsequently interviewed. Of the personal assistants, 9 women and 1 man were interviewed. Ages ranged from 25-41 years. Family and friends were 3 mothers, 1 son, 2 daughters, 2 partners and 2 friends. Ages ranged from 12 – 63 years.

Acknowledgements

A full copy of the thesis is available from the UK Disability Archive
http://www.leeds.ac.uk/disability-studies/archiveuk/
For alternative accessible formats, contact Colin Barnes: C.Barnes@Leeds.ac.uk
Further information about the study from Sarah Woodin: spl9slw@Leeds.ac.uk
School of Sociology and Social Policy, University of Leeds, Leeds, LS2 9JT. Tel: 0113 343 4407