

***I get by, with
a little help...***



Doreen Kelly and Laura Wardrop argue it is okay for staff to be friends with the people they support – as long as they are not the only friends

Keypoints

- A fulfilling life for people with disabilities is about much more than an address.
- Some support workers will become friends with the people they support but not all will, but these friendships are not enough.
- Real lives come from real connections and we must all be working towards this.
- The risk of abuse is not best managed by regulation.
- People are safest when they are loved and cared about.

As more people with learning disabilities get real lives, the issue of whether support workers can be friends to the people they support is provoking a lot of controversy.

People with disabilities want the same things that most of us do – a full life with a job, friends and relationships, but this is proving hard to achieve for many.

Valuing People Now, and its Scottish equivalent, Same as You, lay down what people with learning disabilities and their families can expect from the government and other statutory bodies. There are a lot of promises and a lot of hopes but the question is will they really make a difference and support people to achieve fulfilment?

People with learning disabilities are no longer limited to living in large institutions, but of course quality of life is about much more than an address. Meaningful relationships and friendships are crucial and for many people with learning disabilities their key relationship is with the staff paid to support them.

Partners for Inclusion, a not-for-profit organisation in Scotland, provides supported living services to adults with learning disabilities and mental health difficulties. Each service is individually tailored to the person and they are matched with an individual team of staff.

Key to Partners for Inclusion's work is supporting people to make friends and get connected in their local community, with the recognition that relationships can and will develop between the people supported by the organisation and the staff within it. Partners for Inclusion has been thinking about this issue for some 10 years, with heated debate around these key questions: Is the support worker a friend? Should the support worker be a friend? Strong views are held by both sides and that includes people with learning disabilities themselves, their families, and those who work with them. There are no easy answers.

So firstly, is the support worker a friend? The simple answer to this would be no, not primarily, as the worker is paid to be in the life of the person they support. The support worker is often privy to a vast amount of personal information about the person they support, often without their explicit consent; but the person receiving the support does not have the same amount of information about the worker. This creates an imbalance of power.

However, the person with learning disabilities often spends a lot or all of their time with the support worker, from getting out of bed and having the first cup of tea, to personal care, to talking through very private issues.

The worker should have been recruited to 'match' with the person, that is, to have a similar personality, likes and dislikes and interests in common. So the question is, does spending all this time together and liking the same things in itself amount to friendship, regardless of the exchange of money or information? Many support staff say it does, and that it is not possible for one human being to spend so much time with another without forging a bond of friendship.

Indeed, many people with learning disabilities agree, and that is particularly evidenced through many people starting to use In Control and self-directed services.

As Simon Duffy, chief executive of In Control, points out: "Disabled people often choose to employ family and friends to provide them with support. So the idea that most people want a strong 'professional divide' is clearly false.... Real life is more complex, and a lot better, than that."

This would suggest that people with learning disabilities would rather be supported by people who know and care about them. The desire for a professional boundary is driven by others, perhaps in their desire to manage the actual or perceived power imbalance and address the question of "should the support worker be a friend".

Dave Spencer and Paul Davies, of the Valuing People Team, suggest that: "The challenge set by the Secretary of State... (for) those working with people who have a learning disability (is) to take an approach that starts with each individual, their wishes, aspirations and needs". They go on to explain that to "place a wholesale ban on people forming friendships through paid support is inconsistent with this rights-based approach."

Alongside this, though, is the very real anxiety that funders have around ensuring that the person with a learning disability is not at any risk of abuse. It is perhaps the response to this anxiety that is flawed, namely the creation of policy and rules 'regimenting' making friends.

Partners for Inclusion has been required to create a 'friends policy' to do exactly this. Some local authorities who have commissioned services from us have stipulated that this must happen before any of the people receiving support are able to meet up with a support worker (or their family) outside work. Partners for Inclusion has sought to do this in a sensible and straightforward manner as possible. However, it amounts to a set of rules on how to be friends, which is not how most of us without learning disabilities live.

Of course few of us would argue with the need to ensure vulnerable people are not placed at any increased risk of abuse. The response of regulation effectively makes it more and more difficult for a person to form real and meaningful relationships with anyone.

To care about others and be cared about is ultimately what keeps people safe, not legislation, regulation or policy. For years people with learning disabilities have lived in highly regulated institutions, which have not managed to protect them from abuse on a physical, sexual or emotional level. It is clear that the more isolated any person is the higher the risk of harm.

Every human being has the right to friendship and relationships. If we are to be truly committed to person-centred practice then we must honour the views of the person receiving the support, rather than trying to manage the issue via professional control. More than

the workers and the person should match

75% of local authorities in England are signed up to In Control and its

ethos of placing control as close as possible to the person getting the support.

Perhaps there is a danger of focusing this issue exclusively around whether or not support workers should or should not be friends to the person they support. Without doubt there are support workers whose relationship with the person they support will develop into a friendship; but it is not a given and it is not enough. People with learning disabilities will have had many staff in their lives over the years they have been in contact with services and many staff will describe themselves as a 'friend'. But often contact will not continue through a job change.

If we accept that some support staff may become a friend to the person they support



(or have supported) but not always, and if we handle issues about safety in a sensible manner, we can focus on the real crux of the issue: supporting the person to really become connected to other people who are not paid to be in their life. After all, if the person can make one friend they can certainly make more.

Author, John O'Brien puts it beautifully:

"All it takes is willingness to embrace good reasons to find ways to walk through the walls that keep people with (learning) disabilities and their fellow citizens apart. The discovery of ways through walls begins in the good relationships that people already have with family members, with other people with disabilities, and with service staff."

The support worker may be a friend, but they should never be the only friend. ■

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people would rather be supported by those who know and care about them

Not allowed to come round for tea – a case study*

Partners for Inclusion supported Jean to leave institutional care five years ago. Jean got her own flat and working with Partners for Inclusion recruited her own staff team.

Jean didn't know anyone in her local area and had no family she was in contact with. As she settled in and got to know her staff team, she had a particular bond with Louise, one of her support workers. Louise's husband always picked her up from Jean's when she finished her shift.

Jean wanted Louise's husband to come in for a cup of tea. She loved company and loved being able to make tea for others. This was written in her person-centred plan. In her new place though, she didn't yet know anyone to ask up for a cup of tea.

Louise's husband started coming in for a cup of tea and a chat when he picked Louise up.

Jean really looked forward to this and would go out and buy cakes for the occasion, telling the staff in the bakers that she had a friend coming for tea.

Louise asked Jean if she would like to come round to her house for dinner some Sundays.

Delighted, Jean spoke of nothing else and together with her team they told the care manager about this, sharing it as a celebration, but the care manager said it had to stop straight away and that Louise's husband could not come into Jean's home and Jean could not go to Louise's home for dinner.

Jean was really upset and said she thought she could make up her own mind about these things. The care manager said it was her job to make sure Jean was safe and she could not do that if these visits were happening.

The service leader asked the care manager to relent but to no avail. As director of Partners for Inclusion, Doreen Kelly became involved and spoke with senior people in the local authority. Even her pleas were met with a resounding no. Eventually Doreen met with the director of the local authority but the matter could still not be resolved.

So Partners for Inclusion decided to rewrite its policy and work with that. Jean was then able to go for dinner at Louise's home, and Louise's husband did come in for a cup of tea. Jean has also gone on to meet some new friends through these connections.

*Names have been changed to protect anonymity.