

THE ATTACHED TRANSCRIPT WAS TYPED FROM A RECORDING AND NOT COPIED FROM AN ORIGINAL SCRIPT. BECAUSE OF THE RISK OF MISHEARING AND THE DIFFICULTY IN SOME CASES OF IDENTIFYING INDIVIDUAL SPEAKERS, THE BBC CANNOT VOUCH FOR ITS COMPLETE ACCURACY.

TX: YOU AND YOURS – 24.01.03- SHOULD DISABLED PEOPLE BE ALLOWED TO USE DIRECT PAYMENTS TO PAY A RELATIVE TO ASSIST THEM?

PRESENTER: Peter White

ROBINSON

Since 1997 thousands of disabled people have had the opportunity to organise their own care or personal assistance. Under the so-called direct payments social services gives money to a disabled person who can then choose to spend it - either with a care agency or on recruiting a carer or personal assistant themselves. But there is a catch - if you want to employ a relative then you can't because the rules set by the Department of Health don't allow it. It's a subject that's hotly debated among the groups which represent disabled people. Will Yates has been hearing the arguments. He heard first from Judith Caswell who has Multiple Sclerosis. She could receive a direct payment of £200 a week but she's refusing to take the money because the rules prevent her from employing her husband.

ACTUALITY

Could you open the door for me? Do the push button on the washer and also a bottle of fabric conditioner - we've got a new one, so I can't undo the lid on it - if you could do that for me.

CASWELL

I've had two years of having a carer provided on this scheme. The lady who was coming to help has now stopped but we've not replaced her with anybody since we're so unhappy about the whole situation. My husband was totally sidelined, he felt totally invaded by this person coming into his home, he had to - as it were - stand aside and let her do things for me.

YATES

Judith would much rather pay her husband Stephen to help her but under the rules people can't use direct payments to pay a relative. This is only allowed in very exceptional circumstances and even then it can only be a relative who lives in a different house. Judith finds this restriction difficult to understand.

CASWELL

They are quite prepared to pay out £200 a week that I know of to a complete stranger to come into our home, disrupt our lives and be an intrusion to our privacy but my husband cannot be paid a single penny.

KERRIDGE-SMITH

When my husband is on earlies we have to get my daughter home because he leaves at 4 o'clock in the morning.

YATES

Pauline Kerridge Smith is a wheelchair user who also receives direct payments to fund her personal assistants. Her carers help her during the day, the rest of the time she relies on her husband and

sometimes her daughter.

KERRIDGE-SMITH

It's not possible to get a carer to come in at the hours of sort of 4.00 a.m., it's just not feasible. I'm not happy about the rules, people have to use their family and it makes you feel more independent if you can actually reimburse members of your family.

YATES

However, the main groups which represent disabled people are against changing the no relatives rule. Menghi Mulchandani is co-chair of the National Centre for Independent Living, which advises disabled people on managing their care packages. She insists it's in disabled people's interests to avoid using relatives as carers.

MULCHANDANI

The reason for this is that I think that disabled people should very much keep their relationships separate and I think that when relatives start providing personal assistance it changes the relationship. And I very strongly believe that partners should be partners and children should be children and that your needs as a disabled person should be separate from that. It's also very difficult to manage somebody and get things done exactly how you want because a partner may have an idea about how they want to do it, as opposed to how you want it done. So I think it's a better relationship if you have an employer/employee relationship with somebody totally separate.

YATES

But there are experts in the disability movement who are willing to speak out in favour of allowing disabled people to pay relatives. One of them is Fred Wilenius, manager of the Direct Payments Advice Service in Cumbria.

WILENIUS

Our experience of working with disabled people who express an interest in direct payments is that quite often they don't want to start recruiting someone new, when they already have someone who's been close to them, working with them, giving them support for some considerable time already. This is a particularly significant issue in an area like Cumbria where people are often living in very isolated rural situations, that it's not easy - sometimes actually impossible - for them to recruit someone new to work with them.

YATES

Fred also points out that the ruling can put a disabled person in a difficult position if they and their personal assistant become a couple.

WILENIUS

Where a disabled person employs a carer, support worker, and then develops a relationship with that person the regulations, as they stand at the moment, can often mean that that relationship has to become very secretive and I think it creates a very difficult situation for that individual.

ACTUALITY

KNOCKING AT THE DOOR

Hello Mr Jones, Patrick Eringay from the Direct Payments Information Advice and Support Office, nice to meet you.

YATES

Patrick Eringay is direct payments coordinator for the voluntary group Oxfordshire Council of

Disabled People, he thinks up to 20 per cent of direct payment users would like to employ a relative as a carer.

ERINGAY

They'd feel safer with somebody they knew and trusted and they would also get a much better degree of help. Today in Oxfordshire, for instance, you have 100 per cent employment and it is very, very hard to recruit. Agencies are finding it very hard to recruit and direct payment users are now finding it difficult. And I think by allowing the employment of close relatives that this would help to maintain the service that the user needs.

YATES

Disabled people with high care needs can get extra funding from the independent living fund - a national government body with different rules to social services. Alan Sinclair, operations manager for Oxfordshire social services:

SINCLAIR

There's a discrepancy between the independent living fund regulations and the direct payments regulations in that independent people who receive independent living fund can employ close relatives who do not live in the same household and obviously that is a difference from the direct payments regulations. We find this confusing and I'm sure people with disabilities who are in receipt of direct payments and independent living fund also find that confusing and I think we should be moving towards the same regulation.

YATES

Alan suspects that the real reason the government keeps the no relative rule is because they're worried that any change would encourage more disabled people to take up direct payments and so increase social services expenditure.

SINCLAIR

If the government does change the regulations in relation to employing close relatives I'm sure that Oxfordshire and other local authorities would find an increased uptake of direct payments in their areas. Obviously what Oxfordshire and other local authorities will need to bear in mind, and the government will need to bear in mind, that it does change its social policy in relation to employing close relatives, that there may be also financial impact on local authorities where people who were previously providing care services for their relatives at no cost to the local authority if those people then come through then there may actually be a - if they decide to actually go for a direct payment that may be a financial impact on the local authority that obviously the government and Department of Health would need to take into account.

YATES

The Department of Health is currently carrying out a review of the regulations and is due to publish its results in the next few weeks. It's unlikely this time the government will decide to allow disabled people to pay relatives to assist them, however, people like Judith are desperate for the no relatives rule to be abolished.

CASWELL

The stupid thing is that it seems to be the only solution to this problem is for us to be divorced and if that was the case, if we were divorced, and he could produce an alternative address to mine the county council would be quite happy to pay him because he wouldn't be my spouse.