Body & Soul was established in 1996 and we provide vital support for around 4,000 children, teenagers, adults and families who are living with and closely affected by HIV from across London and nationally. In particular, our services focus on engaging highly marginalised sexual and ethnic minority communities who disproportionately suffer health and social inequalities due to severe poverty, poor mental health, stigma and discrimination. We offer an extensive and comprehensive programme of support that is member-led, person-centred, age appropriate and measured in line with the NHS, Public Health and Social Care Outcomes Frameworks. We are committed to a society free of prejudice, where HIV is no longer discriminated against and where everyone has access to treatment, love and care.

Comments

1. We believe that the Access to Work (AtW) programme is most appropriate for people with a static physical condition that may impede their ability to access work or be work ready. Our members’ who are living with HIV experience complex mental and physical health issues that prevent them from securing and maintaining employment. Additionally, their state of mental and physical health may fluctuate considerably in short time periods making sustained employment difficult. The scheme seems best equipped to facilitate the employment of someone with a stable condition and a physical disability that may be addressed if the appropriate equipment were made available, i.e. visual impairment and/or mobility issues.

2. We agree that there is very little known about this programme and how it works. The feedback we have had from members who used or tried to use it was that the onus and responsibility was primarily with them to initiate the support from the employer. For example, a member was missing a fair amount of work due to hospital appointments. One day she decided to get a taxi from her medical appointment to work to minimise the amount of time out of the office. She asked to claim back the expense and the employer refused to reimburse her. It was for a short period of time while her clinical needs were a high priority that she needed extra assistance, support and understanding. It is unclear whether the AtW scheme can be used on an ad hoc basis to assist someone managing a long term condition like HIV, or cancer can be another example, where there are periods of remission and high need.

3. Our members have concerns around confidentiality and the AtW scheme. They are concerned that when they have to explain why and what type of support they will require, they will be in the difficult position of having to disclose their status and potentially face discrimination. There are worries that the manager or employer may not respect their confidentiality and inform colleagues of their HIV status as well. It may be difficult for an employee to ask for the practical support to address the barriers preventing them from accessing work without explaining the real circumstances. While some people may feel comfortable telling employers, others may prefer to wait until there is a rapport or not at all. It is generally felt that this scheme may force the issue of disclosure for our members without the adequate support in place to deal with any potential fall-out. If the employee does have a negative experience, it will be even more difficult to encourage them to have the confidence to apply for more opportunities in the future.

4. The scheme addresses mainly practical support for physical disabilities and not psychological barriers. People living with HIV experience much higher rates of depression and anxiety and feel that having HIV significantly reduces their career options. We believe it would be best if there was a registry of employers that were signed up to the scheme and people looking for work
could browse the employment opportunities by sector within the registry. This would make the prospective employee feel more confident that the prospective employer they are approaching is open-minded, flexible and willing to work together with them to find creative solutions to facilitate their employment. Also, by having employers registered and pre-approved, the scheme would be ensuring buy-in from the business to support disabled people into the workforce. As said previously, the feedback from our members has been that the onus has been on the employee to encourage engagement or suggest solutions, which increases the burden of stress and anxiety of entering the workforce and reinforces the person’s perception and/or anticipation that they will encounter resistance.

19 June 2014