

Title: Direct Payments in York; Current Issues and Future Direction.

Author: York Independent Living Network and Lives Unlimited.

Prepared by Stephen Lee Hodgkins (Trustee York Independent Living Network).

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Summary:

This document presents our position on the current issues and future direction for direct payment support in York. It outlines the background, purpose of this work and our current position. It also includes six themes relating to current issues and concludes with seven recommendations that we believe will improve direct payment support in York and the quality of life of disabled people and their families.

Background and purpose:

York Independent Living Network and Lives Unlimited have been monitoring direct payment support structures in York for the past three years. This has been through both our collective personal experiences of using them, as well as engaging with a wide range of individuals outside of our organisations. In 2015 we raised issues with the City of York Council regarding changes to direct payment policy and terms and conditions, over the poor communication and lack of consultation with individuals who stood to be affected. We asserted then that we felt the changes worked against the wellbeing principle of the Care Act and would reduce choice and control. As a result of our monitoring of direct payment support structures in York for the past three years we recently held a community event to bring together our positions, debate the issues and promote positive possibilities. This event was held in partnership with York Human Rights City and Making Research Count.

From this we state our current position:

- There is variable lived experience of direct payment use in York, and as a result disabled people and their families are being denied opportunities to maintain wellbeing and achieve independence.

- There are some excellent examples of disabled people and families achieving independence, although this is often more as a result of personal drive and capacity rather than effective support structures. A lack of evaluation of these experiences means a missed opportunity for other people to learn from them.
- There are examples of where disabled people are not achieving independence because current support is inadequate. Some disabled people and families are missing out on life opportunities and experiencing high levels of stress as a result.
- Support and capacity needs immediate development, especially peer support. There should be a focus to develop a local community support resource.
- Disabled people and families have demonstrated that they are leaders in this area and need to be at the centre of driving it forward. Statutory bodies should commit to co-producing improvements in this area and provide the resources to do this.

Without immediate action in this area we anticipate that disabled people and their families will be further denied opportunities to maintain wellbeing and to achieve independence. Additionally, without immediate action we feel local statutory agencies will fail to meet the core principles of the Care Act, and in turn their obligations relating to it. Further we assert that without immediate action local statutory agencies risk being non-compliant with Article 19 of the UN Convention of the rights of disabled people, that is 'living independently and being included in the community'. Considering York recently became the UK's first Human Rights city we believe this is an important focus for work in this area going forward.

Current issues:

The following six themes present further detail relating to our position and were formed by feedback received from the event, contact with individuals relating to this issue and personal experiences. Further details of these are included in the notes collected from the DP event we held on 23 November 2017.

Information – there is a lack of accessible and enabling information and advice provision for disabled people and families in York as required by section 4 of the Care Act. There are no positive real life examples from York of people using direct payments, as is suggested in statutory guidance on information and advice. People are unclear of their rights and entitlements. Agencies are not enabling independent living.

Setting up direct payments – is overly complicated and inaccessible for most people. Statutory process is reported to us as unhelpful and insensitive to individual needs and preference. Direct payment options are often presented as complicated and not relevant for some potential users. As a result we believe there is a low take-up of direct payments.

Ongoing management – in addition to the points mentioned above and of relevance here, there is lack of ongoing support available to support people with staff issues, including pay, training, development, as well as relationship dynamics. We have heard examples of providers giving incorrect information to employers. We have examples of direct payment users being informed of changes to admin arrangements that have omitted the full range of choices and options available to them. There are concerns about the different approaches taken by social care and finance departments that give conflicting messages to individuals. The hidden costs of, and contributions given to, managing a direct payment for a disabled person or a family member are significantly underestimated and have been failed to be truly recognised formally with statutory arrangements.

Workforce matters – there are significant issues relating to retention, recruitment and employment conditions for PAs. There is a lack of a coordinating resource surrounding this that creates instability for many. We have reports where employers allow PAs to set terms of working relationship in order to retain them. This undermines control and puts disabled people at risk of harm.

Principles – the principles of achieving independent living¹ and citizenship and promoting an individual's wellbeing, as set out in section

¹ For disabled people, independent living is defined as having choice and control over their lives. The 'Pillars of Independent Living', or the '12 basic rights of disabled people' (See Spectrum CIL – The 12 Basic Rights are; Appropriate and Accessible Information, An adequate income, Appropriate and accessible health and social care provisions, A fully-accessible transport system, Full access to the environment, Adequate provision of technical aids and equipment, Availability of accessible and adapted housing, Adequate provision of personal assistance, Availability of inclusive education and training, Equal opportunities for employment, Availability of

1 of the Care Act, are not at the forefront of direct payment work in York we feel. A market – consumer culture is dominant and results in lack of creative thinking and flexibility in delivery. We have examples of where people feel left out and isolated without any support to manage their budget, despite paying a support agency to do so.

Capacity – there is a wealth of local talent, yet a lack of local community capacity and resourcing. There are few formal peer support options. Capacity building needs to be undertaken with disabled people and families using direct payments to build a community-based, collective resource that delivers a person centred, innovative and citizenship-focused service; in other words run *by* local people *for* local people.

Future Directions and Recommendations:

As a result of this we put forward the following recommendations. We believe that if undertaken these will help enable greater independence for disabled people and families in York, meeting the aims of York as a Human Rights City.

1. Ensure that the principles of independent living, citizenship and human rights (freedom, respect, equality, dignity and self-determination) are the heart of all work relating to social care, direct payment and personal budgets. There should be a shift in focus from clients, consumers and markets to independence, citizenship and inclusion.
2. Improve information and advice provision for independent living options, direct payments, personal budgets and other aspects of the Care Act related to this area. This should be accessible and include real world examples from a diverse range of disabled people and families in York who are achieving independent living.
3. Develop personal budgets and direct payment support structures in York that are accessible, human focused, flexible, and responsive to diverse use and need that recognises, values and harnesses the wealth of experience and expertise amongst current direct payment holders. This needs to include adopting a social care self-directed

support assessment, independent person-centred support planning, peer support and ongoing training and support for budget holders to enable them to achieve and maintain independent living and be excellent employers.

4. Address workforce issues relating to management, supervision and training, retention and recruitment including improving work and pay conditions and promoting PA roles so that they are seen as desirable careers. Develop PA banks and innovative models for employment of PAs that maximise job security and conditions, e.g. budget holders sharing PAs through collective arrangements.
5. Ensure all departments in statutory agencies involved in direct payment work fully understand and work to the principles, obligations and requirements of the Care Act. This is so that different departments, i.e. social care and finance, are clear in their messages, responsibilities and expectations in negotiating contractual arrangements with individuals.
6. Set an ambitious challenge to increase the numbers as well as satisfaction levels of people and families achieving independent living through direct payments and personal budgets.
7. Form a lived experience group to develop, implement and scrutinise a strategy for this work. This should be made up of people using direct payments (both disabled people and family members), statutory staff and relevant community organisations. This group should have significance within the statutory setting and connect to formal structures.

We would be keen to discuss the implementation of these further with you.

Contact: For further information please contact Stephen Lee Hodgkins, Trustee of York Independent Living Network, M: 079510 50153, E:hiya@stephenleehodgkins.net / admin@yiln.org.uk.

Additional documents:

'Tablecloth Notes' from Direct Payments Event, 23.11.2017

Presentation slides from DP event.