

Case Study: Richmond upon Thames (personalisation)

Introduction

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Overview

A group of young college leavers with learning disabilities in Richmond upon Thames have piloted an innovative way of getting more from their direct payment care package. Supported by a local voluntary organisation, the Richmond Users Independent Living Scheme (RUILS), the young people have pooled some of their money to set up a friendship group supported by personal assistants. The group of four to five young men enjoy going to football matches, the gym and taking part in martial arts together. The work may have spin-offs as families engage in community networking and other disabled groups access a guide written as a result of the pilot.

Main transferable learning points

- Forming a friendship group can avoid the risk of isolation for some disabled young people making their own individual choices after school and college
- Pooling budgets to pay for PAs, activities and transport can mean disabled people get more from their benefits
- Pooling budgets can be a way to get a range of activities off the ground including social enterprises and joint leisure activities.

Introduction

A group of young college leavers with learning disabilities in Richmond upon Thames are pooling direct payments to pay for shared activities with friends. Supported by a local voluntary organisation, the Richmond Users Independent Living Scheme (RUILS), the young people have set up a friendship group supported by personal assistants. RUILS is an independent, grassroots, self-help organisation that serves those who are in receipt of a Personal Budget or use Direct Payments, Personal Assistants or other means of support to achieve greater independence and well being.

Background

The first local group to pool direct payments was a group of people with learning disabilities from the Richmond Adult and Community College. They decided to put their money together to form a non-profit social enterprise, Stepping On Out, that makes and sells greetings cards. Disabled young people involved in Stepping On Out applied for Direct Payments and pooled these into a joint bank account in order to employ a project co-ordinator to help them run their business.

Stepping On Out's experience of pooling budgets to pay for support and services seemed a good model for another group of disabled people in Richmond: a group of young men who all had learning difficulties and were about to leave college. They wanted to form a friendship group to help maintain the friendships they had made at school and college.

Instead of moving on to traditional day centres or supported working schemes, the Richmond young people wanted more choices about the support they needed and a greater say about how they would spend their time, but there were fears that this could put them at risk of becoming isolated as friendships gained at school and college could easily be lost as they each went their separate ways.

Social Services and parents recognised that, although day centres tended to create artificial groupings, they did offer opportunities for socialising. They feared that without the roots of school, college or day centre the young people would be isolated and the transition work to help the young people become more independent and self aware would be wasted. The friendship group offered a solution to this problem and RUILS was brought in to support the families with the next steps. All of them wanted to recruit personal assistants (PAs) for themselves so each family was seen individually and given information about recruitment and employment and it was explained that they could do this together or as a group.

Aims and objectives

The job description for the PAs designed by the young people with their pooled funds sums up the key aims of the scheme:

- To provide support for a group of disabled young people so they are able to participate in a range of social and leisure activities in the local community together as a group.
- To enable an existing group of friends to meet on a regular basis, so friendships are maintained and encouraged.
- To encourage the group to make decisions and take control of the group through their own decision making process.
- To ensure everyone has fun and enjoys themselves, making sure everyone participates and any individual's support needs are met.
- In addition, the pilot scheme is intended to act as a model for other groups of disabled people thinking of pooling their budgets.

Approach

In spring 2009, with the support of a grant from the Transition Support Programme, six disabled young friends aged 18 and 19 made plans to form a focus group supported by workers from RUILS who helped them find ways to pool their individual direct payments in whichever ways they wanted. The group called themselves the Out and About Consortium, with eventually just four young men becoming members and one young man still waiting for an assessment likely to become the fifth member.

Alongside a RUILS worker, who had experience of working with people with learning disabilities, was a self-employed project worker with knowledge of employment law. She observed the process and wrote it up in the form of a guide for use by other disabled individuals and groups. The pilot was overseen by a RUILS manager.

Partnership working was a vital component of the work which involved the RUILS team meeting with parents, the young people and social services. Fortunately a single care manager worked with most of the young people. Co-ordinating six separate care managers' work could have been problematic. Even so, progress chasing the assessment, support plan and personal budget for each young person was important to getting the scheme off the ground.

The young people in the Richmond Out and About Consortium decided to meet up twice a month to decide the way forward. After they had decided what they wanted to do together, RUILS helped the Consortium to write an agreement.

Three members of the group decided to employ their own PAs but use their hours flexibly so that shared activities could be undertaken with just two of them. With the help of RUILS the group wrote job descriptions explaining the sort of job they wanted their PAs to do. RUILS also helped them create a job description although the group were well known locally so had no difficulties recruiting PAs.

All the young men's parents are involved and one with the necessary time and energy took a leading role in organising the group's monthly outings which focus mainly on sporty activities

like going to the gym and football matches and taking part in martial arts.

Challenges

While successful partnership working characterised this pilot, co-ordinating the different people and groups involved was a challenge. Support is needed to co-ordinate the work of professionals alongside the decision making process disabled young people are undergoing with their families at transition.

Each member of the group has a different level of understanding and the process of assessment has taken different lengths of time for different members. With this group parents were a strong driving force but RUILS believes further work with different groups of disabled young people may be able to focus more on developing their ability to make choices with parents being consulted rather than taking a leading role.

Recruiting PAs involves many issues which are potentially daunting to individual families. However, in Richmond, RUILS has a track record of providing back-up on issues such as pay roll, insurance, contracts and recruitment which the Consortium was able to access.

Successes

Members of the Out and About Consortium have the freedom to choose activities with their friends at times they choose. It means they feel more independent, maintain friendships and can access mainstream facilities such as the gym.

The scheme helps them make better use of their resources. For example instead of each person being accompanied to a football match separately by their PA, two PAs can accompany four or five young people at a time.

RUILS has produced a guide, Pooling Direct Payments, which was developed alongside the 10 month pilot. The guide includes useful tools for other disabled people considering

pooling budgets. In the future the guide might be produced in different formats, for example a pictorial version for disabled people with literacy problems.

The work is stimulating community networking in Richmond so may result in new formal and informal groups being formed, for example, parents are using Facebook to learn from each other about transition and support planning, share ideas on how to use personal budgets and work out ways to share PAs.

Conclusion

Now two groups are successfully pooling budgets in Richmond, and the RUILS guide provides the practical know-how to enable the work to expand both within the borough and in other areas. The hope is that groups with different disabilities will see the potential, even if they may need support to take ideas forward.

How to pool Individual Budgets

Key issues and principles

Pooling budgets takes person centred planning a step further with disabled young people working together to agree joint activities and make decisions alongside others. It allows for creative and innovative use of benefits and has the potential to increase access to mainstream facilities for disabled young people.

Barriers

Co-ordinating transition planning and social services care planning along with families' hopes and expectations is complex and potentially time-consuming. Parents' energies can be harnessed to get schemes off the ground, but young people need support if they are to stay in the driving seat. In some areas it may mean overcoming the traditional paternalistic culture where decisions are made by services bypassing the family and disabled young person.

How pooling budgets can be seen as good practice

Ensuring families have early information about what they are entitled to before the young person leaves school or college enables them to think creatively about their choices.

The RUILS Pooling Budgets Guide summarises the decision making process involved in setting up a successful pooling scheme.

The key steps identified in the guide included:

- Deciding who to pool money with
- Organising planning meetings – times, frequency and venue
- Deciding how much money to pool and what to spend it on.

In most cases groups will need to:

- Open a bank account
- Employ staff
- Organise transport
- Check out risks
- Arrange insurance
- Factor in staff liaison and support into cost.

Top Tips

RUILS suggests the following ideas for disabled people considering whether to pool direct payments and how they would spend the fund:

- To set up a social / friendship group
- To set up a club
- To hire venues to meet up
- To hire transport
- To do leisure activities as a group
- To employ a PA (Personal care Assistant) or support worker to support leisure activities
- To pay for training or classes
- To set up a business
- To employ a PA or support worker to help disabled people living in shared accommodation.

Key legislation

The Community Care (Direct Payments) Act 1996 gave Social Services Departments the power to make direct cash payments. The introduction of Direct Payments in 1997 allowed Social Services to assess a person's needs and to make a payment to them so that they could choose where to purchase their support from.

The Carers and Disabled Children Act 2000 extended access to direct payments to 16 and 17-year-old disabled young people.

The Welfare reform Act 2009 gives disabled people a legal right to be told the monetary value of certain support they are eligible to receive, and will deliver choice and control over how those resources are used.

Key policy

White Paper *Our Health, Our Care, Our Say* (Department of Health, 2006) committed the Government to the extension of the principle of 'individualised budgets' for disabled people

Aiming High for Disabled Children (AHDC): better support for families, launched in May 2007, is the transformation programme for disabled children's services. AHDC is jointly delivered by the Department for Education (formally Department for Children, Schools and Families) and Department of Health and includes the commitment to establish a small number of local pilots, offering individual budgets for disabled children and their families.

Putting People First (Department of Health, 2007) envisages that all local authorities will offer personal budgets by 2011 as part of its programme to transform adult services, giving citizens more power to shape their own lives.

The **Individual Budgets (IB)** pilot programme was a cross-government initiative led by the Department of Health working closely with Office for Disability Issues, Department of Work and Pensions and Communities and Local Government. Despite the intention that IBs should include resources from different funding streams, staff experienced numerous legal and accountability barriers to integrating funding streams.

Organisations and websites

Department of Health website on personalisation

www.dh.gov.uk/en/SocialCare/Socialcarereform/Personalisation/index.htm

Department of Health website on direct payments

www.dh.gov.uk/en/SocialCare/Socialcarereform/Personalisation/Directpayments/index.htm

RUILS: Richmond Users Independent Living Scheme

RUILS is an independent, grassroots, self-help organisation that serves those in Richmond who are in receipt of a Personal Budget or use Direct Payments, Personal Assistants or other means of support, to achieve greater independence and well being.

www.ruils.co.uk

RADAR

RADAR is a national campaigning organisation that works to improve the rights of disabled people.

www.radar.org.uk

Resources

Guidance on direct payments for community care, services for carers and children's services

Department of Health, 2009

Independence, choice and risk: a guide to best practice in supported decision making

Department of Health, 2007

Putting People First: personalisation toolkit

Department of Health, 2008

Journey to independence: How to run your life with direct payments

British Institute for Learning Disabilities, 2003

www.bild.org.uk

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National Transition Support Team (NTST)

NTST is working alongside the National Strategies and the Child Health and Maternity Partnership to coordinate the delivery of the Transition Support Programme.

NTST is based at the Council for Disabled Children (CDC), the umbrella body for the disabled children's sector in England. CDC is hosted by NCB.

National Transition Support Team

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