Need 2 KNOW

Life in the Community

Better daytime opportunities for people with higher support needs

A briefing note for commissioners and care managers from the Foundation for People with Learning Disabilities

Introduction

This briefing is for those responsible for purchasing, commissioning or arranging daytime support for people with learning disabilities. We anticipate it being of particular interest to local authority commissioners and care managers.

The Life in the Community project was set up to establish good practice in daytime support for people with higher support needs. Higher levels of support are sometimes required where a person is unable to take advantage of those daytime opportunities available to most people with a learning disability because of the severity of their intellectual impairment, physical disability, mental health problem, behaviours that people find challenging, or autism. People may also require more support in certain situations or with certain activities, such as getting a job.

Aims

The project was initiated in response to 'Having a Good Day?' (SCIE, 2007), a review of day services for people with learning disabilities, which found that people with higher support needs are invariably the last to benefit from the modernisation of services. Despite often requiring expensive packages of support, this group are frequently offered services which are outdated and delivered in congregate, buildings-based settings.

The aims of the project were therefore:

- To work with four organisations from the third sector to improve the daytime opportunities for up to 40 people with higher support needs and help them to be more included in their local communities

- To develop the capacity of the third sector to support this group of people to make greater use of mainstream services and facilities

- To stimulate creativity and flexibility in the support provided to this group.

Making use of the findings

The conclusion of the project coincided with the publication of Valuing People Now which addresses this problem directly by giving a high priority to improving support to people with higher support needs. But there are other reasons why commissioners and care managers should pay particular attention to the needs of this group:

- Demographic data shows an increasing number of disabled children with higher support needs surviving into adulthood and expressing different aspirations from previous generations

- The Government's 'personalisation' agenda challenges commissioners to find new ways to plan and purchase daytime support for people with learning disabilities

- A requirement to meet performance targets for the numbers of adults using individual budgets and direct payments

- There are cost pressures of providing services to this group, many of whom meet continuing healthcare funding criteria. For example, people living in high-cost out-of-area placements are being brought back to their locality as part of the 'Local Services for Local People' programme

- The need to develop new market capacity in social care provision, especially in the third sector .

On the following pages there are some of the main findings of the research, in particular about the potential of 'community connecting' (page 2). Based upon what we learned during the project, we make some suggestions about what you can do to put those findings to good use in your area to help address the needs of people with higher support needs (page 3). The final section provides a selection of resources and links which you may find helpful (page 4).

For further information and enquiries about the work of the Foundation for People with Learning Disabilities, please contact Paul Swift pswift@fpld.org.uk

Foundation for People
with Learning Disabilities

Key findings

A majority of the people who took part in the project achieved a range of good outcomes that included finding work, moving home, joining clubs, setting up a neighbourhood service or making greater use of community services. Reliance upon specialist learning disability services was reduced and there was overwhelming agreement from families and carers that people were more contented, calmer, happier and more engaged as a direct result of the project.

Person-centred approaches and techniques underpinned the support provided to participants in the project. Working in this way led to greater job satisfaction amongst support staff, more choice and control for people at the centre of the process and greater involvement of family and other non-paid supporters.

Circles of support proved a cost-effective way of coordinating planning and action for and around an individual. Many of the good outcomes achieved in the project were driven by families and non-paid supporters, sometimes with help and advice from others (such as a specialist in self-employment). Advocates played a crucial role in helping some people think about their lives and express their needs and wishes. However, commissioners and care managers did not always recognise and value the work of these circles.

Most of the participants and their supporters wished to use individual funding as this gave them greater choice, control and flexibility in pursuing their aspirations. Enthusiastic and knowledgeable care management was the key factor in expediting this for a small number of participants, although others were thwarted by care managers' lack of knowledge about Individual Budgets.

Developing individualised services in the community is about 'relationships' rather than activities or buildings. Activities and being 'in the community' are simply the arenas in which relationships can develop and flourish. Most of the good outcomes were about the development of relationships rather than activities, yet these were rarely recognised and stated in the support that was commissioned for participants in the project.

'Community connectors' had a key role in making it happen for people in the project. Community connecting fills a gap that often exists between person-centred planning and the achievement of good outcomes for people by matching their skills, interests, aspirations and dreams with opportunities in their local communities. As such, it is a form of support brokerage. Community connectors proved very effective at establishing sustainable relationships between individuals, members of a community and community organisations, as well as mentoring direct support staff to work in more creative and flexible ways.

Connecting is a service that is provided at times that are convenient to the person and their family (often evening and weekends) and in a variety of locations. The project indicated that to be effective connectors should be independent of service provision. While aspects of connecting can be carried out by support staff, our experiences suggest they rarely have the time to undertake the mapping and matching tasks that represent the added value of connecting.

Community connectors came from a range of backgrounds and brought with them a variety of experiences. Connectors shared certain personal qualities, as well as local knowledge, logistical and negotiating skills to map and match the individual with community opportunities.

Crucial to the success of community connecting were the structures and management of the third sector organisations offering this service. They had 'flat' structures (one tier of management) and were small enough that managers knew and understood the needs of individual customers.

Funding for community connecting services was irregular despite consistent demand for them and high rates of satisfaction from people using the services.

Anoop's story

When Anoop left college he had no life outside the family circle. The Community Connector from Grapevine, Darren, spent time with Anoop and came to appreciate his gift for being kind-hearted, talkative and having a real appetite for life. He also had a taste for good coffee, so together they sampled all types of coffee from macchiato to lattes in cafes from small and independent to busy chains in bookstores, all over Coventry and Birmingham.

During this time Darren discovered that while Anoop was an eager sports fan, he did not go to games or take part in any sporting activities. To gauge his interests Darren supported Anoop to experience different sports from football to ice hockey. He started to attend Coventry & North Warwickshire Hockey Club where at first he watched practice sessions and spoke to players. Darren got to know the club's organiser, Simon who developed a good rapport with Anoop. Simon both understood what Darren was trying to achieve and could see the mutual benefit of having Anoop play in the club.

Two years on Anoop is photographer for the club's website and organiser of the zone (wheelchair) hockey section. Watch the DVD that accompanies our Connecting People guidance to see how Anoop has become a popular member of the clubhouse.

What commissioners and care managers can do

Be proactive. All markets rely upon the supply of reliable information about what the customer wants and how much they are willing to pay for it. Yet the market for social care for people with learning disabilities is barely a market at all, with a limited range of providers, crude pricing mechanisms and inefficient channels for 'consumers' to articulate their demands. It is therefore imperative that commissioners take a lead in shaping the future for people with higher support needs. Three key tasks are required here. Firstly, spread the message, through public statements and strategic decision-making, that this group will be prioritised in the coming years. Secondly, check out the capacity of local third sector service providers to support this group of people. Thirdly, ensure that care managers are equipped with the knowledge and skills to work with people with higher support needs and their carers.

Be opportunistic. Take advantage of reorganisations, modernisations, 'transformations' and other initiatives, both in the learning disability sector and in the wider social care field, to develop new types of support for people with higher support needs. For example, the 'local services for local people' policy brings people in high cost out-of-area placements back into their locality of origin.

Demand better planning. It goes without saying that all commissioned services should be based upon robust person-centred planning. However, our experience suggests that the quality assurance of person-centred planning systems is often weak. Planning should involve the people who are important to the person at the centre of the plan; it should be about the person's whole life, not just about those aspects that are eligible for public funding; it should have a clear plan of action, stating what commitments the local authority and others are able to make towards the support an individual requires. It is vitally important that care managers engage courage person-centred planning but only lead it where

Promote Individual Budgets (IBs) and Direct Payments. People who are eligible for support and their families are best placed to identify the right support for themselves. The recent IBSEN evaluation contained some encouraging messages in this respect. It found that for people with learning disabilities using IBs to pay for personal care, domestic help and social, leisure and educational activities felt they had more control over their lives. IBs proved cost-effective for their social care, while people with the highest value IBs achieved the best social outcomes

Develop planning and brokerage. Intensive support and extensive training will be needed to develop the specialist support planning and brokerage skills required to deliver IBs and to identify the best ways to use them. The IBSEN evaluation calls for greater capacity in managing budgets flexibly within care management and a wider range of creative responses to individuals' priorities.

Advocacy is important not just to ensure that a person's voice is heard, but also assist in accurate and appropriate planning. Advocacy is likely to be required by some people with higher support needs who have particular communication needs or who do not have family in touch with them. Remember too that Independent Mental Capacity Advocates may be required where people lack the capacity to make important decisions about their life.

Develop capacity in the third sector. Changes to patterns of service provision in the IB pilots were limited by block contracts with service providers and there were 'sizeable implications for local service providers; for the roles of councils in stimulating new types of services; and for service costs if the bulk discounts of large block contracts disappear'. Our project showed that while small third sector organisations are well placed to deliver new ways of supporting people with high support needs, they need to work closely with commissioners to develop a business model that utilises the right mix of core funding and individual budgets.

Valuing people now

Valuing People Now acknowledges that 'people with more complex needs are often not connected to their communities, or given any meaningful programme of vocational, social, leisure or learning activities', and goes on to say that 'new initiatives such as the Life in Community project and Changing Places demonstrate that this does not need to be the case' (chapter 4.10). The Delivery Plan for Valuing People Now says that good commissioning should be based on information from Strategic Needs Assessments and collation of information from person centred planning. A piece of work that identifies how person centred information can be used to inform commissioning at a strategic level will be carried out and the findings disseminated through.

Useful links and resources

The Foundation has published **Connecting people: the steps to making it happen**, a set of guidelines for setting up a community connecting service, written by Clare Wightman from Grapevine in Coventry. A DVD accompanies the guidelines to illustrate how some people with higher support needs have been helped to have a role in their local communities. To obtain copies of the guidelines and other materials associated with the Life In The Community project, please visit our website http://www.learningdisabilities.org.uk/

The SCIE Knowledge review **Having a good day? A study of community-based day activities for people with learning disabilities** asks what has, and what has not contributed to the successful provision of community-based day activities for all people with learning disabilities? The review is available to download at http://www.scie.org.uk/publications/knowledgereviews/kr14.asp

The associated practice guide, **Community-based day activities and supports for people with learning disabilities: How we can help people to 'have a good day'**, is available to download at http://www.scie.org.uk/publications/guides/guide16/files/guide16.pdf

The **Valuing People Support Team website** has several pages devoted to resources and links about 'Being Included' http://www.valuingpeople.gov.uk/dynamic/valuingpeople69.jsp

The **Personalisation toolkit** is an on-line resource to support councils to begin to plan and deliver the transformation of their social care systems, as set out in Putting People First. Join the Personalisation network at http://networks.csip.org.uk/Personalisation/PersonalisationToolkit/

Commissioning for Support Planning and Brokerage is a resource tool for mapping and planning brokerage services locally, involving people who use services. Available to download at http://networks.csip.org.uk/Personalisation/Topics/Browse/Supportplanning/?parent=2673&child=3236

The companion **Good Practice in Support Planning and Brokerage** is available to download at http://networks.csip.org.uk/Personalisation/PersonalisationToolkit/Blueprint/SupportPlanningandBrokerage/?parent=3113&child=3250

SCIE Knowledge review 20: Commissioning person-centred, cost-effective, local support for people with learning disabilities brings together knowledge from research and practice on commissioning person-centred, cost-effective, local support for people with learning disabilities labelled as having complex needs and/or challenging behaviour. It is available to download at http://www.scie.org.uk/publications/knowledgereviews/kr20.pdf

Person centred commissioning - now; a pathway approach to commissioning learning disability support produced by the Improvement & Development Agency explores some examples of what is working well nationally in learning disability commissioning - and how that learning could be used to develop a person-centred commissioning pathway for the future. Available to download at http://www.idea.gov.uk/idk/core/page.do?pageId=8981022

Andrew Tyson's paper **Commissioners and Providers Together: the Citizen at the Centre** argues that the vision which underpins self directed support will only become a reality if commissioners and providers find new ways to work together in order to support people in their desire to become active citizens. The paper is available to download at http://networks.csip.org.uk/Personalisation/Topics/Browse/Commissionersandproviders/?parent=2735&child=2683

Information about the national evaluation of the Individual Budgets pilot projects (IBSEN) is available at http://php.york.ac.uk/inst/spru/research/summs/ibsen.php

Our **Shaping the Future Together** pack includes information to help managers and commissioners improve services based on detailed evidence collected from person centred plans. It can be downloaded at http://www.learningdisabilities.org.uk/our-work/person-centred-support/shaping-the-future/

Kent County Council provides an example of how one local authority is building community capacity through grants to not-for-profit organisations: http://www.kent.gov.uk/publications/social-care-and-health/building_community_capacity_grant.htm

Reminding people about community is a paper written by Alex Hamilton of Quest for the Valuing People Support Team website. It provides an interesting background to the social exclusion of people with learning disabilities and useful information about key concepts around community development for this group. Available at: http://www.valuingpeople.gov.uk/echo/filedownload.jsp?action=dFile&key=389.