Developing new lifestyles with disabled people

There is growing consensus that daytime opportunities for people with learning difficulties and disabled people need to be improved. People want to work, learn and enjoy a greater variety of leisure interests, spending more time in ordinary community settings with old and new friends. Supporting people to achieve this - in essence, a more ordinary lifestyle - is the challenge for service providers. This project implemented recommendations from the national Changing Days Project about how to improve people’s lifestyles. Focusing on people with learning difficulties and disabled people living in four residential homes run by the Joseph Rowntree Housing Trust, the project found that:

Introducing a ‘person-centred’ planning process led to people doing more things they really wanted to do, and realising more of their hopes, dreams and ambitions.

Factors that were crucial to the success of person-centred planning were:
- ‘planning circles’ with members chosen by the disabled person;
- creation of two person-centred planning facilitators a step removed from the day-to-day support role;
- positive, visible leadership and effective workforce planning;
- training opportunities for staff that were tailor-made to underpin person-centred ways of working.

As a result of focusing more on what individuals wanted over a third reduced their use of day services. For day service providers it meant that, overall, 17 days of service per week were freed up.

Many people wanted to get a part-time job. Because most had never worked before, or had limited experience, intensive long-term support was required. Access to supported employment workers was important.

It was easiest to support people to develop their leisure and educational interests directly from where they lived. This had implications for staffing resources in the residential homes.

Some people developed more involvement in the community and built friendships with other citizens - leading to the development of ‘natural support’ - but it took time, deliberate action, persistence and creative thinking by staff.

Setting up a cross-service residents’ group which discussed common interests and took part in service evaluation was really empowering for people, and helped the organisation hear people’s views.
Background
This project grew out of the UK-wide Changing Days Project (supported by the Joseph Rowntree Foundation and the Gatsby Charitable Trust). The findings from the UK-wide project were used to improve daytime opportunities for disabled people living in Joseph Rowntree Housing Trust residential accommodation.

Person-centred planning
“IT’s very interesting - you plan things about your future.”
Two residents

Finding out what people living in the four homes wanted - their preferences, ambitions and dreams - was at the heart of the project. An early consultation day revealed that each person wanted different things and that it was important to focus on individuals. This was achieved through the introduction of a ‘person-centred’ individual planning process across the homes. Focusing on each person as a unique individual was particularly important because people were living in group residential provision where the wishes and needs of the many can overshadow those of an individual.

Each person had his/her own ‘planning circle’ – a group of people who cared about the person and were committed to improving their life - to help them work out what they wanted to achieve and how to go about it. Planning circles helped draw people in from outside the service. This made an important contribution to changing the service culture.

Good organisation and facilitation of planning circle meetings was crucial to ensure that:

• people were supported to make arrangements for their circle meetings;
• the person’s needs and wishes remained the central focus;
• planning was done in ways which involved and empowered the person;
• everyone’s views were heard and valued, and differences of opinion were mediated;
• goals were agreed and action planned;
• action agreed was not governed by service-led options and constraints;
• members of the circle received support and encouragement to stay involved.

Staffing for the project
At the start of the project eleven people were trained to facilitate planning circles for people living in the homes. All were senior staff or managers from the homes and from local day services. After nine months it became clear that these staff were having great difficulty in keeping the process going.

Pressures on their time and ‘conflict of interest’ issues arose because their position within the service made it extremely difficult for them to maintain the person-centred principles and objectives of the planning circles.

A decision was made to create two half-time posts with a specific remit to facilitate the planning circles. Being one step removed from the homes the two facilitators did not experience the same conflict of interest, for example when liaising with parents and family members, or with managers. They could hold more firmly to the principle that the person should be the driving force in the planning process without jeopardising working relationships in the homes. They were able to focus fully on keeping the process moving, developing their facilitation skills, and ensuring that the person’s wishes were central.

“Having the facilitators has been the most useful thing.”

“Bring outside facilitators in early.”
Two members of staff

The role of keyworkers and managers was also found to be very important. There were a number of things that needed to be done to make person-centred planning work well. It was crucial that people at all levels in the organisation understood that they have a role to play.

Empowering disabled people to take more control
Person-centred planning helped people to speak up about their personal hopes and ambitions and to be more in control of their lives. People’s horizons expanded and became more ambitious as they saw other people doing different things, as they themselves started to achieve things, and as they got more used to thinking and talking about the opportunities they wanted.

Staff and people involved in planning with individuals needed support to think ‘beyond the
comfort zone’ though. They needed to be challenged to think about who does what and decides what for the person; what more the person could be supported to do and what decisions s/he could take charge of or be more involved in. Managers needed to think about what might be stopping people taking more control, and how the service could be changed to enable them to do so.

The formation of a cross-service residents’ committee played an important part. The group organised events that brought people from the homes together to discuss common interests, questioned managers about policy and practice, and undertook an evaluation of the quality of life for people in one of the homes. This was viewed as:

"...a good idea ... if you don’t ask questions you don’t learn. We were trying to learn what they do in the home."

The evaluation went beyond consultation to real involvement. Disabled people gathered the information and made the judgements about what they found out. What made it even more empowering was that the Director of the Housing Trust’s care services met them to discuss their report.

Having someone from beyond the organisation to support the group was critical in avoiding conflicts of interest and staying focused on residents’ perspectives.

Building relationships and natural support through community involvement

"My circle is quite good. I get to meet people and do things."

"I now go to watch football matches and have bought a season ticket."

Two residents

The project aimed to involve as many ordinary citizens as possible in people’s planning circles. For several individuals, particularly those with higher support needs, this was not easy to achieve and focused effort was needed to draw people in. However, the more people participated in community-based activities the more their social networks grew and the more mixed their planning circles became.

It was a distinct advantage to be working with people directly from where they lived, especially when trying to improve their leisure activities, most of which ordinarily happen in the evenings and at weekends. However, staff and circle members needed regular support and encouragement to think beyond services and segregated opportunities for people. Some of the other things that helped were persistence, focusing on a person’s talents, not being afraid to ask people to do things, planning well, being flexible and prepared for the unexpected, finding people valued roles, and deliberately nurturing relationships.

The changes in people’s lives

After 18 months the project found that there had been a significant change in the daily pattern of life for some people. At the start of the project 25 residents were using day services provided and/or purchased by City of York Community Services. Eighteen months later:

- 24 people were using day services provided and/or purchased by City of York Community Services;
- 15 people had changed their day service use in some way - nine had reduced their use, four were using services for the same number of days but differently, and two had increased their use by one day a week;
- Of the 15, two people had completely moved out of day services, offset by one person who had started using a service one day a week.

Implications for services

The project analysed the themes emerging from people’s plans to see what was wanted and the implications for existing services. It was evident that, if people were to get to do the things they wanted to do, support in both residential and day services had to be organised in a more focused and deliberate way around individuals’ goals. There were consequent implications for commissioners of services.

Some people needed only a small amount of ongoing support with their chosen pursuits. The short-term investment in increased support paid off in longer-term gains for individuals and in freeing up places in day services. Seventeen days of service per week had been freed up, the equivalent of 3.4 full-time places across all the day services. However, this ‘saving’ to the local authority could not be converted...
into money because of the way the services were organised and funded. Essentially, the block funding of large group provision made it difficult to extract funds to pay for alternative, more appropriate support packages for people.

"It’s about moving the Titanic around."
Local authority manager

Existing service models proved a barrier. The project concluded that reorganisation of services was needed to enable people to achieve their goals, particularly moving away from residential and day services which congregate disabled people together within special buildings.

Many people wanted to get a part-time job but existing employment services were not meeting their needs. Access to a supported employment scheme was important to secure the intensive and long-term support people required. Change, however, took some time to achieve so that the numbers taking up some form of employment before the end of the project were small. Support for residents wanting to work is continuing and some positive outcomes are anticipated.

About the study
The project took lessons from the national Changing Days project and applied them in a voluntary sector residential service for disabled people and people with learning difficulties. All the Changing Days work has been based on the core beliefs that:

- disabled people have the right and ability to become full participants in their local communities;
- better daytime opportunities can be achieved by working in partnership with disabled people, carers and staff to plan and shape the future;
- the future for disabled people should be away from segregated day centres and building-based services towards being supported to participate in ordinary activities in community settings;

The project worked through day-to-day practice challenges around:

- person-centred planning;
- residential staff supporting people to do things from their home base;
- change management;
- partnership working across organisations;
- developing people’s community involvement, social networks and natural support;
- supporting people to get and keep jobs;
- moving from group care to an individualised lifestyle chosen by the person.

It aimed to enable people living in the homes to realise their own hopes and wishes, have more individualised day opportunities, become more involved in their community, and be less reliant upon attendance at day centres.

How to get further information
The full report of the project, "We want our voices heard": Developing new lifestyles with disabled people by Angela Cole, Barbara McIntosh and Andrea Whittaker, is published for the Foundation by The Policy Press as part of the Community Care into Practice series (ISBN 1 86134 287 X, price £16.95). It is available from Marston Book Services, PO Box 269, Abingdon, Oxon OX14 4YN, Tel: 01235 465500, Fax: 01235 465556, email: direct.orders@marston.co.uk (please add £2.50 p&p).

A summary of the project for people with learning difficulties is available free of charge as part of the Plain Facts series. from Plain Facts, Norah Fry Research Centre, 3 Priory Road, Bristol BS8 1TX, Tel: 0117 923 8137.

The four publications from the national Changing Days Project are available from the King’s Fund, 11-13 Cavendish Square, London W1M 0AN.

Further information can be obtained from Angela Cole, Tel: 01621 857819; Barbara McIntosh, Tel: 0207 928 7994; or Andrea Whittaker, Tel: 0208 346 7325.

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