

Chapter 4:

Day Opportunities for People with a Learning Disability

Overview

In the United Kingdom over the past 20 years and more, Government policy in learning disability has been dominated by the resettlement of patients from long-stay hospitals. This in turn has led to increased scrutiny of the various models of residential services that is offered to this client group.

By contrast, there has been little radical change in the provision of day services, although as Simons and Watson (1999a) noted: *“the way day services are currently organised is widely perceived to be problematic; there is a collective disaffection with current arrangements”* (p.7). These authors also note that *“there is relatively little evidence about the outcomes achieved by different models of provision ... many forms of day service are largely unevaluated”* (p.5).

Although research is limited, the evidence does suggest that centres under-perform in terms of the outcomes they offer to people with a learning disability; they perpetuate a segregated model of provision that is increasingly out of tune with modern values and they do little to enable people to form relationships within their communities. These truisms should encourage a critical review of existing expenditure in day centres and caution against extending this model of provision.

There is a growing consensus of the need to widen the range of options available beyond day centre attendance. This includes Further Education, Vocational Training, Work experience, Paid Employment, Voluntary work, Social and Leisure activities. However these alternatives are not without their difficulties. The range of choices is not always available in any one locality; monies required to initiate and sustain new services are not readily available and the co-ordination of diverse services is not easily achieved.

The solution probably lies in refocusing the ‘problem’ of day services from one that is addressed as a subset of learning disability services to an issue of social inclusion for a marginalized group of people within our society. This means engaging with a range of statutory and non-statutory agencies across many different sectors rather than relying solely on health and social services to deliver new forms of services. Nonetheless for the foreseeable future, they will continue to have lead responsibility for this

client group as they negotiate with and support other agencies in undertaking new roles.

The chapter is divided into five main sections.

Section 1 examines Day Centre provision;

Section 2 focuses on Further Education;

Section 3 outlines options for Vocational training and Supported Employment

Section 4 reviews research into Leisure and Friendships.

Section 5 considers new service strategies, with particular emphasis on the transition period of 14 to 25 years.

Section 1. Day Centres

Day centres are the bedrock of day service provision in Northern Ireland as elsewhere in these islands although this was not always so. In December 1962, over 1,800 persons were resident as 'special care' patients in Hospitals whereas 833 persons – children and adults – were enrolled in 19 day schools and occupation centres (Scally and McKay, 1964). By 1982, the balance had shifted as the number of places in day centres rose to over 2,000 and ten years later in 1992, this had increased to over 2,800 places with some 3,100 people receiving a service (DHSS, 1995).

In 2002, an estimated 4,000 persons are registered with day centres/training centres and workshops (DHSS&PS, 2002: NB with correction for an over count in one Trust). This represents around 70-75% of persons aged 20 to 64 years living with family carers or in their own accommodation (McConkey and colleagues, 2000, 2002, 2003a, 2003b).

However the number of places provided in centres is lower because a proportion of persons attend centres on a part-time basis. In the financial year 2001/2002, day centres cost £24.5 million.

Comparable figures for Scotland in 1998 were 8,300 attenders at a cost of £53 million (Scottish Executive, 2000) and for England over 60,000 attended local authority day centres at a cost of around £240 million (Department of Health, 2001).

Although these figures may not be strictly comparable, they do suggest that the per annum cost for each person attending a day centre in Northern Ireland is around £6,100 whereas in Scotland it is £6,400 and in England it is £4,000 (NB the lower figure for England may reflect the net cost after charges have been deducted.)

The data from the three countries suggests that there are more people attending day centres in Northern Ireland (23.5 per 10,000 of total population) than in Scotland (15.1 per 10,000) and England (12.0 per 10,000). The lower figures for Scotland and England may reflect greater numbers of people in other forms of provision or not in receipt of any other services.

In the Republic of Ireland around 6,700 people living with family carers or in community accommodation attend some form of day provision. This is equivalent to 17.2 people 10,000 total population with an average cost of around €9,000 (£6,100).

Who attends day centres?

A total of 77 day centres were identified during the Northern Ireland Review of Day services (McConkey, 2004 a). A postal questionnaire sent to the managers yielded 48 replies (62% response).

The median number of people registered with the centres was 44 but the range was from 2 to 170. The median age of attendees was 40 years (range 16 to 87 years). The centres served a diverse clientele. For example, each centre had a median of 8 people with severe challenging behaviours ; 6 persons with profound disabilities; 3 wheelchair-users, 1 person with autism and 1 with dementia. In addition 25% of centres had at least one person who was technologically dependent (one centre had six persons.)

Research conducted in Foyle HSS Trust (2000) contrasting centre attenders in 1994 and 1999, found an increased number of people with medium and high dependency allied with challenging behaviours. One Derry centre in particular had transformed into

a 'high dependence care facility' as more able clients had moved on to vocational training, supported employment and outreach centres. This finding is common throughout these islands and has led some to argue that centre attendance in the future should be restricted to those individuals in need of 'social care'.

Demand for places

The number of people in Northern Ireland seeking places in day centres continues to exceed the vacancies that arise through retirements or deaths.

An estimated 180 children with severe and profound learning disabilities leave school each year – 900 in the coming five years (McConkey, Spollen and Jamison, 2003). If all were to be accommodated in day centres; this would require an increase of around 20% in the number of places and an additional revenue cost of £5.5 million. To date the main way in which this pressure has been responded to is by increasing the number of part-time placements.

More attention need to be given to the alternative options. For example in one HSS Trust, of the 49 school-leavers over a five year period; 80% were estimated by their teachers to require day care (Sperrin Lakeland HSS Trust, 2000). By contrast nearly half of the parents (47%) in a Belfast survey would like their special school-leaver to get a job and another 8% thought a mix of activities would suit their son or daughter best. Only one third felt a daycentre place was required (Smyth and McConkey, 2003).

Functions of centres

In the United Kingdom the form and functions of day centres have changed over the years. Originally conceived as 'occupation centres' with an emphasis on sheltered work, they gradually transformed during the 1960s into Adult Training Centres with a focus on independence and skill development through to Social Education Centres in 1980s when leisure and recreation came to the fore until the present day when the vogue is for Resource and Activity Centres with the aim of supporting outreach into the community (Simons and Watson, 1999a).

The N.I. survey of day centres (McConkey, 2004a) identified the different functions that centres attempted to fulfil. The following functions were those that at least two-thirds of managers reported as meeting for most of their clients (the percentage of centres is given in brackets: N=48).

- Provide opportunities to have fun and enjoyment (94%).
- Keep an eye on people who may be vulnerable to neglect or abuse (92%)
- Give people a break from being at home (89%).
- Provide opportunities to socialise, make friends, develop relationships (88%).
- Provide personal care in safe and respectful ways (85%).
- Encourage social inclusion and use of community facilities (76%).
- Encourage self or group advocacy. Promote positive self-image (69%)
- Stimulate the person through senses, creative arts (69%).
- Provide a resource base for health and dental checks (66%)

Surprisingly fewer centres rated the functions of providing educational opportunities, vocational training and employment as being met for most of their clients. This suggests some differentiation of the primary aims of day centres away from the functions of skill development and training that had featured more strongly in the past.

Several reasons could be advanced for this: the changing needs of people attending centres; the growth of alternative options for providing these functions such as FE Colleges and the advancing 'social care' ethos that permeates day care for all client groups.

However there was variation among centres in the functions they identified and the extent to which they met them for their attenders. Likewise, Beyer et al (1994) in a survey of Welsh centres found wide variations in what people actually did in centres even within the same local authority. It appeared that personalities and precedents rather than a coherent service philosophy determined what was offered to clients.

The views of people attending centres

Recent reviews of day services in Northern Ireland have ascertained the views of people with disabilities through individual and small group interviews, and consultations events with presentations being given by Day Centre Committee members. Among the aspects most valued are opportunities to meet friends, different activities both in and outside the centres; work placements and having a job, getting money (many centres make payments of up to £4 per week); the support and friendships of staff in the centres and a chance of becoming more independent.

They identified many improvements including, better transport arrangements, more staff, more training placements and work opportunities, more leisure activities especially in the evenings and at weekends, an end to bullying within centres, more advocacy and better 'wages' (McConkey, 2004a).

Reconfiguring centres

One particular constraint in redefining the function of centres is the actual building used. Often these were not built for the purpose they are now called on to serve nor are they located in settings that easily foster community integration.

Large centres draw people from a wide geographical area which makes it difficult for people to maintain contacts with their centre friends at evenings and weekends. However the primary concern has been with the time people spent travelling to/from centres (especially in rural areas). In NI, only 20% of centres were able to transport most of their clients from home to the centre in 30 minutes or less. Furthermore transport costs are estimated to absorb up to 25% of the centre's revenues costs plus the added capital costs.

A favoured solution to the transport issue has been the development of smaller and more local 'satellite units'. In Wales, 39% of centres had developed such units by the mid 1990s (Felce et al, 1998) and there is evidence of this happening also in Northern Ireland (McConkey, 2004a). The theory is that these units will also enable people to access community resources more easily although as yet there has been limited evaluation of their effectiveness on so doing. Felce et al (1998) found little evidence of increased individualisation of the service or difference in activities undertaken within smaller units. A major reason for this, is that staff perpetuated their familiar work routines into these new settings rather than changing to accord with the new opportunities.

A related development has been the idea of a 'drop-in' centre which is controlled more by users who decide on the activities and they are responsible for managing the centre with the support of facilitators (McIntosh and Whittaker, 1998).

Centre closures

A more radical view has been to promote the closure of all day centres along similar lines to the resettlement programmes from institutional care and to replace them with individually-based, “services without walls”. However few, if any authorities have taken this step and it does not appear to have widespread support. For example Mencap (2000) argued that *“there will always be a place for building-based services – even if more of these are resource centres and most activities take place elsewhere”*(p.12).

Rather the emphasis has been on defining more clearly the clientele that is served by day centres and the specific services provided by the Centre. The Mental Health Foundation (1996) proposed that centres *“should be encouraged to evolve from within, developing services tailored to the individual needs of their users.... Those who attend should be offered an individual contract with the centre, setting out the nature of the services they will receive, to be reviewed regularly.”* (p. 39).

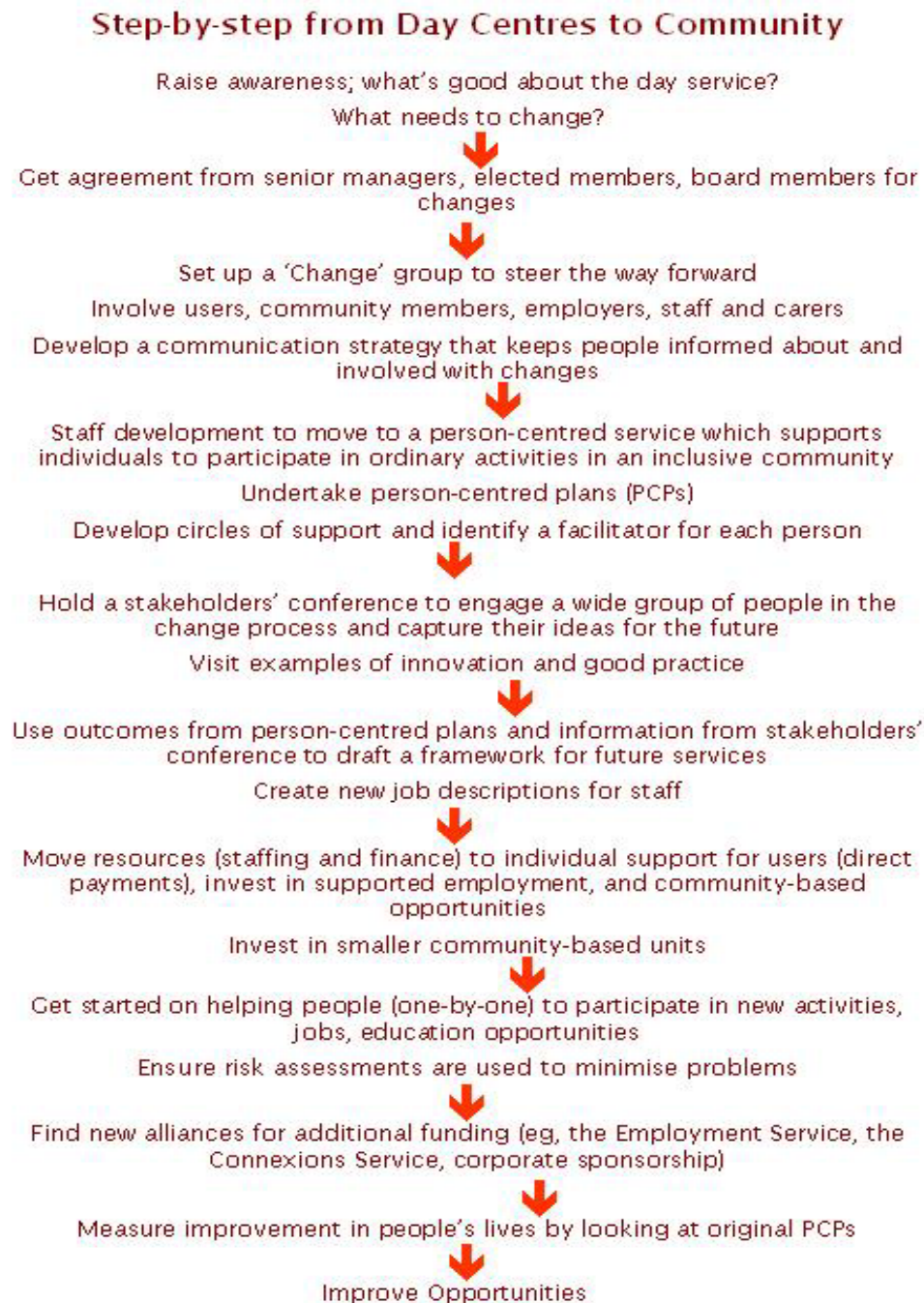
Changing Centres

McIntosh (2002) directed a five-year ‘Changing Days’ development programme based in the King’s Fund Centre and involving nine sites throughout the UK. The key aim was to improve people’s day opportunities and a core element was re-formulating the form and function of day centres. A major stumbling block was the culture within statutory services. Among the main issues identified were:

- Ten years of budget cuts and constraints.
- Little input from care management in many day centres and a sense that some care management services were acting as a rationing service.
- Financial issues were complex. Few managers had a good understanding of how to manage financial changes and shift funding to the community and to individualised support.
- Managers overwhelmingly felt that they had no guarantee that capital raised in selling a day centre would come back to the learning disabilities service. This proved to be a barrier in itself.
- The day centre culture was busy and friendly but most of the energy of staff went into maintaining existing routines. It was exceptional to see examples of planning which moved towards individualised lifestyles.
- The friendly environment of many day centres acted as deterrent for some staff to look outwards to the community”.

From experiences gained in effecting changes, the research identified key stages in moving from centres to community. These are summarised in the Figure overleaf.

McIntosh (2002) concluded that: *“All of these changes ask service users, staff, and parents to be energetic and committed in finding new solutions and to be more creative in the use of public funding.... The challenge remains to show that individual by individual, and community by community people can receive the right support, retain the best of the past, and have new positive experiences in the community”*.

Figure: Stages in changing from Day Centres to Communities (McIntosh, 2002)**A service for carers?**

Day centres are not just for people with a learning disability. A major function is the respite they offer family carers in particular but also the substitute care they offer for people living in residential services. (In Northern Ireland on average 30% of day centre attenders are in some form of residential accommodation). This has led Dowson (1998) to question to closure of centre-based services and Mencap (2000) to argue that "day centres should only close if there are good places to go to instead" (p.13).

The implicit contract with carers, is that centres will offer year-long, five-day placements for a specified number of hours per day with transport provided to/from the person's residence. With demand exceeding supply, part-time attendance at centres has become increasingly more common (Mason, 1998). Sometimes service-users attend alternative services (e.g. College or work placements) but others are home-bound. It has proved very difficult to offer carers a guaranteed five-day service all year round in ways other than through attendance at the same day centre. This more than anything, may account for the resilience of the centre-based service model, especially when the views of the person with learning disability are not sought or heard.

This demand is further reinforced by the lack of access that Northern Irish carers have to respite breaks at other times such as evening and weekends (Sines, 1999; McConkey and Adams, 2000).

Variations consultations were held with family carers as part of the NI Review of Day Services (McConkey, 2004) and as part of the day services reviews in two trusts (Foyle, 2000 and Sperrin Lakeland, 2000). They valued the role centres played in helping their relative become more independent, to socialise and to take part in a range of activities. They also found the staff supportive and helpful. However they identified many inadequacies; notably the need for longer opening hours, staff shortages, excessive travelling times to and from centres; improved contact with clinicians, better information and support for carers; work opportunities, wider range of activities and more individualised planning. In sum, the day centre service was not planned to meet the explicit needs or wishes of carers. This is ever more apparent for carers who are in full-time employment and for those caring for a multiply disabled relative.

Carers of school-leavers expressed concern about the age range of people attending centres and were more willing to explore alternatives such as Colleges and employment (McConkey and Smyth, 2002).

What happens in centres?

A growing body of research has looked at the experience of centre attenders in terms of their level of engagement in activities and the amount of time spent in non-segregated settings.

Levels of engagement appear to vary considerably across centres; from 18% to 92% of clients' time spent in activities within Welsh Centres (Lowe et al, 1991). The main reasons for disengagement tended to be time spent 'waiting' although for people of lower ability, not being allowed or enabled to participate was the most common reason. People with greater support needs spent on average only 12% of their time engaged in activities (Pettifer and Mansell, 1993).

A study of 17 English day centres (mean of 81 places in each) found that on average each person had around 20 hours of timetabled activities; mostly arts and crafts, personal development and sports (Felce et al, 1999). External paid work or voluntary work were marginal activities accounting for only 3% of activities noted. Overall, only 13% of person-hours were organised as individual activities; most time was spent in groups. Users had staff attention for around 16 minutes in each hour and were engaged in activities for 54% of the time but this fell by half in sessions for people with high support needs. The researchers concluded that people with high support needs within typical day centres had only about 5 hours of constructive occupation per week.

The picture is similar in the way centres respond to people with challenging behaviour (Allen and Hill-Tout, 1999). Fewer numbers of these individuals attend the centres than

would be expected; suggesting that such people are actively excluded. There was also little evidence of any special planning around the behavioural needs of clients and where plans did exist, they were predominantly reactive in nature.

However levels of engagement for people with additional needs could be boosted when they were given intensive support by centre staff who had been specially trained in these methods (Jones et al, 2001).

Comparisons of engagement levels across different settings are sparse but Kilsby and Beyer (1996) and Bass and Drewett (1997) reported near doubling of engagement levels in supported employment settings compared to day centres.

Although centres have become more outward looking, Beyer et al (1994) reported that two-thirds of person hours were still spent within centres. However even when people use community facilities they may do so as a distinct group, for example in the use of public swimming pools (SSI, 1995) or attend a satellite unit established by the centre but based in a community building.

Although similar data is not available for centres in Northern Ireland, the data presented earlier on the functions which centres serve, does suggest a predominance of a care and leisure ethos. In part this role may have been forced on centres due to resource constraints.

Pressures on Day Services

The main pressures identified by existing centre managers were lack of staffing, lack of access to better resources and equipment; inadequate building and better access to transport (McConkey, 2004). In particular managers noted:

- Services have difficulty in recruiting and retaining staff. Salary levels and grading structures need to be reviewed. There is insufficient staff to cover holidays and sickness. More training is required.
- Journey times to/from centres are too long. More suitable vehicles are required.
- All services have to cope with clients with a wide range of abilities and ages among the clients.
- More funding is required, with employment services emphasising the need for guaranteed long-term funding.
- The majority of respondents felt that incentive payments should continue to be paid by centres although a sizeable minority did feel they should be discontinued.

Diversification of functions

In recent years, there has been a shift away from multi-functional centres. A national survey in the Republic of Ireland (McConkey and Murphy, 1989) identified four types of centres (serving an estimated population of 6,500 people): short-term training centres (18% of all attenders were placed here); long-term training centres for more able clients (18% attenders) ; long-term centres for the full range of clients (42% attenders) and short and long-term centres for people with a mix of learning disabilities and other disabilities (22% of total).

A Welsh survey of day centres (Beyer et al, 1994), identified four 'models' based on the pattern of activities they offered; namely Recreation (mainly arts and crafts and sports); Recreation plus personal development (as before plus personal care and social skills); Employment (focus on work experience and paid employment) and Occupation (mainly

contract work). However these models were not linked to particular local authority or size of centres which suggests they are not linked to specific policy initiatives.

Similar conclusions had been reported by Seed (1988) in his study of Scottish Centres. He proposed the way forward should be through the promotion of three types of resource centres: a 'work resource' centre focussed on obtaining paid work for clients; a 'further education' centre that concentrated on developing the skills needed for living more independently in the community and a 'community resource centre' designed to strengthen client's links with people and facilities in their local communities. A consequence of this analysis, is that each model would require distinct staffing, resourcing, curricula, location and management. One centre could not deliver these three models simultaneously.

Seed's tri-partite conceptualisation has been validated by subsequent reviews of policy in day service provision, e.g. by Mencap (2000), Mental Health Foundation (1996) and Department of Health (2001) but with one important difference. Further Education and Employment services are seen to be the responsibility of mainstream services rather than of health and social services which flowed from a new emphasis in Government policy on social inclusion and equal opportunities for people with disabilities.

Conclusions

The existing model of day centre provision needs to be radically reviewed.

A major challenge for Health & Social Services has become one of persuading and ensuring that mainstream agencies accept their responsibilities with regard to ordinary needs of this client groups. Additionally mechanisms need to be devised to co-ordinate the various services that each individual receives.

When and if these developments happen, it will be somewhat easier to re-define the functions of day centres provided by social services but meantime centres will probably have to struggle with trying to meet too many diverse aims for too many people with a wide range of needs and aspirations.

Section 2. Further Education

The inclusion of adults with a learning disability in the further and continuing education sector dates back to the 1970s in Great Britain and from 1982 in Northern Ireland. However it was not until the 1990s that this provision became more widespread. In Wales the number of places doubled in the period 1983-1995 (Perry et al 1998). This has been attributed to changed management and funding arrangements for FE Colleges that took place in Great Britain which increased the autonomy of colleges and provided financial incentives for the enrolment of special needs students (Simons and Watson, 1999a). Similar arrangements are now in place in Northern Ireland.

Although the changes were broadly positive a review undertaken by Macadam and Sutcliffe (1999) identified a number of shortcomings. The booming provision for people with moderate learning disabilities tended to squeeze out places for people with more severe disabilities, which in any case was very limited. The curriculum had narrowed to focus on literacy and numeracy skills and vocational courses. The increased emphasis on nationally accredited courses meant fewer courses that specifically met the needs of people with a learning disability. Much of the FE provision consisted of special classes and courses rather than including people with a learning disability in mainstream courses. This consequently limits the opportunities for social inclusion.

A major shortcoming has been the lack of evaluation of the value of these courses to the learners and of systems for inspecting the quality of provision on offer. Two further concerns are the lack of progression from FE provision and the failure to instigate effective cross-agency collaboration involving education (Simons and Watson, 1999).

A review of FE provision in Northern Ireland for students with a learning disability (DHFET, 2000) found significant variations across Colleges in the number of these students enrolled as a proportion of the student body – 0.4% to 18.5%. However the average level of enrolments (4.1%) was lower than the mapped incidence for England (5.7%). The differences in full-time enrolments was even more marked – 11% of all students with a learning disability in N. Ireland were enrolled on full-time courses, whereas in England the comparable percentage was 45%.

The report concluded that: *“a formal and coherent approach to the principles of .. inclusiveness is underdeveloped in the FE Sector in terms of policy, planning, management, resourcing and identification of unmet need”* (p ii).

There are however good examples of innovative practice taking place in Northern Irish Colleges for pupils with severe learning disabilities (e.g. McConkey, McCallum and Patterson, 1999). The curriculum of one fulltime course covered adult basic education, the use of information technology, independent travel, health promotion, work training and a work experience placement. An evaluation of the course at the end of the second year involving the 17 students enrolled and their families, found that all but one had coped with the College environment; the course had increased students' confidence; the student's learning had been accredited, the work placements were particularly valued; and the parent's initial reluctance had dissipated. Ongoing issues included transport from home to College; the need for ongoing links with the Special School; developments in the curriculum; and the student's inclusion in other College activities and post-course provision.

A consultation conducted by Mencap NI (2003) in their Northern District into FE provision noted the range of courses being taken on a part-time basis by people with a learning disability: cookery and food preparation, hairdressing, office skills, first aid

courses, adult literacy, art and craft, gardening, personal grooming, music and physical education. They commented on a reliance on day centre transport for getting people to and from college and that active steps need to be taken by colleges to encourage and promote the inclusion of people with a learning disability in all aspects of student life. Also in some areas the absence of a local college meant that people with a learning disability did not have the opportunity to experience student life in a college.

People who have taken courses at colleges generally speak favourably of their experiences both in terms of the subjects studied and achieved attained but also in terms of their social and personal development (e.g. Harrison, 1996; Skill NI, 2000). However a more structured and organised system is needed within Colleges to support their learning with greater attention being paid to their individual aims and aspirations and planning the learning process in association of students. They also valued having someone in colleges whose help they could enlist in representing their requirements (Skill NI, 2000). The appointment of Special Educational Needs Co-ordinators within Colleges could go some way to meeting these needs.

A consultation conducted by a group of young people with disabilities (Educable, 2000) concluded that the low expectations of teachers and often parents had left them unprepared for life after school. They identified the need for independence training to be more practical and started earlier in life; for more informal education opportunities to promote confidence building, self-esteem and assertiveness and for the non-academic learning to be accredited in National Awards.

Conclusions

There is great scope for further developments within the FE sector in Northern Ireland even to bring it in line with practice in Great Britain. However this will require major commitment from colleges to address adequately the needs of this group and for them to forge partnerships with other agencies in these endeavours.

A Special Educational Needs and Disability Order for Northern Ireland should come into place in 2005. If it follows English legislation it should give people with disabilities new rights in adult and community education, further education, higher education institutions and youth service provision. Likewise the Disability Discrimination Act has been extended recently to further and higher education.

Nonetheless further education is another step in life's journey but in itself is not the end. A critical issue is what happens when College courses are completed? The need to prepare young people with disabilities to take their place in the workforce must be to the fore throughout their education (Monteith and Sneddon, 1999).

Section 3: Vocational Training and Supported Employment

Although in past years work was always an option for people with a learning disability, this was largely done in the context of sheltered settings with an emphasis on contract work that typically involved boring, repetitive tasks with little monetary reward for the so-called 'workers'.

However the advent of supported employment from North America, with its slogan 'real jobs for real pay', has opened up new possibilities for people who previously were deemed unemployable in the open job markets.

Supported employment is based on the principle of 'place and train' (Beyer and Kilsby, 1997; Anderson, 1998). Job opportunities are found for the person in line with their talents and interests. He or she is then trained on-the-job by a 'job coach' who also adjusts the working environment if necessary and enlists the assistance of co-workers. The job coach gradually fades out but remains in contact with employers should any problems arise.

This approach is directly counter to the 'readiness model' which aims to prepare people for work through special training programmes; a model that had dominated in the field of disability nationally and internationally. However a low proportion of trainees actually obtained paid employment in the open labour market (Beyer et al, 1994).

There has been considerable growth in supported employment in the UK over the last decade with some 200 agencies in 1995 who were supporting in excess of 5,000 people and the numbers were growing.

In the Irish Republic nearly 1,000 persons with earning disabilities are in supported employment projects which recently received a major boost when the Government 'mainstreamed' these services into the FAS; the agency for training and employment and provided around €4 million per annum to support schemes provided mainly by voluntary sector consortia.

At present, the NI Union of Supported Employment has over 15 non-statutory agencies in its membership plus many other day centres are involved in this work.

In the main, these supported employment services have focused on clients with mild and moderate disabilities although there is some evidence that people with severe disabilities and challenging behaviours can benefit also (Martin et al, 1999).

There is also growing evidence of the cost-benefits of these services (Beyer et al, 1996) with high levels of user satisfaction. However one of the main disincentives has been the impact of earnings on social security benefits paid to people with disabilities and their families (Simons, 1998a).

To date the main funders of supported employment services in Great Britain have been social services and health authorities although in Northern Ireland and the Republic of Ireland, European monies have provided the bulk of the costs. However these funds are not guaranteed in the longer term. Also recent experience in the Republic of Ireland has shown the difficulties that can arise in ensuring that supported employment services fully meet the needs of people with a learning disability when they are provided through mainstream training and employment agencies who measure success in terms of the number of people placed in employment within specific time periods.

However there is growing evidence in Northern Ireland as well as elsewhere that young people leaving school and their parents aspire to having paid work. Nearly 50% of

parents and over 90% of young people in a Belfast survey mentioned having some form of paid work as their preferred activity after leaving school (Smyth and McConkey, 2003).. Many of the young people appeared to be influenced by the work experience placements they had undertaken either in school, FE College or the day centres. The most commonly mentioned jobs were in shops (7) office work and computers (7) and catering/cooking (5).

Likewise a survey of 275 persons attending three, day centres in Belfast suggested that upwards of one-third aspired to having a job and their key-workers thought that one in five would be able to hold down a job (McConkey and Mezza, 2000). These proportions were higher among those persons who had previous work experience placements and/or who attended courses at Further Education Colleges. Centre staff viewed poor concentration, communication skills and motivation as the most common obstacles to obtaining paid work. The main benefits to the individuals they saw were increased self-esteem, independence and confidence.

Other training and employment models

In addition to supported employment, a number of other approaches have been developed to better prepare people for employment and to give realistic work experiences. McGrath (1995) classified them as follows:

Vocational training: These provide time-limited courses linked to nationally accredited awards such as NVQs. Often they are linked with unpaid work experience ideally in a range of jobs so that people have ‘tasters’ of what work is like and whether it matches their expectations.

Social Enterprises and Social Firms: These have been created specifically to give employment for people with disabilities. They pursue a market-orientated production of goods and services on a commercial basis. Employees are paid at least up to maximum allowed by social security benefits. Opportunities for work experiences can also be offered and some employees may move into supported employment in comparable businesses.

Supported Volunteering: The concept of people with a learning disability acting as volunteer workers to help other people is largely underdeveloped. However there is growing experience of their aptitude and competence in these tasks which to date have included childcare; home helps and assisting in residential care settings.

In sum, opportunities to work and the prospect of paid employment can be a reality for sizeable numbers of people with a learning disability if they receive appropriate training and support.

Experiences of employment-related schemes in Northern Ireland

The NI Review of Day Services (McConkey, 2004a) identified 31 employment related schemes; 17 of which responded to the questionnaire. In addition to vocational training, work placements and supported employment initiatives, a wide range of work opportunities and social firms were reported including recycling schemes, horticulture, café and catering, pottery and business centres.

Unlike day centres, these services identified only two main functions they fulfilled for most of their clients: namely the provision of vocational training, career education, work experiences and supported employment (80% mentioned this) and to provide educational opportunities in social skills, literacy and numeracy (69%).

The median number of people registered with the schemes was 44 (similar to day centres) but the median age was lower – 30 years (range 16 to 67 years). Each service had a median of 3 persons with autism and 1.5 persons with severe challenging behaviours. Typically these services had no persons with profound disabilities; or who were wheelchair users or had signs of dementia although some of the services had people who fell into each of these categories. The majority of people lived with family carers.

The main improvements that managers of these services wanted were: more long-term funding; more opportunities for work/work placements; improvements to the benefit system to take away the disincentives to obtaining paid employment; more staff and better staff training.

There has been limited evaluation of vocational training initiatives in Northern Ireland. Taylor, McGilloway and Donnelly (2001) evaluated four schemes provided by various agencies under the V.O.T.E initiative with over 70 beneficiaries with disabilities. They concluded that the schemes had achieved significant success in terms of improving trainee's employment prospects although the numbers actually gaining paid employment were small. They concluded that future services and projects should focus on the identification of suitable types of training, work placements and employment; the selection of appropriate candidates for different types of schemes, paths or settings; ways of supporting employers to adapt working practices and 'culture' and to support mechanisms that will enable more young adults with disabilities to cross the important step from improved qualifications and useful work placements to paid employment.

Evaluations of supported employment schemes have likewise documented the benefits to trainees; the approval of family carers and the support given by employers and co-workers (Anderson, 1999; McConkey, 2000; McConkey; Mezza and Wilson, 2000). However few of the trainees in these schemes had made the transition from training placement to paid work. Among the possible reasons are a reluctance by family carers to move off benefits, the type of placements selected not leading to paid work; the employer's unwillingness to make payments and the longer time required by these clients to make the transition from training to work.

Even so, a growing number of people with a learning disability are reported to be in some form of paid work, albeit individuals who are more capable. In the EHSSB and SHSSB areas, 10% and 8% of people with a learning disability were reported to be in paid employment; mostly part-time work; a figure that is broadly comparable with England and Wales.

Consultations with people who had experienced work highlighted how much they valued having a job and the benefits it brought not just financially but in terms of social inclusion, self-esteem and the opportunity to become a valued member of the workforce (NIUSE, 2003)

Future Prospects

These recent experiences allied to changes in legislation, such as the Disability Discrimination Act and Section 75 of the Northern Ireland Act, has resulted in increased commitments towards widening employment opportunities for people with a learning disability.

The Scottish Review of learning disabilities concluded that: *"Many people with disabilities want a decent job. They want to get on in life and have friends at work. The*

Scottish Executive's social inclusion strategy ranks having a job high in the list of measures to help people to be included in society. Employment has, so far, rarely been an option for people with learning disabilities. If they are to be usefully included in society, that has to change." (Scottish Executive, 2001: p. 58).

Likewise the English Review placed particular emphasis on creating more opportunities for paid work as their unemployment rates are greater than for people with other disabilities. The target set was "*to increase the employment rate of people with learning disabilities and reduce the difference between their employment rates and the overall employment rate of disabled people*" (Department of Health, 2001: p. 85).

In Northern Ireland this will necessitate closer working relationships between Health and Social Services with the Department of Employment and Learning than has hitherto been the case.

Conclusions

Many people with a learning disability aspire to having a job and increasing numbers of parents hold this aspiration for their teenage sons and daughters.

A range of vocational training courses leading to accredited awards have been developed tailored to the needs of this client group.

Various special initiatives, notably supported employment, have proved successful in creating work placements and paid employment.

Greater commitment is required from the Department of Employment and Learning and closer working relationships need to be established with Health and Social Services agencies.

Section 4. Leisure and Friendships

Many people with a learning disability live lonely lives. Most of their free time is spent in home-based pursuits such as watching television and listening to music with few friends of their own age.

Smyth and McConkey (2003) interviewed the parents of over 50 school-leavers from two special schools for pupils with severe learning difficulties in Northern Ireland. Three in five of the young people (58%) were reported to have no friends of their own. Of those reported to have friends (16 students in all), 12 were from the same school or centre as the young person attended although two of these also lived in the neighbourhood of the young person. Only one young person had a weekly meeting with her school/centre friends outside of the school setting; more often it was fortnightly (3), monthly (4) or occasionally (4).

Four students were reported to have non-disabled friends from the neighbourhood (11%) although only one person met his friend weekly usually in clubs or pubs.

In all 90% of parents would like their son or daughter to be more involved with friends of their own age and they mentioned the need for more clubs (10) and for more sports and leisure activities (6).

A similar picture emerges for adult persons (McConkey and McCullough, 2002). Over two in five people report that they have no friends outside of the day centre they attended and four was the most that anyone reported. The most common activities undertaken with friends were going to discos and social clubs but most of these were organised specifically for people with a learning disability, such as Gateway Clubs.

A study of 65 persons resettled from a long stay Hospital in Northern Ireland into nursing home and residential care (McConkey et al, 2000) found that only 14 people (21%) had regular or frequent contact with friends outside of their residence. This included contact with people in day centres. Only five people were reported to meet their friends away from the centres; through visits to the residence (4) or going out with them socially (2) or for shopping (1).

Overall, the mean number of different leisure activities residents had engaged in during the past four weeks was 5.6. However people living in nursing homes had a significantly lower mean score (3.1 activities) than those in residential (mean score 5.8) or community homes (7.4 activities). A similar pattern was reported by Emerson et al (2000) when comparing people living in residential campus settings and those living in dispersed community housing.

Overall people with a learning disability tend to lead more sedentary lifestyles than the general population and engage in significantly less than the minimum levels of physical activity recommended by the Department of Health (Messent et al, 1998). Levels of obesity appear to be rising among adults with a learning disability in Northern Ireland (Marshall et al, 2003).

The views of people with a learning disability and carers

People with a learning disability often express dissatisfaction with their community, recreation and leisure activities (Sands and Kozleski, 1994). They mention in particular the need for more evening and weekend activities and greater opportunities to take part in community events. Among the obstacles they currently experience are the lack of public transport and the prohibitive costs of taxis, problems with physical access to

premises such as cinemas, night clubs, bars and restaurants and the lack of a companion – befriender – to accompany them (Educable, 2000).

A study in the SHSSB area (Gordon, 2003) found that proportionately fewer young people with disabilities attended youth clubs, youth organisations and participated in summer schemes. The attitudes and practices of youth workers and leaders may be a major factor in this. It recommended better training for staff and increased resources provided by Department of Education.

Many family carers are also concerned about the lack of leisure opportunities (McConkey, 2004a). Among the suggestions they made were:

- Drop in centres and more social clubs
- Weekend or short breaks away
- Befriending schemes with long term commitments
- Education of the general public about learning disabilities
- Community Access/Support Workers to allow individuals to attend events/concerts rather than depending on their ageing parents/carers to take them
- Day centre facilities utilised in the evenings

Existing provision

Relatively little monies have been expended by social services in promoting the social and leisure lives of people with a learning disability. Often this has been left to charitable groups (often led by parents and relatives) and they continue to be the main provider of leisure opportunities outside working hours with a heavy reliance on volunteers.

The NI Review of Day services identified over 100 groups and schemes throughout Northern Ireland. Based on responses from 24 leaders, the median number of people registered with each scheme was 51 persons (range 6 to 409) with a median age of 30 years (range for 3 to 6 years). Most lived with family carers. Their primary functions were to:

- Encourage social inclusion and use of community facilities (96% mentioned this).
- Provide opportunities to socialise, make friends, develop relationships (91%).
- Provide opportunities to have fun and enjoyment (91%).
- Give people a break from being at home (86%).

The main improvements they felt were necessary included more funding, more staff and volunteers, better transport, more support from statutory agencies and better public awareness of disabilities.

However critics have suggested that special clubs perpetuates the segregation of people with a learning disability. Latterly a more tolerant approach has emerged largely based on the wishes of people to have friends who were also disabled (McConkey, 2004a). Intimate friendships are also more likely to be formed from within these networks.

Befrienders

The main service innovations in this area has revolved around the concept of befrienders; ideally a person of similar age, background and interests recruited to share some of their leisure time with a chosen partner. A Northern Irish survey identified this as the fifth most popular form of voluntary activity with an estimated 80,000 people involved across all client groups (Holloway and Mawhinney, 2002).

A number of dedicated befriending schemes have been set up by a range of agencies in Northern Ireland mostly in the non-statutory sector although as yet there has been no evaluation undertaken of their impact and sustainability.

A variant is the use of adult family placement schemes in which people with disabilities are placed with a carefully selected family for short-breaks. This has evolved out of family-based short breaks for children although to date fewer schemes involve adult persons and rarely have been they targeted at older carers whose need for breaks is well-attested.

The experiences of 25 carers, aged 55 years and over, of people with intellectual disabilities using one of two placement schemes in Northern Ireland were studied along with a further 20 carers who had been recommended for these schemes by their social worker (McConkey et al, 2004). Semi-structured, individual interviews were used to obtain the views of carers, people with intellectual disabilities and placement providers.

The placement schemes were very favourably received. All the carers wished to continue their involvement and most of the older carers not using such schemes expressed an interest in participating. The main benefit offered to carers was the chance of a break but they also valued the relationship they had built with the placement provider. Individuals with the disability reported that they had greater opportunities to participate in a range of activities while on placements.

The majority of placement providers were recruited from the care sector and many had previous experience of people with intellectual disabilities. Overall they were very satisfied with the way the schemes operated. The main complaint was the low level of payments.

The study identified a number of key issues affecting the further development of such services, notably recruitment of male providers, training and registration issues of placement providers and the difficulty in meeting the needs of multiply disabled persons who require special equipment.

However befriending schemes do have some potential drawbacks. The matching of 'friends' is often done by a professional worker or scheme coordinator; hence the person with a learning disability has very limited scope for choosing and developing their own friendships. The 'friendship' that develops runs the risk of being artificial in the sense that the able-bodied person is invariably cast in the role of helper and supervisor. Through time this can place quite a strain on the relationship. If the able-bodied person is no longer able or willing to continue, there is the added problem of finding a replacement while dealing with possible feelings of disappointment and loss in the person left behind.

Another approach attracting much interest recently is that of creating 'circles of support' or 'circles of friends' (Neville, 1996). There is no prescription for the form and format these take, as they will be guided very much by the wishes and needs of the person with learning disability as identified in their person-centred plan. That said there are some common strands in such circles.

They might include family members – siblings, cousins, aunts and uncles; neighbours and acquaintances; co-workers for people in work settings; members of clubs, churches and such like who know the person. The circle deliberately does NOT have professional workers as members although they can have a key role as facilitators or ‘go-betweens’ in starting the circles.

The depth of friendship will vary across the members of the circle. Some may be prepared to be intimately involved; others will continue as acquaintances but they will be better informed than previously. The circle can support people in educational, employment as well as leisure settings.

Circles Network – a UK-wide organisation – established a Northern Ireland Office in 2000 with charity monies to promote circles of support.

This idea can find expression in other ways. For example Key Ring is a Housing provider for people with a learning disability that works by building up mutually supportive networks among the tenants living within a geographical area as well as linking them into the communities where they live (Simons, 1998b). Likewise new forms of day provision often operate on the basis of creating social networks for their clients by slotting them into educational, employment and recreational opportunities in the community (Towell, 2000). As yet, there have been few formal evaluations of these networks as to whether they fulfil their promise.

Conclusions

The quality of people’s lives can be enhanced considerably through social networks and active participation in community life. A growing appreciation of this fact will hopefully provide a much needed spur for greater attention and energy being devoted to making this a reality for more people with a learning disability.

Ironically much more resources are expended on treating the possible consequences of social isolation –such as challenging behaviours and depression – rather than investing in preventative actions. However new strategies will be required as existing provision has demonstrably failed to produce these improved quality of life outcomes.

Section 5. Transitions from school to adult services

A recurring theme in recent British policy has been the need for joint commissioning of services across health and social services. To a large extent this stemmed from the twin sources of funding that have traditionally underpinned service delivery in Great Britain that does not apply in Northern Ireland. However this issue has arguably overshadowed a more complex agenda that is equally applicable to Northern Ireland; namely that of joint commissioning of services with other agencies, notably, education, training and employment services, and community leisure services. This theme will be developed more fully in Chapter 10 but it must also feature in any review of transitions from school to adult services.

Transition from school to adult services

The transition process has been defined as *“a change in status from behaving primarily as a student to assuming emergent adult roles in the community. These roles include employment, participating in post-secondary education, maintaining a home, becoming appropriately involved in the community and experiencing satisfactory personal and social relationships”* (Dunn, 1996). It is generally taken to cover the age range from 14 to 25 years of age.

Four dimensions have been identified in the transition (OECD, 1986); the move into employment and productive activity; the growth of personal autonomy and independent living; social interaction and community participation and the taking on of adult roles within the family; including marriage and parenthood.

Past research in these islands and elsewhere has focussed mainly on young people with physical and sensorial disabilities (Hirst and Baldwin, 1994; Monteith and Sneddon, 1999). The findings suggest that these young people are less likely than their non-disabled peers to be in paid work and to be living independently of their parents. They also had limited social lives with greater reliance on their families for leisure pursuits.

Although fewer studies have focussed on older teenagers with severe learning difficulties, those that have done so, paint a similar picture (McConkey, 1989; Redmond, 1996) with parents having to juggle their aspirations for a ‘normal’ life with a realistic appraisal of their offspring’s needs and their vulnerability (Heyman and Huckle, 1993). Equally the views of these young people have not been sought by researchers although the difficulties in doing this should not be underestimated (Stalker, 1998).

However within services, transitions has been interpreted more narrowly as the move from schools to adult learning disability services. This has attracted a great deal of criticism from family carers in particular who point to a striking contrast between the services available to them and their children with the lack of options available after school. Mencap’s (1991) conclusions of a decade ago are still echoed in parent’s comments today: *“Young people (leaving schools) were switching from five days a week of planned and structured activity based on individual assessment to a slot (sometimes part-time) in a service not designed for them and not leading anywhere”* (p.3).

Studies in England (Ward et al, 2003) and in Northern Ireland (Monteith and Sneddon, 1999, McConkey and Smyth, 2001) have documented the various difficulties that families and young people encounter during the transition years. These include lack of transition planning (despite the legal obligations to do this under the Code Practice for

Special Educational Needs under the Education (NI) Order: 1996), lack of post-school alternatives, dearth of employment and leisure options, and the need for increased respite breaks for carers.

Two main improvements have been proposed for the transition stage (Department of Health, 2001). These are being implemented in England and Wales (as well as in other countries) and preliminary schemes are operational in Northern Ireland. The NI Review of Day Services, drawing on a wide range of professional expertise and carers' views, recommended that:

1. Education, Dept. of Employment and Learning, and Social Services need to take joint responsibility for transition planning and arrangements for young people aged 14 to 25 years. Local co-ordinating committees should be in place in each trust area and joint funding should be in place for transition services. Non-statutory services can have a major role to play as the lead provider agency (McConkey and Mezza, 2000).
2. There needs to be a designated transition officer for each person in transition (independent from school and social service personnel). This is similar to the proposed Connexions Service in England and Wales and it has been or is about to operate in various parts of Northern Ireland. The funding for these posts must be assured and not linked to short-term grants.

In addition, families and young people need to be given information about the range of options that are available – colleges, vocational training, work placements, supported employment, leisure and volunteering as well as attendance at day centres. This should be done through videos, booklets and a programme of visits.

Families, schools and service agencies need to work together in promoting the young person's life skills, notably independent travel, money handling and social skills.

A person-centred transition plan should be developed in association with young person and family. This should cover the individual's interests and needs – therapeutic services, leisure, friendships, education and employment as well as the development of life skills and vocational skills. Greater use should be made of Direct Payments to fund these service packages.

However Ward et. al. (2003) sound a cautionary note based on their English study of over 200 persons in the transition process. They found that whether or not youngsters had received transition planning seemed to make little difference as to what happened to them after school because of the lack of options available, especially in housing and employment opportunities.

Conclusions

Transition planning requires urgent attention in order to meet the changing needs and aspirations of young people and their families.

More effective means must be found for inter-agency planning.

Further research and evaluation is required to identify new service models and determine their outcomes.

Concluding Comment

Chapter 3 documented the development in accommodation options that are available for people with learning while this chapter has noted the changes that are evolving in day opportunities. There are many commonalities; especially the shift from institutional-type provision towards service that reflect ordinary living.

Perhaps the time has come to dispense with the traditional distinction between day and residential services. To a large extent this has been inherited from institutional models of service provision and has no place in modern services that aim to be person-centred, local community based and supportive of the person's choices.

Rather services in the 21st Century will probably consist of various inter-related strands which individuals will access as their needs change. These will include support for family carers, accommodation and supported living arrangements, and specialist assessment and treatment services in addition to those covered by this review. Hence planning for what was previously termed 'day services' must be done within an overall service framework.

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