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PROJECT PAPER

Number 50

AN ORDINARY WORKING LIFE

Vocational services for people with mental handicap

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Bringing it All Back Home: getting mentally handicapped people out of hospital (King's Fund Centre Discussion Paper, June 1982, price 75p);

Developing Community-Based Residential Services for People with Mental Handicap by David Towell (King's Fund Discussion Paper, May 1984, free).

All these papers are available from the Centre. Prices include postage and packing.

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King's Fund Centre

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Foreword

In February 1980, the King's Fund Centre published *An Ordinary Life* describing how locally-based residential services for all people with mental handicap could be provided through the use of domestic housing. The working group who produced this paper defined its aim as 'to see mentally handicapped people in the mainstream of life, living in ordinary houses in ordinary streets, with the same range of choices as any citizen, and mixing as equals with the other, and mostly not handicapped members of their own community'. At that time it was necessary to look abroad (notably to Eastern Nebraska) for 'working models' of services consistent with this aspiration. In the subsequent four years, however, there has been a significant shift in policy thinking (most clearly expressed in the All Wales Strategy) and encouraging, if still modest, progress towards the implementation of residential services based on *An Ordinary Life* principles in several parts of the country (for example, in Bath, Bristol, Cardiff, Derbyshire, Lancashire, Northumberland, Southwark and Winchester). Indeed, among the many King's Fund initiatives of recent years it is arguably this programme of work on services for people with mental handicap which has had most practical impact.

This impact has arisen not so much because of the originality of *An Ordinary Life* but rather the reverse: the clear statement of ideas in the 1980 paper appeared to resonate with the way many people – including policy-makers, planners and parents – were already thinking. Subsequent progress with local initiatives has also owed a great deal to the willingness of a growing network of innovators to share with each other what has been learnt from their particular experiences of service development. The Centre has tried to be a resource to this network, arranging meetings, offering information and advice, and publishing a series of further papers (listed inside the front cover) enlarging on different aspects of the *An Ordinary Life* theme. This work, with its focus on residential services, is continuing.

Success in these efforts has increasingly drawn attention to the contradictions apparent in the total patterns of local provision. While residential services are seeking to meet the individual needs of people with mental handicap through ordinary housing dispersed in the community, day services continue to reflect rather different principles. Indeed, despite important developments in adult training centres in recent years (partly encouraged by the National Development Group's 'Pamphlet 5' on day services, with its commendation that ATCs be redefined as social education centres), the dominant mode of provision (used by over 40 000 people daily) still involves congregating large numbers of people with mental handicap together in institutions segregated from the activities of non-handicapped members of the community. Moreover, where the training role of these centres involves their users in work tasks, these tasks do not constitute a real job and rarely, now, preparation for one. They are also very badly paid. Certainly there is an enormous gulf between the employment situations sought (even if with decreasing success) by most adults and the opportunities available to people with mental handicap.

Accordingly, over the past year the King's Fund Centre has convened a new working group (membership listed on page 5) to examine the implications of *An Ordinary Life* principles for the vocational services which should be available to people with all kinds of mental handicap. The working group itself, chaired by Chris Gathercole, brought considerable experience and expertise to this mission. The group has also been greatly helped by consul-

tations with representatives of the Manpower Services Commission, employers and trade unions, and also by a survey of British initiatives being undertaken by Jan Porterfield, with support from the Joseph Rowntree Memorial Trust.

An Ordinary Working Life is the first product of the year's discussions. In it, the authors set out to examine the meaning of work in our society and to identify its significance in the lives of people with mental handicap. From this starting point, they suggest a set of basic principles to guide the design of vocational services. Looking to the most promising British initiatives and also to American experience, possible ways of realising these principles are considered. All this enables the working group to outline their vision of comprehensive, local vocational services and to begin identifying the strategies through which such services might be implemented.

The working group see this paper as no more than a beginning. As with the *An Ordinary Life* initiative as a whole, progress in improving mental handicap services is only likely where workers in different localities come together to learn from each other's experiences and establish means of mutual support. From discussion and debate it may thus prove possible to refine and develop the ideas in *An Ordinary Working Life* and test them more fully in practice. Members of the working group are keen to join with others to extend current thinking, strengthen the networks linking people engaged in innovation and find ways of encouraging further local initiatives. So comments, enquiries and suggestions arising from this paper – addressed to the group's secretary, Joan Rush – will be very welcome.

An Ordinary Working Life presents a great challenge to everyone concerned with services and opportunities for people with mental handicap. Many of our fellow citizens – over four million on some estimates – are unable to find suitable paid employment. People with mental handicap represent a very small part of this total. At the same time, unemployment on this scale has not weakened the value we place on getting decent jobs or the importance of work to our identity, status and income. The working group ask us to start from the principle that people with mental handicap have the same rights as other citizens to valued, rewarding and unsegregated employment. The challenge is to use our creativity and initiative to develop vocational services which offer people with mental handicap opportunities to achieve these rights and provide the situational support necessary to sustain worthwhile roles in the world of work.

David Towell
1984

Members of the Working Group

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Robin Elder	Senior Principal Assistant (Day Care)	Sheffield Family and Community Services Department
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Acknowledgments

John O'Brien and Connie Lyle provided guidance, and contact with developing vocational services, which we gratefully acknowledge.

'I don't want to stay on at school any more, I'd like to get out to work. I want a proper job.'

A young woman about to leave special school

'That every handicapped person is not capable of competitive employment (and some may never be) does *not* mean that everyone is not capable of a real job.

– the variable is not who is employable and who is not
– the variable is not when someone will become employable
– the variable is how much support a person needs to get and hold a real job.'

Yates and Blaney (1981)

'The largest barrier to overcome is often the perception on the part of many individuals that the person who is handicapped is not capable of benefiting from training or becoming competitively employed.'

Vocational Education Alternatives (1981)

'Research on habilitation of the severely and profoundly retarded provides an ample basis for viewing these individuals as potentially vocationally competent persons.'

Bellamy, Inman and Schwarz (1977)

Contents

Susan Walker lives in a staffed house. She cannot hear and has very limited sight which can only be partially corrected with glasses. She has been labelled as severely mentally handicapped and has a history of problem behaviour, mainly tantrums. She is now communicating with some gestures, although communication is still difficult. Susan lived in a mental handicap hospital for 30 years, from the time she was seven years old until she came to live in the house 2½ years ago. In the hospital, she pushed a doll's pram everywhere she went.

After moving into the house she attended an adult training centre but staff found her behaviour very difficult and said they would rather she did not attend. Despite the obvious difficulties, staff working in Susan's house decided to try to get a job for her. Since she appeared to like to clean the house a job was found with a contract cleaning firm. A member of staff went with her to her job and taught her to do the various tasks. After she knew the tasks the member of staff stayed with her to check on the quality of her cleaning. Unfortunately Susan became upset in front of a group of managers of a business she was cleaning. Although this upset was fairly minor, the cleaning firm decided to end her employment.

Subsequently a cleaning job was found in a local pub as long as staff covered her jobs if she was ill. She started working two days a week for two hours. A member of staff again went with her to teach her the job. This took six months of carefully planned teaching. When the pub's regular cleaner left, Susan was offered the job. She now works from 9.30 – 11.30 Monday to Friday. She is paid £15.50 a week which is the rate for the job. Her pay will soon be increased at a union negotiated rate. After she had worked for a year her contract was revised so that staff do not need to cover for her when she is sick, which is rare.

The support Susan now gets although time consuming, is minimal. Someone, a volunteer three days a week and member of staff the other two, helps her get to and from work. Although her helper stays at the pub while she works and occasionally checks the quality of her work, there is rarely a job that needs to be done again. The landlord is happy because Susan is doing such a good job. Susan is now able to do a real job for real pay. She has widened her contacts with non-handicapped people and is now able to buy things for her room and is saving for a holiday.

Introduction

This project paper is the product of a working party convened by the King's Fund Centre to examine the provision of day services for people with mental handicaps. It is a companion to an earlier paper, *An Ordinary Life*, which recommended comprehensive local housing and residential support services, and it shares the same goal expressed in that document:

> 'to see mentally handicapped people in the mainstream of life, living in ordinary houses in ordinary streets, with the same range of choices as any citizen, and mixing as equals with the other, and mostly not handicapped members of their own community.'

Day services (mainly adult training centres) are at present overstretched. Many centres have waiting lists and are faced with increasing demands for places from school leavers and people who are moving from hospitals back to the community. We must decide whether we want more traditional day provision or something more in line with emerging thinking on community participation.

Throughout the deliberations of the working party we tried to evaluate the extent to which present employment and day services measure up to the principles expressed in *An Ordinary Life*. We concluded that traditional day services have inherent problems which prevent these principles from being implemented.

If we assume that people will never work then they will not be given the chance to work. It is safer to assume that everyone can do a job of value to the community and which they will value themselves if they are given adequate help. The only way to learn a real job is to do a real job. You can't learn to swim on dry land. Our main task is to find out what work people want and then identify what help would be needed for them to pursue their choice. This line of thinking parallels the approach in planning for a place to live. Previously it was assumed that some people could not live in an ordinary house and so they were put into a hospital or hostel. If we make the assumption that everyone can live in an ordinary house we are challenged to think carefully about what support each person needs in order to do so.

The idea that a person with severe and even profound handicaps might be enabled to do a job of work will be greeted with disbelief by many people. We were surprised to learn of a number of people with severe handicaps who confounded all expectations by succeeding in paid employment. We came to realise that our low expectations are possibly the biggest barrier to progress in vocational services. We also came to realise that there are many possibilities of shared work arrangements in which a person with few abilities could participate with benefit. Eventually, after thinking carefully about principles for designing a vocational service, we arrived at the view that opportunities for paid employment should be available as a right. We recognise that this will take time to achieve but at least the direction in which services should develop is now clear.

A number of innovative employment services have been developed which aim to provide meaningful jobs for people. Some of these schemes, like the Mencap Pathway Scheme in Britain, have successfully used co-workers to support many people with mild disabilities doing a wide range of jobs.

During the 1970s, a number of researchers, including Gold and Bellamy, using modern teaching technology began to teach people with severe impairments a variety of useful work skills. Contrary to many people's expectations, this showed that the knowledge and skills are now available to teach complex tasks to people thought to be unemployable. A number of employment schemes using these improved teaching methods have focused on people with severe and additional disabilities, employing them in productive jobs, albeit doing a limited range of assembly work.

It may be argued that this is the wrong time to address the issue of employment for disabled people and that with high unemployment the jobs that do exist should go to traditional breadwinners. We question the assumption that a person with handicaps has fewer rights than other people. There is already a gross imbalance in the way jobs are distributed. While 86 per cent of the general population available for work are employed, a tiny proportion of people with severe mental handicaps have paid jobs (probably less than five per cent). The job sharing proposals discussed later provide ways for some of those in work to help some of the 95 per cent of people with severe disability who need employment. We are arguing for the right of people to contribute to meeting society's and people's needs by their efforts. There is no doubt that there are many human needs still to be met and many people who want to work at this but who have so far been prevented from doing so.

Some forecasters suggest that mass unemployment will be the pattern for the future because of new technology, and that to seek employment for people previously denied it is both unrealistic and inappropriate. Some point to different and better kinds of employment for the future rather than an end to employment, with shorter hours, greater flexibility and more concern for the needs of workers. Whatever scenario we accept, all that can be said with certainty is that patterns of employment will be different.

Global predictions for the future can have a paralysing effect and they are no excuse for inactivity now. We know that individuals can be found jobs *now* that they want and that have value, as the Pathway scheme has demonstrated. We know that new jobs are being and can be created even if many traditional ones are being lost for ever. There is much work to be done, now as ever before. One difference is that much of it that was demeaning and unpleasant no longer has to be done by people.

Our argument is that nobody should be excluded from these opportunities for employment on the grounds of any label attached to them or any disability they may have. They should have a fairer share of and access to what employment there is, along with other people who have been discriminated against, including women and black people.

An employment service

A successful employment service would achieve a number of objectives: it would provide people with work roles which are socially valued; it would equip people with work skills; it would provide continuing experience of work and work places; it would support relationships between handicapped and non-handicapped workers. Even where we do not yet have the educational skills to enable people with profound disabilities to do a job, we can employ them alongside other workers so that they can participate in the experience of work and relationships with people at work. We do not just mean that people tag along but that the job is structured to promote their involvement in the task being done. In practical terms, this could mean that a secretary who operates a photocopier in an office would organise this job so that a worker in a wheelchair with limited dexterity and concentration does some of the

tasks involved in the job some of the time throughout the working day. As well as the experience of the work tasks, the worker would acquire skills, both general workplace and specific task-related skills, albeit possibly very slowly. He or she would also become a worker whom other people know and care about. For the secretary there would be the gains of companionship, an enhanced job and in some cases, assistance with the job itself.

This new kind of service will mean using resources in a very different way. It will mean employing job finders and job support workers attached to mainstream employment services, rather than employing staff from welfare services attached to special buildings.

The purpose of this paper is to encourage people to set up innovative employment schemes. We are not suggesting large scale reorganisation of services overnight. We are saying there is scope for projects which aim to take a person all the way to a worthwhile job. We want people to adopt an open ended commitment to valued work and not make do with second-best solutions. We do not have all the answers now but this is not a reason for abandoning a worthwhile goal. We know that if the methods now used in the best schemes were employed in all our services, everyone in the main training centres, and a proportion in 'special care units', could do a worthwhile job. And these methods are ten years old.

Outline of this project paper

Throughout we have been guided by the following principles.

Employment services should not exclude people who are thought to be too disabled to work.

Whatever support is needed to enable a person to work should be provided.

The personal choice of the worker should be the priority determinant in the search for work.

The service should maximise contact between a disabled worker and non-disabled people.

The service should ensure an adequate income.

We start with a discussion of *the importance of work* in society, in people's lives and particularly for people with mental handicaps. Then we describe some *principles of service design* based upon the fundamental values which inform our thinking. This is followed by an outline of some of the *problems with existing day services* and then concrete examples illustrating different existing *work options.* We go on to examine *choice* both in terms of preparation for working life and in the continuing experience of a range of employment options. A *vocational service* is detailed in the next chapter. This includes a description of the different components of such a service and how they might work, with suggestions for staffing the service. Then we look at some possible *sources of funding.* Finally, we look at *local strategies for change*, and consider some ways in which people can get local initiatives off the ground.

In writing this paper we have struggled with the issue of how to refer to the people for whom we are advocating. Many differing terms are in evidence in speech and in literature: intellectually impaired, mentally handicapped people, people with mental handicaps and intellectual disabilities. The title of the paper refers to 'people with mental handicaps' since it was felt that this term would be most readily understood. We are very conscious of terminology influencing whether a person is seen in positive or negative ways. For this reason we have

used the terms 'people with intellectual disabilities' and 'people with intellectual handicaps' as alternative and perhaps more precise ways of referring to 'people with mental handicaps'. As far as possible we have tried to avoid labelling people. The reading of the text will make it clear that we are referring to people who are users of services.

Notes

A review of research on vocational habilitation is provided by Rusch and Schutz (1981).

Work, society and people with mental handicaps

The role of work in society

The distinction needs to be made between work and paid employment. Paid employment is that work for which we get remuneration and which has a given structure. Under different conditions the same activity could be considered work or paid employment. For example, the mother looking after her under five year old child is working, but possibly without much recognition, while the nursery nurse who may do the same job of work gets paid and receives the status of being in employment. We live in a wage-based society where people are largely defined and valued according to whether they have employment and what kind of employment they have. Prevailing values have it that employment is a good thing. The income and status accorded to people by their employment are central measures in determining the value placed upon them. The value placed on employment does not seem to have been undermined by the presence of mass unemployment in our society, by the recession or by the restructuring of the economy. Indeed, these values are being reinforced, with large scale efforts being made to maintain those young people who are out of work in the work ethic.

Employment vitally affects our lives. This is true for every one of us. Employment is the main source of income, status, occupation, purpose and, particularly, social relations. Employment cannot therefore be considered as a discrete part of our lives since it bears on all other aspects of it: the range of our life chances; where and how we live; how we structure our day-to-day lives; what we can afford to do; experiences we can have; and even the range and nature of our friendships and other relationships.

The role of employment in people's lives

Preparation for employment starts very early in childhood. From the age of two or three, children's consciousness of employment is exhibited in their play. The expectations of the family have a profound effect upon the developing child's own expectations about its future working life. Children learn much of their behaviour by imitation. This applies as much to employment as to the imitation of domestic or play activities. The primary role that the family plays in this respect is then complemented and developed by the educational system. Through this process people develop expectations about their own future working lives. But individual expectations develop within the context of wider societal expectations regarding 'appropriate' employment. Family, educational and individual expectations are likely to be consistent with these because of society's over-riding influence.

Some things interfere with the realisation of these expectations for people as they grow up. The mass unemployment now being experienced is one of these influences. It also exacerbates other factors, such as ideas about the working potential of women, which affect their employment opportunities. People with handicaps, together with women, black people and people of other ethnic minorities are less likely to get jobs. They tend to be confined to employment which is poorly paid, poorly valued, less secure and less pleasant.

What we look for, and what we get out of employment

Employment is associated with a number of highly valued things. Different employment situations may provide different combinations of the following: money; structure; control; relationships with other people; a valued role; a valued self-image.

Money

The wage or salary that someone is paid for the job they do is an index of their value in our society. It also makes other things possible. Money gives the opportunity to participate in many leisure and social activities. In a predominantly market economy it is money which gives access to a wide range of opportunities and experiences. There is an enormous disparity in the money that comes from different kinds of employment. While earnings are not always a direct index of status, it remains true that income is a good index of the status of the job. Consider the earnings and status of a consultant, a hospital porter, a managing director, a cleaner, a cabinet minister, a judge, a child minder, a home help.

A fundamental feature of the financial situation of intellectually disabled people who are in some form of employment is how much they get paid for the work they do. Another feature is the source of this income, in particular the images associated with the source. The main source of income for service users is non-contributory welfare benefits which carry a highly devalued image. The level of reward paid in adult training centres for work done bears no relation to the level of reward in open employment. The current maximum level of payment in adult training centres is £4.00 per week. The justification for such low levels of pay is the idea that increased levels of pay would interfere with benefits.

So long as people work for low pay and are dependent on benefits, their value in society will be low, and they will be unable to buy things which could improve their lives. An example of paid work is provided by the Gillygate bakery project in York which enables workers to earn £50 for a 35 hour week (see page 30).

Structure

Employment provides a structural framework to our lives. It helps to differentiate between work and non-work. It provides a structure which prompts other decisions about the use of time in our lives. For example, it prompts us to get up in the morning and arrange our meal times. It structures our relationships, with whom we spend a large part of our day, and the type of relationships we have with other people. To illustrate the importance of the structure which employment provides, consider the effects of unemployment. If a structure is not provided by employment, the lack of norms and expectations regarding the use of time, and goals, can contribute to anxiety and depression. These in turn make it more difficult to structure life, thus creating a vicious circle.

There is also a myth about a 'leisure class'. Some people appear to hold the belief that people with handicaps desire and benefit from a life of leisure. The evidence is that many people attending adult training centres do, in fact, want jobs. Too commonly, however, the daily structures available to a person with an intellectual disability are either staying at home all day or, alternatively, the late start, long journeys and early returns associated with training centre attendance.

Control

The rewards that come from employment, both in terms of money and status, are a major factor in the control we have over our lives. For example, the range and degree of choice we can make in life can vary considerably according to the amount that we earn. But an important component of this control is the control we may have over the actual work itself. Again, this varies according to the type of employment. Some jobs offer the opportunity to choose hours of work, use of time during working hours, choice of tasks and how to organise the tasks that are to be done.

Intellectually disabled people suffer an exceptional lack of control over their own lives. Because of their economic dependence, they are likely to have to remain living at their parents' home, or live in highly regulated institutional settings. Another experience of this lack of control is in the work situation. Frequent experiences associated with adult training centres are having to wait, be moved around and do things at other people's convenience, not at your own. Generally, there is no choice in whether you go, where you go, when you go, how you get there, who you go with, who you spend time with when you are there, or what you do when you are there.

Images and self-images

The job that we have is *the* central way in which we are defined by others outside our immediate family. When we meet someone, one of the first questions we are asked is 'What do you do?'. The jobs that people have, or whether they are unemployed, send powerful messages to others. Other people generalise readily from what they know of our jobs in making assumptions about us as people. For example, people are likely to make a whole constellation of assumptions about our lifestyle, especially what sort of interests we might have, whether we have a car, what sort of house we live in, our political affiliations, and indeed whether we are interesting to them as people. People may jump to all these conclusions on the basis of knowing what our job is. These images affect how other people respond to us.

In turn, our own self-image is largely determined by how others behave towards us. We all, to a considerable extent, internalise the views other people have of us. This effect can be especially powerful when other people's views coincide with our own perceptions. When people feel that their jobs are poorly regarded by others their perception of their own work and hence themselves is similarly likely to be poor.

Because most intellectually disabled people are not now in employment, the image projected to other people is that of dependent non-workers who are not even capable of employment. People who attend adult training centres are often acutely aware that their daily occupation is not real, useful work, and that others also perceive what they do as make-work. This perception is reinforced by the nature of their work, the lack of financial reward, the hours which they are expected to work, and a host of other cues which reinforce this perception.

Relationships

The key source of social contacts, other than through the family, is through the workplace. The particular isolation that many women face has long been associated with spending most of their time at home rather than in a place of employment. Employment opens up many opportunities to meet a variety of other people in different walks of life. Equally important, the workplace provides a situation where we measure ourselves against other people, learn and absorb accepted behaviour, and express ourselves within an accepted social culture. This may provide a sense of identity and belonging. Thus, while at work, we compare what people talk about, what they wear, and what they do in their leisure time, with what we do.

For a large number of the people who attend adult training centres or sheltered workshops, their working lives are spent with other people who are similarly categorised as disabled or handicapped. They work there because of their disability, not because of their skills or because they have chosen to do so. They work with people only a very few of whom are likely to be seen as valued members of society. Thus their opportunities for building relationships with a variety of ordinary people are massively curtailed by the fact of their attendance at such a centre.

If a person is given opportunities to work alongside non-handicapped people many other benefits follow. Working alongside others gives an opportunity for learning a variety of accepted social behaviours from other people. Handicapped people who spend most of their time with non-handicapped people will also be seen as more like their valued colleagues.

Unemployment

People identified as intellectually disabled are a heterogeneous group of people with widely different abilities, circumstances and experiences. But as a group they have mostly been excluded from the labour market. At present there is a very limited range of options open to them after leaving school. These consist mainly of going to adult training centres, staying at home, or for a small but increasing number, going into further education. Thus many service users have been largely denied access to this major determinant of lifestyle and identity. Even when access is available, choice is minimal or non-existent. Indeed, service users are mainly restricted to welfare alternatives which constrain their experience, keep them segregated, and mean that they have few independent economic or other resources.

The expectation for most of us is that as children we will go to school, then go on to an independent life and, hopefully, employment. Despite the current high unemployment, most people will continue to devote an enormous amount of energy in pursuit of this goal. For most of us these expectations and goals are fostered from a very early age but this is not so for intellectually disabled people. At home intellectually disabled children are rarely offered a desirable future. Parents who have such hopes may be discouraged by professionals who see them as unrealistic. Furthermore, goals at school are about personal educational development; they are not generally about future employment. There is, therefore, a contradiction because desire for the person's development becomes confused with the reality for most people of an eventual placement in an adult training centre. Even this opportunity is denied for some.

People with an intellectual disability are also given little support to develop an expectation of themselves as workers. Even when they have expectations of themselves as workers, these are unlikely to coincide with the expectations of others. Many professionals do not see people with mental handicaps as capable of useful and rewarding employment. Thus the inadequacy is seen as lying with them rather than with the services provided to help them. If people are to get access to valued employment, these expectations and attitudes will need to change.

We can make better sense of why most people with an intellectual disability who are in employment are restricted to its less attractive sectors when we consider what that employment market is concerned with. It generally demands a workforce that can function independently with minimal support and guidance, whose evidence of ability is by academic or vocational qualifications. Most people with an intellectual disability do not fit readily into this system of employment.

If people are to have an increased opportunity of valued employment, opportunities will be needed which are sensitive to their particular needs, abilities and support requirements. As things are now, many people can undertake all kinds of tasks but are still denied employment. An approach which starts by looking at what *support* a person may require to hold a job, and to providing that support, may offer a way out of this situation.

There *are* examples in this country and abroad of intellectually disabled people carrying out work which they value and which is socially valued. Finding jobs where people could work

alongside their non-handicapped colleagues could change the lives of handicapped people more than any of the other improvements in services which have taken place in recent years. This would also change and improve the lives of non-handicapped people. When we are thinking about the employment needs of people who have traditionally fared poorly in the conventional employment market, we should not forget the role that a number of local authorities are taking in the local economy. In trying to prevent the loss of jobs, create new ones and support local initiatives, many local authorities have paid particular attention to the needs of people who have generally been discriminated against in employment, such as women, young and black people. However, more needs to be done to increase the awareness of local authorities to the employment needs and abilities of other groups, including people with mental handicaps.

Retirement

The need for a valued, active and purposeful retirement is an issue which has rarely been considered so far, probably because most intellectually disabled people have not been in regular employment for most of their lives. Retirement probably means no more than the ending of their attendance at an adult training centre. The prevailing pattern of employment is one which entails a fixed age of retirement. It is therefore important for a person who is disabled, just as it is increasingly being seen for the rest of us, to be equipped and prepared to make the most of retirement.

People with additional needs

The basic philosophy of this document is that people with intellectual disability should have the same opportunities as everyone else. This means that no one should be denied opportunities because they are seen as too handicapped or too old or too difficult. Our understanding of the term 'additional needs' includes the small number of people who require close supervision because of profound disability, physical or sensory handicaps, epilepsy, or problem behaviours.

Often people with additional needs are given separate consideration and separate services. Separate services have arisen as people with very different needs have been treated as a single group. Typically these services are of lower quality, afford fewer opportunities, and are less able to meet individual needs adequately than services to other more able people. These services may maintain handicaps or even add to them. It is our view that people with additional needs do not require separate services. It is our view that low expectations and denial of opportunities from an early age restrict the potential of many people.

Equal opportunities must be made available to all people right from the start. One of our own early opportunities is to experience, through others, work in its widest sense. Throughout childhood and adolescence we are geared to the working world. At present, many of these opportunities and expectations are denied to people with mental handicaps and virtually none are available to people who are considered to have additional needs. People should have the same opportunities for these experiences as their non-handicapped peers from childhood onwards. In providing valued employment opportunities for people with additional needs the same processes, mechanisms, questions and answers which are relevant to others are equally important. The amount of resources and degree of effort, flexibility and creativity will vary, *not* the mechanisms. If a person with additional needs is to be given *real* opportunities this can only be made possible by ensuring that the type and degree of support necessary to make use of the opportunity is provided. Support could be in the form of sophisticated aids, new technology, or simply for another worker to spend all of

their working day with the person. The principles of the service are the same for *all* people. Whilst some people will require only a very small amount of support for a short time, others, particularly those with additional needs, will need a great deal more support over a longer time.

Examples of people with additional needs working in valued integrated settings are hard to find at present in this country and we recognise that pursuing our philosophy will present many difficult challenges.

The actual number of people with additional needs is small and we have emphasised in this document the central principle of addressing the employment needs of individuals. Individual programme planning is essential to ensure that employment is sought which is relevant to the person's needs and interests. People who are generally regarded as having additional needs are not a single group. It is essential that those who aim to develop employment options have detailed knowledge of each person's strengths and work preferences. Individual programme planning will also ensure that an individual's impairments and disabilities will be identified and dealt with to minimise the effects on that person's working and social life.

Finding employment for a particular person with additional needs may well require the skills and experience of a range of people; for example, industrialists, educationalists, psychologists, designers, electronics experts. This area is virtually unknown but a growing body of knowledge, technology and expertise is available from individuals who have successfully dealt with the specific difficulties which may be found in people with additional needs. Many of the commonly associated physical and functional problems have solutions which are applied to people not labelled mentally handicapped; for example, all the skills and technology relevant to blindness, or locomotor problems. We know of people with, for example, severe sensory, physical locomotor or neurological difficulties for whom solutions have been found which enable them to work. Indeed many people earn a living while coping with a mixture of such problems.

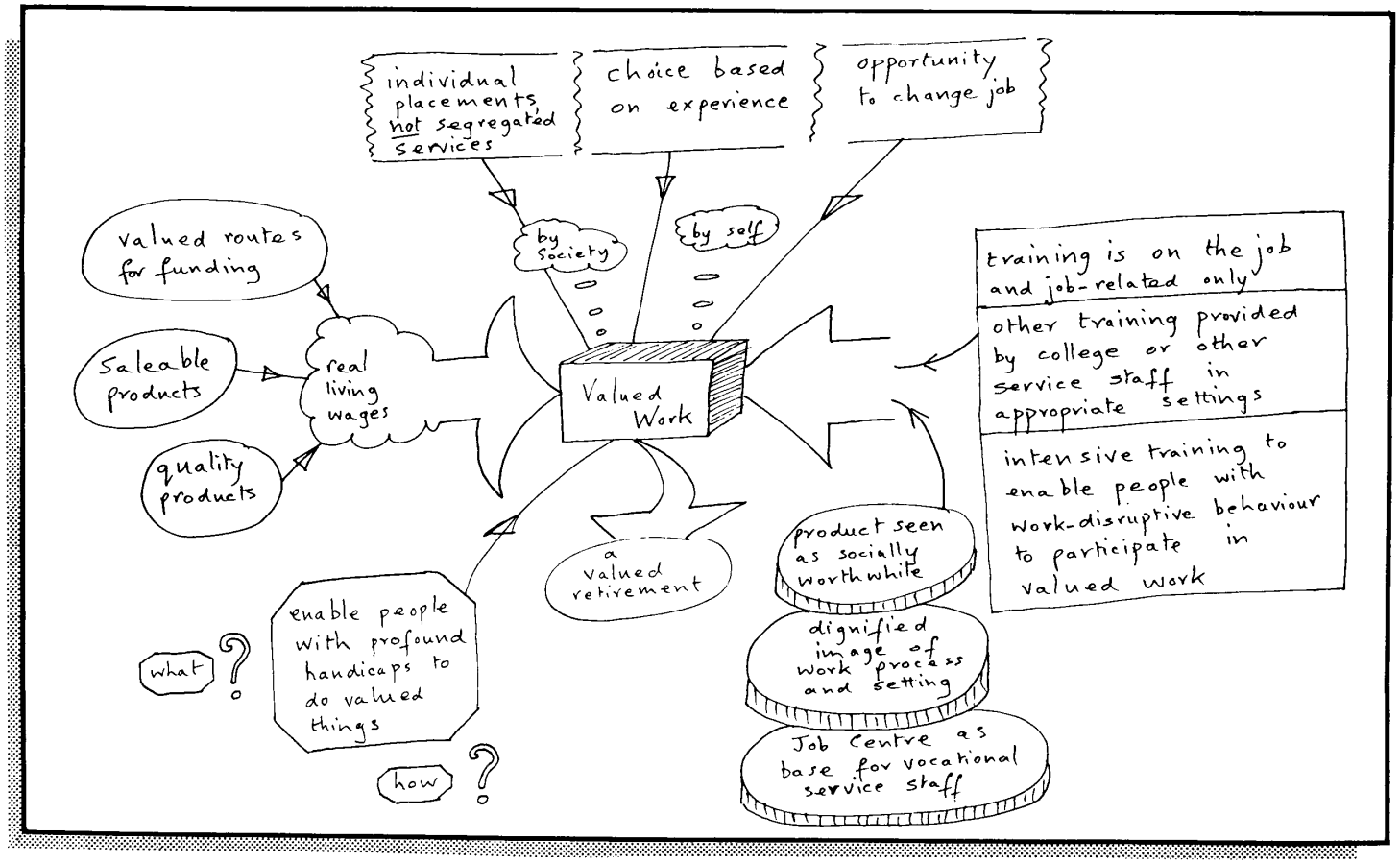
Finding employment for people with additional needs will require flexibility, imaginative exploration of possibilities perhaps through brain-storming and other aids to creative planning, and the bringing together of people, skills, aids and equipment tailor-made to the needs of each individual person.

That no one should be denied opportunities to participate in the world of work is one of the fundamental principles on which this document is based. A great deal of time, effort and commitment will be required to make progress towards this goal. The benefits to people with additional needs of experiencing the world of employment would be immediate and far-reaching. It is for these reasons that continued effort is particularly important.

Notes

The role of work in society is discussed by Wallman (1979).

Wandsworth Social Services (1976) provides evidence on the wishes of people at adult training centres for real jobs.



Some ways of increasing the social status of work for people with intellectual disabilities

Principles of service design

We start from similar basic assumptions to those underlying *An Ordinary Life:*

A person with intellectual disabilities has the same human value as anyone else.

A person with intellectual disabilities has the same rights as other people to valued, rewarding and unsegregated employment.

Services must recognise the individuality of a person with intellectual disabilities.

What do these general principles imply for services which aim to provide intellectually disabled people with employment?

First and foremost, these principles mean that people with intellectual impairment, need and have the right to do a real job of work. Vocational services should therefore focus on finding clients real jobs, and arranging the necessary support to ensure they can keep those real jobs. We cannot stress too strongly that this approach to employment asks *what support is necessary* for someone to hold a job, not whether they are 'ready' to hold a job.

What do we mean by a 'real' job? A real job is one which provides pay, security and opportunities to work amongst and alongside non-handicapped people. Real work is that which provides employment with the status of an employee. It might possibly involve an apprenticeship. Training schemes may have a place in providing training, but placement on such schemes is not adequate as a permanent option for the future.

The principle that services must recognise the individuality of a person has many implications for the choices which people are given about the kind of work they do. Services should try to discover a person's personal preferences and provide support in pursuing those preferences. Part of this process will involve providing a range of work-experience schemes which meet the needs of people to find out about different types of work. A person with severe or profound handicaps might, for example, spend some weeks with a co-worker who is in regular employment on a particular job.

The opportunities and the quality of life for people with intellectual disabilities depend to a very great degree on their opportunities to *integrate* with non-handicapped people during the working day, as well as outside the working day.

Segregated services are a frequent consequence of the labelling process to which people are subjected. Well intentioned as a way of providing a 'specialist service', in practice segregated services usually end up further devaluing the individual. Individual needs are usually met very inadequately by segregated, 'specialist' services.

A very important principle, which follows from the assumption that a person who has mental handicaps has the same value as others, is that of *inclusiveness*. All too often, human services exclude a group of people because they are too old or also physically handicapped or incontinent. This means that there are people who are denied a service, left without education, or a family home, because they are 'too handicapped'. This is inconsistent with

If employment services are to meet the requirements in this chapter then they should:

1 Address the employment needs of every person no matter what their disability

Foster employment opportunities which provide for the worker's needs and are not necessarily tied to the competitive demands of the commercial labour market.

Focus on work-related activities and ensure that ***other*** appropriate services teach non-work-related skills, such as grooming or cooking, in appropriate settings.

2 Make support available to enable each handicapped person to do valued work

Ensure that the conditions of employment for handicapped people are at least comparable to those that generally apply; for example, terms of employment, health and safety, access to facilities.

Ensure access to training for all people to develop their skills, knowledge and competence.

3 Discover personal preferences for work and provide support in pursuing their choices

Help people to find real jobs of their own choice. People should not just be expected to fit available jobs nor should they be confined to a limited range of jobs which have come to be seen as 'suitable for handicapped people'.

In order to match jobs to individual preferences, jobs should be sought or created or developed which offer flexibility in hours and job-sharing.

Ensure that people have an effective say in their conditions of employment and the work process.

Enable people to change jobs when they want.

Ensure the availability of adequate advice, information and counselling about work and careers both at school and later.

Children should be oriented to the world of adulthood alongside non-handicapped people.

Provide for career development.

Enable people to get experiences of the world of work to help them learn how to choose the kind of work they wish to do.

Enable people to speak for themselves.

4 Integrate, in work relationships, people with and without handicaps

Enable people to use employment services which are available to the rest of the community, if necessary supplementing those services with specialist help.

Services should use and be based in existing mainstream facilities. They should not use segregated centres for training or centres providing sheltered work for segregated groups.

Provide integrated jobs. Integration means not only working alongside non-handicapped people but also not having a number of people with handicaps in one setting.

Encourage every opportunity for non-handicapped members of the community to meet with and learn from people with disabilities.

Ensure a normal working day and week, working the hours that people generally spend at work.

5 Ensure an adequate income

Ensure as far as possible that workers are paid a wage which frees them from reliance on income-maintenance state benefits and enables them to live an ordinary life.

Protect job security through adequate notice of termination of employment, pension, membership of trade union, sickness benefit.

our first principle. We see the services we are suggesting as being provided for all people, however disabled. The greater the disability, the greater the support needed to provide a job. It is the degree of support which we see changing according to individual circumstance, not the right to the service.

This raises a fundamental issue in which we think misunderstanding is all too likely. The prevalent, usually unrecognised, assumption of all our mental health services is that a person must be 'ready' to progress from a more segregated to a less segregated setting. This prevalent assumption is the 'ladder' or continuum assumption: that service users must progress gradually, step by step, up the 'ladder' from, for example, hospital to hospital flat, to hostel, to supervised flatlets, and so on, as they are ready for each stage.

Counter to this we believe it is easier, and meets needs better, to *move directly to providing whatever support the person needs in the integrated setting which is desired.* As the person needs less support, that support can be withdrawn. The difference between these two approaches is quite fundamental, and for that reason we stress it. It is rare for human services to adopt the second, situational support model. That model, however, has been shown to be demonstrably faster and better, in providing integrated living and working conditions than the former, widely unquestioned, 'readiness' model. It is the role of employment finding and support services to help people find work and support them in it, not to prepare people, often indefinitely, for a goal which is never reached.

Notes

Bellamy, Horner and Inman (1979) and Thomas, Firth and Kendall, (1978) show the benefits of supporting people in living and work as contrasted with the continuum model.

Existing day services

We believe that there are major difficulties within existing day services because they do not meet all of the criteria listed in the chapter, Principles of Service Design (pages 20-22).

We have identified a range of existing day services for people with mental handicaps including:

village communities – which often focus on gardening or craft work;

industrial and occupational units within institutions;

special needs or special care units often attached to adult training centres;

adult training centres or social education centres;

pre-vocational programmes, which are often part of colleges of continuing education;

sheltered workshops;

sheltered industrial groups;

work stations or enclaves in factories;

employment placement services (Pathway and disablement resettlement officer);

employment rehabilitation centres.

These services attempt to provide daytime occupation or diversion for people with a very wide range of skills and needs. They do not, however, form a rational, coherent vocational policy for people with mental handicaps. Amongst the range of day services are those which are very large and segregated from non-handicapped people. Some serve people in ordinary work or education places but still group people with handicaps together and provide them with a different curriculum. Other services provide one-to-one intensive work-experience but the work may often be of low value or not interesting to the worker.

If a person with severe handicaps receives any day service at all it is likely to be at an adult training centre or in a hospital based day unit. This pattern of service suffers from several major drawbacks. First, many of those people who have been asked, say that they would rather have a job. Second, training centres have come to serve many different and sometimes incompatible purposes. Most centres try to train people for jobs, serve as a factory, provide academic and life education, occupy people, serve as a primary health clinic, and as a sports club, and also provide respite care for families. This mixture causes confusion amongst service users and staff so that no one is clear about what they are doing, efforts are diluted and client progress is much slower than it could be.

The third drawback is that these centres are supposed to fit into a developmental continuum of services. As people acquire work and social skills, they are supposed to progress from, perhaps, the special care unit of the centre, into the main centre itself, then to an advanced training centre, sheltered workshop, enclave scheme and eventually into open employment. In fact, very few people progress from one stage to the next. For most people, day services

provide an unchanging regime year after year. Their material poverty is matched by the narrowness of their experience. This model of service still results in segregation, despite the efforts of some centres to break out of it. A person in a centre is not working alongside non-handicapped people, nor going to the same classes as non-handicapped people. The traditional centre, by grouping people with handicaps together, perpetuates their separation as a stigmatised group. The growth of residential services in the community and the continuing shortage of day services for people living at home presents the opportunity to try to develop a different kind of service geared to worthwhile jobs.

We recognise that there is much untapped staff skill and expertise that is not being used to its best advantage. An enormous contribution has been made by staff in teaching very severely disabled people. We think that if this staff expertise was channelled more purposefully into supporting people in real employment, day services would be greatly improved, and staff job satisfaction would be greatly increased.

Manpower Services Commission services to disabled people have recently been changing. Disablement resettlement officers have reduced their case loads so as to focus their efforts on people with more severe disabilities. The MSC has also recently begun a Disablement Advisory Service to let employers know about the help which the MSC can provide to support disabled people in work. This help includes financial aid in adapting the workplace, the Job Introduction Scheme in which a grant is paid for up to 13 weeks to an employer who takes on a disabled person, assistance with fares to work, special aids for employment, the sheltered industrial group (SIG) scheme, and more.

A number of voluntary organisations are involved in developing employment opportunities for people with mental handicaps. Mencap's Pathway schemes are spreading to many parts of the country. Pathway officers function as job finders and support people once in work. However, like DROs they are selective about who they will place and so exclude people with more severe handicaps. MIND also has a number of employment placement officers who include people with mental handicaps in their work. The Spastics Society has careers advisory officers available to people with mental handicaps. The Shaw Trust, based at Devizes, Wiltshire, has development officers in the south and west of England placing people singly in integrated work settings mainly using sheltered industrial groups (SIGs).

Some local authorities, Leeds for example, have appointed employment liaison officers finding jobs for people with mental handicaps. Also some health authorities, such as Lewisham and North Southwark, are doing the same.

A major source of difficulty faced by people with disabilities and placement services is to do with benefits. Some benefits may be lost if a person earns income from employment. This should not leave a person worse off than when they were unemployed but it may leave them no better off. Many people, especially parents, are afraid that because some benefits may be reduced, taking a job may actually make a person worse off and so discourage getting paid work. The whole topic of benefits and work incentives for disabled people is very complicated and is being investigated by the Social Security Advisory Committee, the official body which advises the government. This Committee states: 'The benefit system recognises no half way house between incapacity for work and fitness'. Clearly a much more flexible system is needed which provides incentives to work no matter how disabled a person is.

Notes

Wandsworth Social Services (1976) give examples of people at adult training centres wanting integrated jobs.

The Annual Report for 1982/83 of the Social Security Advisory Committee discusses the relation of benefits and fitness for work.

Examples of people with severe mental handicaps in integrated work settings are provided by Porterfield (1984).

Some employment options

Below we describe some possible employment arrangements and provide some real life examples. These options are not mutually exclusive, indeed many real life situations will include elements of a number of these options. For example, a person might share a job with another person which also involves on-the-job training and supervision. The components of these work options incorporated in an individual's job will vary over time to accommodate changes in the work situation and changes in the worker's skills and needs.

Own job

A person could work independently, full-time or part-time, without support from the service once established in the job.

Examples

In the North East of England 82 people have been employed over a five year period. Each person had previously attended one of the local adult training centres. On taking up work, people were supported with a visit once a week during the first three months and subsequently less and less until no visits at all were required. Actually on the job there is no direct support or special supervision, but the employment liaison officer is available to employers or employees to give advice and support when requested. The low level of involvement of the liaison officer in the immediate work situation is deliberate and is due to the belief that, 'I don't think you do the worker any favours by visiting him at work in front of his new colleagues'.

The Department of Employment administers a Young Workers Scheme for persons under 18 years who are still within one year of leaving school and who have not been previously employed. Previous training on a Youth Training Scheme project does not count as employment within this scheme and any type of employment qualifies except that within public services and private households. Employers can pay the person up to £50 a week and then claim a subsidy of £15 a week from the Department of Employment. The young worker has to undertake at least 35 hours a week of paid work. The scheme is designed to secure school-leavers a real job or to offer a follow-on to a Youth Training Scheme placement (see below).

Job sharing

There are several different ways of sharing a job. One possibility is for two people to time-share a job. In time-sharing the two people are not required to share actual time on the job. For example, one person works in the mornings, one person works afternoons, or both work alternate weeks. Some jobs can be broken down in that certain operations involving certain skills come at one part of the day or week, and others at other times, For example, in small manufacturing firms, the work is split into production work and delivery, crating and packing work. A person with the appropriate skills could do any part of the job. A kitchen assistant's job involves preparing vegetables and washing and cleaning. Two people could be employed to do different parts of the same job at different times of the day.

Another option for job sharing is when two or more people spend time together in completing a particular job and receive the pay that goes with the job. Two handicapped people could share one job and the pay that goes with it.

Another possibility is where one handicapped person and one non-handicapped person work together. This may involve one of the pair doing anything between one per cent and 99 per cent of the work. A third possibility of job sharing is where two or more disabled people share one job with one non-disabled person.

Any degree of support or sharing of the work is possible with this option. It may also involve any combination of sharing of the actual work and training the disabled employee. In this way, supervised work options may form a continuum with job sharing options.

Examples

Carol Shelton at Options Incorporated, Belchertown, Massachusetts, has developed a range of job-sharing possibilities. An example would be a transport company which advertises a job for a loading dock and warehouse worker. A fully qualified, non-handicapped, worker applies for the job with the expressed stipulation that he or she will share the job with a second, handicapped, person. The qualified worker has a commitment to offer some training to the handicapped worker. As a result of this agreement the pair of workers receive the pay for the job advertised and in addition the qualified worker receives a supplement for providing training to the handicapped worker and the handicapped worker receives a training allowance. In Eastern Nebraska there are examples where two handicapped people take on a single job and work together. These two people work independently, without supervision or the help of another person, and they share the money associated with the job. Working for a construction company, three handicapped workers share one job. They each have different levels of productivity and none is currently able to produce the full amount required by the job. Together, however, they produce 100 per cent of what is required. What actually happens is that one worker produces 30 per cent of the requirement, another produces 50 per cent and the third produces 20 per cent. The wages of the people concerned reflect the work performed.

Sheltered work group

In this work option handicapped people could find themselves working in a completely segregated setting or as a small group of handicapped workers within the organisation of a larger work force.

Examples

Remploy and sheltered industrial groups (SIGs) operated under the Manpower Services Commission are examples of sheltered work groups, although since a SIG arrangement can be made for one person in a non-sheltered, non-industrial setting it may not be sheltered, industrial or a group.

A group of disabled workers operating their own assembly line or forming their own separate production unit in a factory is known as an enclave.

Another example is the Specialised Training Programme developed by Bellamy in the United States. Each programme is a contract assembly business employing about 18 workers, 15 of whom are mentally handicapped. Within this sheltered group people with differing abilities and needs work together.

A worker at Olympus,a Specialised Training Programme in Seattle, is Adam Johnson who is 27 years old. He has Down's syndrome and impaired vision. He has been labelled as severely mentally retarded and is unable to read, write, tell the time, manage money, cook or do his own laundry. He is independent in his eating skills and toileting. He has very limited speech. He commutes daily to work, travelling independently on public transport. He can complete 17 electronic assembly tasks including a 56 step circuit board insertion and a 20 step circuit board testing task. He was previously considered to have 'no vocational potential', but has maintained an attendance rate of 90-96 per cent over his five years of employment and earns an average of 150 dollars per month at present (Canadian Association for the Mentally Retarded, 1983).

Work-experience

Work-experience enables a person to learn about the working environment without necessarily being offered training, a permanent job, or payment.

Examples

There is a work-experience scheme associated with an adult training centre in Berkshire. Between July 1979 and December 1980, 51 trainees (almost half of those attending the centre), have been in work experience placements. Forty-one have travelled independently by public transport or by walking to and from their places of work. The work experience officer was originally an instructor at one of the adult training centres who began to work half-time on the project and eventually full-time.

In Sheffield a person in the industrial training unit who took on the role of industrial liaison officer, negotiated and worked with a variety of firms, arranging for handicapped people to spend 6-12 weeks gaining work-experience at the job place. Places of work included hydraulics firms, kitchen assembly firms, catering, homes for elderly people and steel firms. After six weeks each person could choose to stay another six weeks or work in another situation. In 1982/3, 18 people, through work experience, were given full employment or placed on a sheltered industrial group scheme.

Job attachment

A small number of people may achieve only minimal productivity. Nevertheless, experience of work in the form of attachment to a fully competent worker would be of great value in their lives, especially in widening their circle of personal relationships with non-handicapped people. Such an attachment would be long term.

Training schemes

In this work option, a person is offered the opportunity to train for a particular type of work. Training schemes are generally time limited and do not offer long-term, permanent employment.

Examples

The Manpower Services Commission Youth Training Scheme is currently available to all school leavers between the ages of 16 and 19 years but can be extended for handicapped people to 21 years. Skill centres, established to retrain redundant workers, could be a valuable resource but people with mental handicaps do not appear to have been encouraged to attend. Similarly, employment rehabilitation centres could be more used by people with mental handicaps.

Barnardo's have a catering training project in Harrogate which draws on the catering skills of staff in a national restaurant chain. Trainees work in a restaurant with a view to future employment within the many catering establishments in the Harrogate area, especially those that have links with the chain. In addition to the catering and educational programmes, social skills are taught.

Supervised work

Under this work option, a non-handicapped person is employed specifically to supervise a mentally handicapped worker as distinct from job-sharing in which the non-handicapped person assists directly with the workload.

The employment agency could arrange for a non-handicapped person to be employed initially to learn a job. Then a handicapped person could be introduced, to be trained and supervised by the co-worker until competent to do the job fully when the co-worker would withdraw. The non-handicapped worker could be an adult training centre instructor who knows the handicapped worker, thus facilitating the transition from centre to open employment.

For a person whose handicaps are great and who needs more help and supervision, two non-handicapped workers might be employed. A full-time worker would spend perhaps half the time supervising and teaching skills. A part-time worker would assist in completing tasks so that the full-time worker is free to attend to the handicapped worker, knowing that the productivity requirements will be met. Gradually the part-time worker would be phased out as the handicapped worker becomes more competent. Any amount of support needed by the handicapped worker can be accommodated by this pattern of work.

Examples

In Massachusetts a self-employed carpenter agrees to the following arrangements for the apprenticeship of a person with intellectual disability. The carpenter will work alongside a person who has expressed an interest in carpentry. The carpenter is paid a supplement to his self-generated earnings in order that he will also provide training and supervision. The apprentice is paid 15 dollars a week as a training allowance during the apprenticeship period. The former apprentice could then go on to become a carpenter's assistant or a self-employed carpenter in partnership with the master carpenter.

In another creative work illustration from Massachusetts, an approach is made to a wholesale fruit company to employ three workers, none of whom are able to produce the full quota of work expected of an individual worker at the plant. The following agreement is made: the company agrees to employ three workers and pay them a proportion of the usual wage for the work they do depending on their personal productivity. This agreement is contingent on the vocational services staff, who are seeking employment for these three people, providing a full-time person to train and supervise them. It is recognised, however, that the supervisor might need to remain permanently with the workers if they continue to need supervision.

In addition to these work options which involve people working for an outside employer there are a number of more flexible options in which the worker is not an employee in the traditional sense.

Cooperatives

Collectives and cooperatives are the best known examples of non-hierarchical work settings, where people share responsibility and pay particular attention to each other's needs. In recent years we have seen the emergence of workers' cooperatives in which the work of different kinds which contribute to the cooperative are equally valued and equally paid. There are cooperative development agencies in many parts of the country, available to advise on setting them up.

Examples

The Camden Society for Mentally Handicapped People has been involved in a scheme to provide real work and wages for local people. The scheme they are working on will enable eight people to work together, five of whom have handicaps. The aim of the project is to provide real wages and there is an intention to pay union minimum rates, or wages based on National Joint Council scale rates wherever possible. This would mean for a 35 hour week, each worker would receive a minimum of £70 on today's wages. Although the project is being set up as a company limited by guarantee, the intention is that this will be converted into a workers' cooperative following the Industrial Common Ownership Movement model rules.

Another example of a cooperative is the Gillygate Wholefood Bakery in York set up in 1975 to provide food that is not adulterated by preservatives or over-refined. It created employment for disadvantaged people and functions as a cooperative, owned by the people who work in it. Two of the 16 members of the cooperative have mental handicaps. They work in the bakery and contribute to discussions about the way the bakery is run.

Self-employment

This option can offer the worker flexibility in working hours, personal control and contact with unlabelled people.

In using this option it would be possible to benefit from advice and financial assistance available from government agencies. At the same time there are drawbacks such as working alone and financial insecurity.

Example

We know of a young woman with Down's syndrome who is successfully running her own bakery business. Having had support from her family she has made such a success of work her next step is to learn to drive in order to deliver the goods.

Employer

Being an employer affords similar advantages and disadvantages to being self-employed. The essential difference is responsibility for employees.

Family business

Perhaps one of the most accessible but least documented opportunities for employment is within an existing business owned by the person's family.

Parents are doing business in painting and decorating, catering, upholstery, the rag trade,

farming, market gardening, shops and so on. Within the family business someone could be employed as an independent worker. A more severely handicapped person might be involved as in job attachment. Full productivity may not be demanded but the benefits of a working life may be experienced nevertheless. The drawbacks may be isolation and over protection, plus the possibility of not being considered a 'proper worker' and receiving pocket money rather than real wages.

Example

We know of one man in the south who works in the family fish shop. He may not get real wages but he does get up for work daily where he meets and serves customers.

Notes

The work in Massachusetts is discussed by Shelton and Lipton in the 1983 issue of Mental Retardation on employment.

The story of Adam Johnson is one of several published by CAMR (1983).

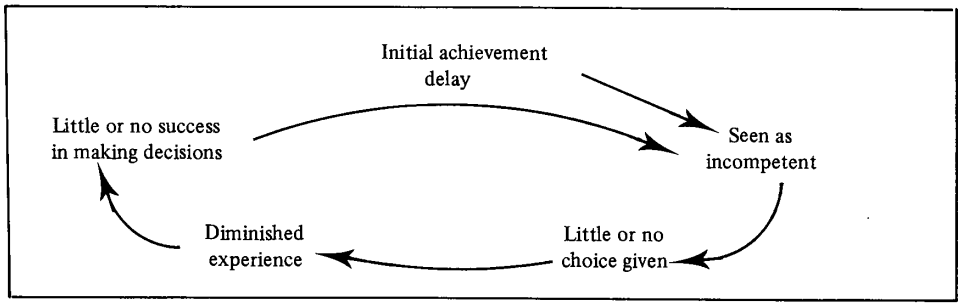
The Berkshire work-experience scheme is described by Pagliero (1981).

Choice

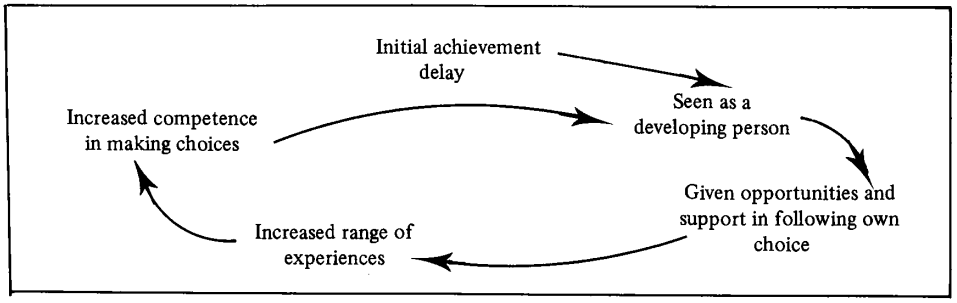
One of the fundamental principles guiding the development of our thinking is that people should be enabled and encouraged to determine, as far as possible, the kind of work they wish to do and with whom they wish to work. Most services, whether concerned with residence, education, leisure, or work, tend to be paternalistic and fail to encourage the development of decision-making on the part of the people they serve. If the people are seen as children the danger is that they will be regarded as irresponsible, and over-protected, both physically and socially, in order to minimise risks of exploitation, abuse, and physical danger. If, in addition, low expectations are held about their possibilities for learning and development then choices are likely to be very limited and training, which will allow the development of choosing as a skill, even less likely.

The more status a person has, the more choices are generally open to that person. One way of increasing the status of people is to help them gain greater control over as many aspects of their lives as possible by broadening the range of options available and supporting people in the choices they make. Facilitating choice might also contribute to a person's motivation in work which could serve to disconfirm the low expectations which others have. When people are never given the chance to do what they want to do, the prophecy of failure becomes self-fulfilling. When they are given the chance, there is the possibility that the prophecy of failure will prove to be wrong.

Choice in the lives of people with mental handicaps



Breaking into the vicious circle



If choice is to be a major guiding principle then all concerned, parents, school teachers, college and vocational service staff, need to consider the implications. In order to make a choice, there must be alternatives from which to choose. A person needs experience in how to make choices and to learn from the consequences of making those choices. We will need to look afresh at our paternalistic behaviour, our protectiveness, and our fear of possible risks of failure.

For a person who is not able to express choice it would be important to ensure that an advocate is available to promote the needs and interests of that person.

When we talk about choice we mean it in the sense that we would expect it for ourselves or anybody else. Say, for example, someone wants to work in engineering – that is their choice and they should be helped to find out more about engineering and see it for themselves. But if a job is not found for them in engineering, then the choices for them, again as for us, are that they have the opportunity to continue looking for work in engineering, or to give up the idea of a job altogether, or to look for a different kind of job elsewhere. That is the range of options we would normally expect to have and there should be no difference here, except the the extra individual support and assistance people may need. We envisage 'choice programmes' – that is, individual plans or programmes to help people better understand about and be able to make choices.

What can parents do?

In the past, parents have had little encouragement from professionals to think of their son or daughter ever getting a job. If they are told that their children cannot learn very much they are likely to have low expectations about their future.

Since the function of schools for children with severe mental handicaps is seen mainly as preparation for life in an adult training centre, teachers are not likely to convey a view of employment as a possibility. Since hardly anyone who gets to an adult training centre ever leaves for work in the world outside, parents have not had much hope of anything else.

If parents are to see work as a possibility for when their child grows up, they need to hear about people with mental handicaps who are doing a job of work. They need to hear about imaginative support arrangements so that they can believe that their son or daughter can benefit from work and will receive the help required.

When parents are persuaded that future employment is not out of the question then there are many ways they can prepare their child throughout childhood. These are all the things that parents do with their non-handicapped children. But it is worthwhile making a conscious decision to take advantage of any opportunity to orientate their child to the world of work, such as:

play based on jobs – dressing up, toys related to work, pretending to be a lorry driver, shopkeeper, teacher;

making scrap books about work;

listening to stories which include information about work;

doing jobs around the house – washing-up, keeping own room tidy;

going to a parent's workplace during school holidays;

visiting places of work and discussing the jobs people are doing;

talking with family friends about their jobs;

using normal experiences to see people at work;

talking about 'what do you want to do when you grow up?';

doing part-time jobs such as a paper round, perhaps shared with a brother or sister or a friend.

All of these activities are ways of widening the child's experience of the world and providing topics for discussion within the family. A child who grows up with these experiences is more likely to be aware of the options which may be available in the future and to expect to do a job of work.

There are many other ordinary childhood experiences parents can make available to help develop skills which may be useful in employment:

having a daily routine with a set getting-up time and bedtime;

attending pre-school provision such as nursery and play school with non-handicapped children so as to share attitudes towards work in the usual way;

having pocket money and a post office or bank account;

using the telephone;

getting around by bus and train;

getting on with others and learning socially acceptable behaviour;

taking part in clubs which encourage independence, self-reliance, being part of a group;

giving a child tasks and responsibilities;

giving a child risks and challenges.

By thinking about all these issues, parents can begin to create pressure to change services so as to open up more work opportunities for their sons and daughters. They can learn about the vocational services that support people with handicaps in integrated work settings. They can meet other parents to discuss these matters and they can talk with service providers to help change services to meet needs more appropriately and effectively.

When the time comes to look for a job, parents can help with personal contacts, and knowledge of openings. Some parents have even created employment opportunities which enabled their sons or daughters to work.

What can schools do?

In order to prepare people with mental handicaps to make choices about employment it will be necessary to make dramatic changes in educational philosophy and practice (See Wilcox and Bellamy, 1982). Schools are more likely to provide preparation for work if teachers think of their pupils as possible future employees. At present, very few children with severe mental handicaps have opportunities for orientation to work when they enter the special education system. Placing children in special education not only deprives them of learning along with their non-handicapped peers, it is also likely to end any expectation of future employment. With the introduction of the 1981 Education Act more children with handicaps will be educated with non-handicapped children and will therefore be exposed more to the

choices available when they leave school. By educating children together in ordinary schools, children with handicaps will have the same opportunities for developing work skills and to experience the same variety of work situations as other children. It is only when children have this range of skills, experiences and expectations that they can begin to make informed choices amongst work options.

In the meantime, whether children are in an integrated or a special school, they should have available:

- contact with teachers who have positive expectations about work for all students;
- contact with careers officers;
- careers conventions;
- a teacher who has special responsibility for careers guidance and the provision of information about careers;
- assistance with enrolment at a college of continuing education;
- help in selecting courses at college;
- help in arranging the support needed at college – such as adaptive technology, tutors, and student assistants to ensure participation in college courses.

Schools should liaise closely with colleges to facilitate the transition from school to college.

Teachers can help to increase parental involvement by developing their awareness of post-school training, and employment resources. When teachers and parents meet at parent-teacher association activities, at careers conventions, and when parents visit school to talk about their child's progress, issues to do with employment can be raised and possibilities explored.

Schools could develop work preparation programmes to provide each pupil with an opportunity to spend time in a variety of workplaces and experience normal daily work routines and conditions in their last year or two at school. The emphasis of the programme should be on work and not solely on academic achievement. Any classroom teaching should link with the work experience. Each work experience should be designed for one person only and not for a group of students. Each student should be actively involved in designing their own programme and in deciding on work placements.

Work-experience based on individual choice and need should be very varied. It can enhance a person's development through actual participation in a job, contact with other people, work routines and so forth.

Some practical ways in which work preparation can be provided are:

- short visits to a variety of workplaces;
- watching videos of people doing real jobs;
- visits to job centres;
- role playing interviews;
- practice in filling in job applications;
- practice in talking about themselves;
- learning about benefits;

projects, shared with non-handicapped students in which information about jobs is gathered;

talking to trade union members;

learning about health and safety at work;

learning how to relate to supervisors and co-workers;

learning about time-keeping.

In order for work preparation to be effective there is a need for increased communication and cooperation between staff in schools involved in work preparation and the employment services. This could formally take place at each person's individual programme planning session, through greater collaboration in designing the work preparation curriculum and through continuing links as the programme develops.

Those involved in work preparation need to be aware that more people lose jobs through inability to get on with work colleagues than through lack of actual work skills. One problem faced by those preparing a person for work is the fear of raising expectations which cannot be met. Expectations in themselves can lead to pressure to provide opportunities. It is less likely that expectations will be unrealistic if those involved are aware of the range of local opportunities that may exist if creative thought and imagination are used.

What can colleges do?

In addition to the usual range of courses available at colleges of continuing education – including life skills, literacy, physical education, and so forth – colleges can provide specific vocational orientation through the following:

Careers awareness and exploration which develops the work preparation done at school. Courses should broaden students' awareness and knowledge of specific occupations by providing information and experiences which will enable them to make informed choices, assist in breaking away from stereotyped job expectations, develop a 'vocational vocabulary' and introduce students to employment agencies.

Promoting self-advocacy so as to increase students' knowledge and assertion of their human and civil rights. This will improve students' skills in deciding what jobs they want and how to find and apply for jobs.

Close liaison with staff from vocational services to facilitate the transition from college to employment.

Developing job seeking skills to assist students to get jobs themselves as far as possible. This would involve sources of job leads, application preparation and interviewing.

Notes

Wilcox and Bellamy (1982), and Croft, Tuckwell and Beresford, discuss the need for change in educational philosophy and practice.

Williams and Shoultz (1982) outline self-advocacy.

Job finding is described by Azrin and his colleagues. Materials based on the work of Azrin and developed by Judy Hutchings and Steve Hobbs are available from Chris Gathercole, Montague Health Centre, Blackburn, BB2 1PP.

A vocational service

The service we envisage will be individually oriented to the particular employment needs of each person served. In order to meet those needs for the full range of people with disabilities, a number of tasks can be identified which a vocational service would need to perform. These tasks are outlined below. Some of these tasks may currently be performed by disablement resettlement and Pathway placement officers, but nowhere in Britain is there a thorough implementation of all the service components listed here.

We do not attempt to lay out a detailed blueprint for implementation with job descriptions and organisational arrangements specified. Our aim has been to outline *what needs to be done* and to leave it to local services to work out *how to do it.*

We assume that the development of a vocational service will take place within the context of a plan for comprehensive services designed to ensure that the full range of needs of people are met. Without this, there is a danger that non-vocational needs may go unmet and then pressure will be exerted for the vocational service to meet these other needs. Support in non-job areas, such as cooking and recreation, should be given in the settings in which those activities would naturally occur – at home and in the community. If the vocational service takes on these tasks it will merely drift into a confused and incoherent mess without focus, possibly doing more harm than good, certainly wasting its resources. Rather than take on these non-vocational needs, the staff of the employment service should exert pressure for appropriate services to be developed by other service providers.

The order in which the tasks are listed here is intended to suggest the sequence in which a new vocational service might be introduced.

Essential ingredients

Assessment and individual programme planning

Purpose To identify a person's employment preferences and the support and other service components needed.

Methods Discussion with clients to find out the kind of work they might be interested in – school leaver vocational preparation, classes in career awareness and exploration, self-advocacy classes, and work experience. Discussion with relatives and other personnel concerned in developing a person's individual programme plan. On-the-job assessment allows continuing review of a person's progress in real work situations. Work-experience can be especially useful for this.

Comment Formalised testing and assessment is *not* generally necessary in order to determine a person's eligilility or potential for particular services, instructional classes or jobs. Such tests have doubtful predictive validity and have often been used to put stigmatising labels on people such as 'unemployable', 'ineducable', 'low grade'. In addition they are often extremely expensive in time, energy and money. Vocational assessment has been widely misused to exclude people from services and choices by attempting to determine whether a handicapped person is 'ready for work'. Only if their 'work readiness' is considered appropriate is the person considered for job placement.

The alternative approach adopted here is to use assessment in a constructive way to determine what help a person would need to do the work he or she wants to do. Client choice is therefore the priority consideration.

Keeping contact over a long period of time will be part of the vocational service, even when a person appears to be having no problems. If unemployment strikes, people should be able to call on the vocational service for help. Assessment of what help is required should therefore be continuous and not a once-and-for-all exercise.

Coordination and monitoring of individual programme plans

Purpose To contribute to the review and individual planning for each person. To coordinate the means of meeting vocational needs. To monitor the implementation of means to meet vocational needs.

Methods Individual programme planning at least annually, to include person, family and other relevant service staff and volunteers. The mental handicap team to create mechanisms for coordinating service delivery at individual level.

Comment A dispersed service requires clearly stated and recognised coordination and monitoring mechanisms for staff to ensure that users needs are met. These are complex issues which each service must address. They should be of special concern to the body which is charged with the task of developing comprehensive services in the locality.

A variety of advocacy schemes should be developed to ensure that people's needs are not neglected: self-advocacy, ombudsman, class advocacy, citizen advocacy and so forth.

Guidance for service users

Purpose To act as a source of guidance, friendship, practical assistance, emotional support, encouragement. To enable service users to understand their disabilities as they relate to employment (for example, epilepsy, cerebral palsy, autism, mental illness). To overcome low self-esteem, motivation and unsuccessful social interactions in seeking or training for jobs or job retention.

Methods Assistance and support given freely and informally to any service user who requests it or seems in need by employment service staff. Requires a thorough knowledge of disabilities and ability to impart this knowledge in various ways.

Transport assistance

Purpose To help a person get from place of residence to place of work, using transport available to anyone. Some people may work at home and some will be able to walk to work, but it is likely that every person will need to use some form of transport on a regular basis.

Methods Teach the use of public transport; advocate rights to use all transport options; insist that various modes of transport are redesigned to accommodate handicapped people; encourage parents and workmates to help; accompany people on bus and train routes until they are familiar with them – withdrawing support as appropriate; help people to join car pools and to use employers' own transport; help people to use taxis if necessary; help people to to use bicycles and to learn road sense.

Comment For many people, transport assistance is a critical issue in getting and retaining jobs. So although it may not seem to be a specifically vocational matter, an employment service should ensure that transport assistance is available. If it is not provided by other services then the employment service should provide it directly.

Help in getting vocational training

Purpose To facilitate participation in generic job skill training.

Methods Work with local colleges of continuing education to: inform handicapped people of what is available; help select areas of study; assist with enrolment and registration; arrange support needed such as adaptive technology, tutors, and student assistants; advocate on behalf of clients; support self-advocacy efforts; help negotiate training provided by employers and by skill centres.

Links with employers

Purpose To establish contact between the employment service and employer, to facilitate job placements, to obtain work experience opportunities, and to get advice from employers on various issues.

Methods Create positive awareness of the employment service; explain to potential employers what can be expected from the employment agency; contact employers to employ specific clients, and also to find out possible job openings; help employers in developing and designing jobs.

Guidance for employers

Purpose To ensure appropriate work situations, training, supervision, and appropriate welfare, workers' rights and career opportunities.

Methods Give guidance to employers: to provide personnel with some knowledge of handicaps or ability to obtain assistance/advice if necessary; to obtain grant aid or subsidies to provide satisfactory facilities if necessary; on making access, alterations, toilet facilities, and so on, necessary for the handicapped worker; on the provision, where necessary, of suitable devices/personnel for communication; on the provision of additional insurance if necessary; on the provision of visual, aural or tactile communications as appropriate, for warnings, alarms, and so on, as well as for general convenience and instruction, trying not to make the person rely on other people.

Comment At the present time, legislation does not require employers to provide accommodation or facilities for handicapped workers nor for handicapped visitors, repair persons, deliverers and others. If all new places of work were required to conform to a minimum standard, as with mobility housing, then handicapped persons may well feel much more confident about applying for jobs and purpose-made work situations would be a rarity. It does not necessarily follow that such legislation would cause substantially increased capital expenditure. More forethought may be sufficient.

Job development and placement

Purpose To help people find and secure jobs of their choice.

Methods Discuss job preferences and capacities with people to learn what job openings

would be appropriate for each person; match each person to the type of work he or she would like; review employment adverts, various job listings, and other sources of job leads; examine criteria of job openings and explore revisions of criteria where possible; examine design of jobs and explore job redesign; coach people for interviews (if necessary, accompany a person to the interview and act as spokesperson in dealing with the prospective employer); keep helping a person seek another job after unsuccessful interview or terminated jobs.

Comment Too often people have been put into jobs by staff or parents who think they know best. Sometimes they have been pressurised to do work to which they object. Client interest and motivation are vital to job success and personal preference should be given priority over any other factors, including assessment results, staff views on what is best, what the family prefers, and what the employment service has done in similar situations before. Dignity begins with choice.

Care should be taken to avoid one employer taking the majority of disabled people in one area. This could lead to a concentration of disabled people not only in one place of work but also in nearby housing. Also, if disabled people are to have maximum opportunities for contact with non-disabled people, the ratio of disabled to non-disabled workers should be low.

Job retention

Purpose To help people keep their jobs.

Methods Make periodic phone calls to the worker and/or job supervisor or co-worker; make visits to the job site – both pre-arranged and unannounced; provide support and practical assistance to workers as needed, especially when there are changes in the job or the work setting; encourage employers to promote workers to more challenging, higher paid jobs; arrange job skill training; coordinate other programme components, such as transport assistance and links with employer.

Comment The first few weeks and months are usually the most difficult. Adjustment from unemployment to full-time work requires support from employer, co-workers, and employment service staff.

One issue which most employees face at one time or another is a desire to change jobs. The vocational service should be responsive to a person's interest in change. It may be that having developed a particular skill, a worker might be encouraged to consider trying for promotion to do work of higher value with better pay. It should be regarded positively when a worker expresses a desire for a change of employment. New training and possible additional support may be needed. If the person is made redundant or decides to walk off the job or gets the sack, this should not be seen as a disaster but as an opportunity for learning by the person and the employment service.

A danger to be avoided is refilling a vacancy with another disabled worker. The job might come to be seen as a 'handicapped job' with stereotypes about the kind of person who does that kind of work.

Arranging co-workers

Purpose To provide workers with guidance, supervision and modelling by co-workers at the job site, whether in a paid job or work experience.

Methods Develop effective methods of recruiting co-workers; determine worker performances which will be required for termination of co-worker supervision; determine appropriate payments for supervisory work; arrange for substitutes for co-workers. Substitution is necessary given the paramount importance which must be assigned to the commitment made to each employer.

Comment 'The concept of a Job Sharing Model is based on methods of job training . . . where one skilled and experienced worker teaches the skills needed for a job. Historically, this approach dates back many centuries when job skills were learned through apprenticeships: people learning skills by working alongside a master artisan.' Jobs are not developed by 'appealing to the business' public and charitable spirit: each job arrangement will be developed and maintained so that the needs of the employer for a productive worker are met. Job Sharing allows for those needs to be met while meeting the employees' needs of skill development and personal support.' (Mentor)

Work-experience

Purpose To provide people with opportunities for career exploration by experiencing, first hand, a job in which a person may or may not subsequently be interested.

Methods Employment agency staff member: seeks out potential work experience sites; matches a person's preferences and needs with work experience openings; arranges job skill training as appropriate; defines a termination date, clear objectives and performance criteria for moving on to a real job; gives clear guidance to work-experience employer on the purpose of each placement and criteria for appropriate placement.

Comment Work-experience should be 'hands-on', take place in a realistic setting and allow the person to learn about their own capabilities. The dangers of inappropriate use of work-experience should be actively guarded against. Work-experience should not provide a place for people to spend their time while they are on a waiting list for an appropriate setting, or provide prospective employers with free labour.

Job skill training

Purpose To teach each worker the skills required for a particular job when starting, but also if the job changes.

Methods One-to-one intensive instruction, usually at the work site (care should be taken to ensure that individual training is provided in a valued way and stigmatises the person as little as possible); coordination with other resources such as mobility training programme, aids and adaptations; use of task analysis, and precision teaching methods; use the actual job situation as much as possible and simulation as little as possible.

Comment Most current practice is geared to teaching general work skills, the philosophy being that a person needs a thousand and one skills before being deemed 'ready' for work. For example, it is usually assumed that a person who is incontinent and does not speak should not be allowed to work until those deficits have been overcome. A very different approach is to focus only on what is required for the particular job in hand. This enables a person to gain the skills to perform that task in the shortest possible time. Of course the person should receive help with other needs but the vocational service should not be directly involved, except to recruit the services the person requires.

Teaching specific skills means that whenever the task changes, more teaching is likely to be required. Training might be done by the employment agency's staff or by the employer's own training department. The job skills trainer should therefore be available for consultation by the employer whenever a change in the job is envisaged.

Job design

Purpose To tailor a job to make it possible for a worker to perform it adequately, who otherwise may not have the strength, dexterity, judgment or speed required.

Methods Change the physical setting where the job takes place, for example, space, noise, height of work table, lighting; modify equipment used; use tools, prostheses, and aids to complement a person's limitations; change the actual tasks to be performed, for example, the number and sequence of steps; eliminate unnecessary activities or tasks; provide extra assistance in certain aspects of the work.

Comment Job design should be considered in relation to job skill training and job retention efforts. Priority should be given to helping the person adapt to the demands of the environment, before adapting the environment to the person, but the two approaches should be considered together.

Improving community and professional acceptance

Purpose To assist parents, voluntary associations, instructors, lecturers, teachers and others to facilitate vocational development.

Methods Training in a variety of settings using films and case histories of work progress.

Comment This component should not grow to be a major activity as a more effective approach to acceptance is probably in demonstrations of worker's progress. Staff time should not be diverted from direct assistance too much.

Staff

All staff concerned would need:

to be familiar with the principles outlined in this paper;

to be committed to respecting the choices of service users and facilitating self-advocacy;

considerable communication skills in order to explain what is required to clients, parents, teachers, employers, work-mates, supervisors and others who may be involved;

to be able to work with considerable independence and on their own initiative;

to take a personal interest in the clients with whom they work, to be sensitive to their needs, able to listen and observe;

to know about the various handicaps people may have.

The various tasks which an employment service for people with mental handicaps would need to perform have been discussed above. There are probably a number of ways of combining these tasks, but at least two main roles might be identified. *The job finder* could combine: links with employers, guidance for employers, work-experience, assessment, job development and placement, job retention and arranging co-workers. Knowledge of the field

of employment and extensive links with local employers would be required of the job finder. *The job skills officer* could combine: job skill training and job design.

If there are separate staff for different functions, care has to be taken that employers and workers are clear about who to contact and what the different roles are. Close liaison between employment service staff, school and college staff is essential.

To be successful, the job finder needs to be well-versed in industry and the language of employers. Negotiation, public relations and selling are key aspects of the work. Job finders must avoid the supplicant approach to employers, asking for charity. An approach which is much more constructive appeals to the self-interest of employers, aiming to show how the service can be of benefit to employers. Such a positive approach is described in Galloway's (1982) *Employers as Partners.* Job skills training and job design is a more technical and specialised role which requires the kind of experience which Bellamy's workshops provide. Training for all these tasks will have to be developed.

Appointments might initially be made using money from health, social or voluntary services. However the employment service should, from the start, operate very closely with job centres, disablement resettlement officers and other parts of the Manpower Services Commission. The service should come to be seen, not as a part of health or social or voluntary services which are inappropriate, but as part of the generic employment services. It would therefore be helpful if it were based in a job centre.

What is a reasonable case load has yet to be determined in practice. It is essential that staff do not become so overstretched that they fail to provide clients and employers with the support needed. During the first 15 months of Vocational Education Alternatives, 190 people were served, 83 of whom were placed in competitive jobs and others placed in unpaid work-experience settings. There were eight staff, including a director, an office manager, a job retention specialist, a job developer/job placement specialist, two employment coordinators, a vocational preparation coordinator to link with colleges and schools, and a work experience coordinator (Parent Information Resource Center, 1982).

Notes

Excellent reports on vocational services are available in Breedlove and Johnson (1981) and Du Rand and Neufeldt (1975).

Assessment is discussed in Menchetti, Rusch and Owens (1983).

For a discussion of a positive approach to employers see Galloway (1982).

A work-experience scheme is described by Pagliero (1981).

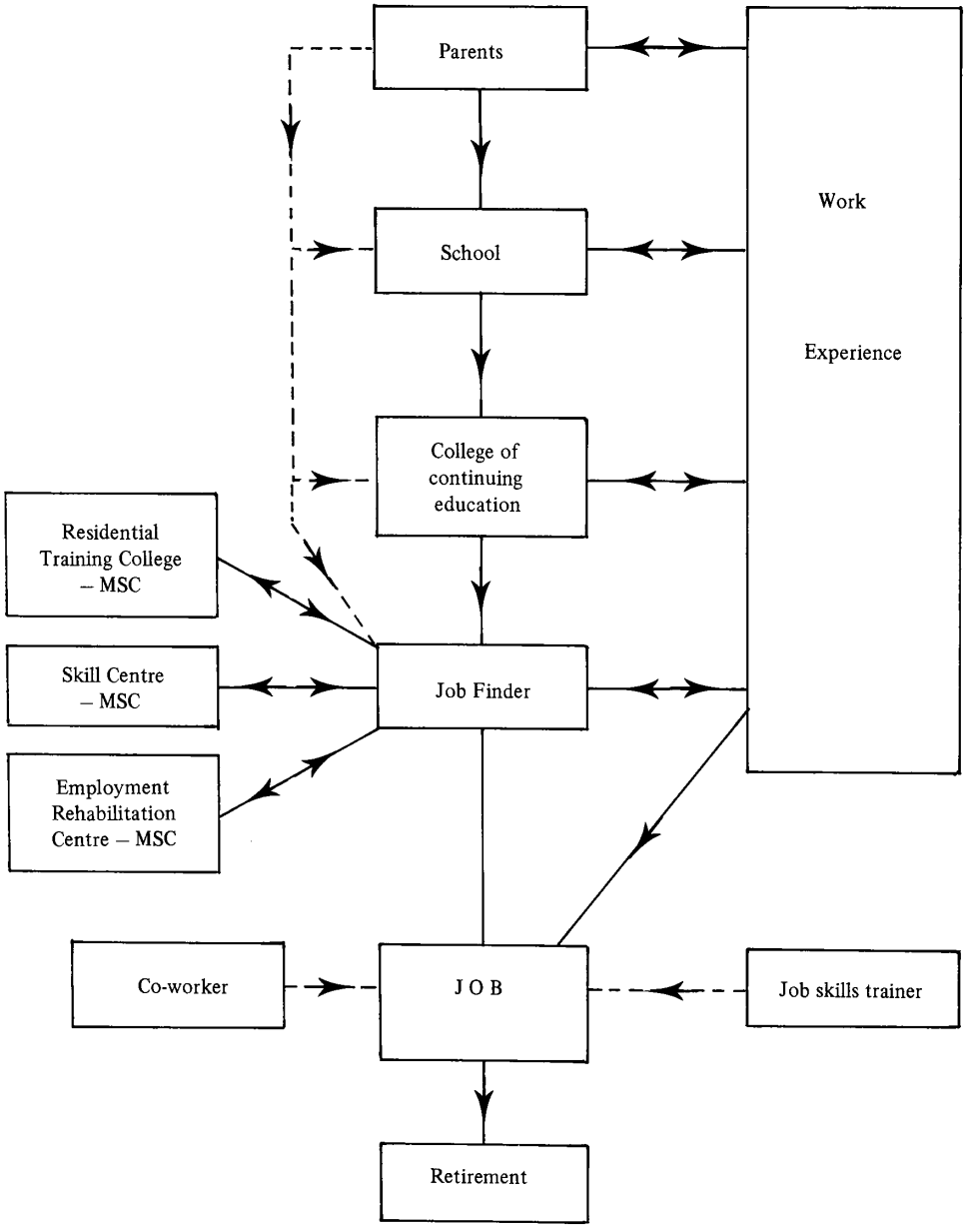
Job skill training and job design are described by Bellamy, Horner and Inman (1979).

Concorde Films, Ipswich rent 'Try Another Way', a series of films on Marc Gold's work on job skill training.

Individual Programme Plans are discussed in *An Ordinary Life*, King's Fund Centre (1982).

Various advocacy approaches are outlined by Wolfensberger (1977).

A job finding system



Continuing education and work-experience for someone with profound intellectual disability

The model we have outlined includes vocational orientation and preparation at school, usually leading on to some time in a college of further education, polytechnic or other establishment of continuing education. Such continuing training may be full-time, part-time, sandwich training or part of a phased programme of work-experience and training. We see the combination of time spent training and time spent on the job as very individual, according to the needs of each person at a given point in time. Opportunities for learning or training are an essential part of all valued work. This opportunity for personal career development may take many forms: counselling, self advocacy classes, career development classes; teaching blocks for self-help skills or interpersonal skills for use in social or employment situations or for survival and daily living skills; classes in the use of leisure or creative skills; and classes to help people learn locomotor skills or any variety of skills which may not have been mastered by the time the student has left school.

We would therefore expect that many people who now attend special care units in existing adult training centres would instead attend continuing education colleges for perhaps four days out of five, learning gross and fine motor skills, language and comprehension skills, sign language and other basic living skills. Occupational therapists, physiotherapists and speech therapists might come in to teach very small classes within the college. One lecturer at the college might have responsibility for a daily living course attended every morning by a group of students who spent their afternoons on a work-experience course in various catering and retail establishments. Another lecturer might be responsible for an environmental appreciation course for five students, all with profound intellectual handicaps, two of whom were unable to walk, one of whom was also partially sighted, and another deaf. With help from visiting specialists, these students might explore the extent to which they could use new technology to move around and choose different environments and different sensory experiences. During part of each day, or for some days each week, a work-experience programme might mean

Katherine Watson is an active 22 years old woman whose three forms of verbal communication are laughter, screams or yells, and a repetitive polysyllabic sound. She can walk, has some manual dexterity and can pull her clothes up and down. She has learned to take herself to the toilet to urinate in some settings, but not all, and does not use a toilet to defecate. She will freely take and eat food on display if not monitored and prompted. She dislikes sitting in one place for more than a few minutes.

Ms Watson might attend a basic daily living class at an FE college, learning a variety of skills such as food and drink mixing, packing and unpacking foods, basic dress and hygiene, appropriate social and communication skills such as shaking hands, basic sign language, and some academic skills such as word recognition. Her chief work-experience placement might currently be assisting and observing a co-worker employed in domestic work in the university hall of residence. Although not perhaps the most valued of work placements, her job finder would be aware of this and hope to negotiate something better. Several half days per week, might be spent in a small factory with a co-worker on a contract assembling switches for a firm making small computers for the home market, paid a salary by a special employment agency funded for three years by the local authority.

either observing in two different work settings, or participating in one task with a co-worker at just one placement.

For a very few people such college-based developmental learning might continue to occupy the majority of their working day for many years. For everyone, however profound their disabilities, some of their working week would be spent experiencing what work is like for others in valued work settings. That part of their week spent in continuing education would be spent in a valued educational setting for adults where the methods of teaching were, as far as possible, appropriate to their age.

Financing new approaches

Innovative pilot projects will have a vital role in demonstrating what is possible. They may get finance from a variety of sources, although many of these sources will be limited in either size or duration of support. Joint Finance monies are frequently used to provide staffing for extra training centres or special care places at present. Such finance could be used instead to pay the salaries of job finders, or job support staff. Projects might get finance from urban aid grants, or the EEC special employment budget. Voluntary organisations might set up trusts to underwrite small demonstration projects. Authorities or voluntary organisations might attract Manpower Services Commission funds through their sheltered industrial group schemes. The use of sheltered industrial groups, whose minimum size is one worker, means that most of the difference between a worker's productivity and a living wage is taken up by the Manpower Services Commission (the sponsoring organisation must fund only 5 per cent of this difference). Sheltered industrial groups can be set up for workers whose productivity achieves a minimum of 30 per cent that of a non-handicapped person. In the present financial climate we foresee much change becoming possible through changing the use of existing resources, rather than through the availability of new money. The employment of one effective job finder by a social services department could, within two years, release many places previously taken up in adult training centres. Once the number of trainees actually attending adult training centres is reduced, it should become possible to release further staff who can support people in paid employment alongside co-workers.

It is clearly extremely difficult to make any accurate assessments of the actual costs of running the kind of service envisaged here. Nevertheless, we attempted to estimate what such a service might cost. To do this we considered a particular authority, and attempted to conceive the kind of project which might be provided for the clients currently attending its training centres and special care units. The authority is a typical authority in the north of England. Its present average cost per client is below the national average.

Table 1 (page 48) sets out the current costs for this authority which serves a population of 250 000, and provides 200 places in ATCs for people living at home or in other local accommodation, together with a 15 place 'special care unit' part funded through joint finance arrangements. The authority does not provide a service for people currently living in hospitals outside the area.

This service presently employs two ATC managers, two deputy managers, 16 instructors and 18 care assistants, domestic and catering staff, escorts and drivers. The special care unit staff consists of one deputy manager and five instructors.

A job finding and job support service for the same 215 clients might involve the following kinds of projects.

1 *Open employment* Thirty-six people in open employment with support provided by two job finders who also provide follow-up support. Cost: salary for two job finders.

2 *Cooperatives* Four people might be working in cooperatives with at least a weekly visit from a job finder.

Table 1 Present costs for one authority: day services for people with a mental handicap (cost at January 1984)

	Main ATCs (assuming 2 ATCs for a (population 250 000)	*Special care unit (assuming one 15 place unit, under joint finance arrangements)*
Debt charges – Interest	£40 000	N/A (Joint Financed)
Principal	£5 000	N/A (Joint Financed)
Premises – rates, maintenance services	£30 000	£2 500
Supplies, including trainee allowance	£77 000	£5 500
Transport	£48 000	£10 000
Administration expenses (telephones etc)	£2 000	£1 000
Employees salaries (including superannuation, etc)	£240 000	£57 000
	£442 000	£76 000
		(Part of this cost will be recoverable by the LA through Joint Financing Arrangements)
Total from all sources	£518 000 for 215 clients*	
Average cost per client per week	£46.33*	

* These costs have been calculated as if the full cost of the joint finance arrangements were borne by the local authority. This will be the case at the end of the joint finance period; in the meantime actual costs to the local authority will be reduced proportionately.

3 *Sheltered industrial groups* Fifty people might have employment under this project in a variety of settings, mostly supported by the Manpower Services Commission. The vocational service agency would fund 5 per cent of the difference between productivity and earnings for these workers. If their productivity averaged 50 per cent the agency would need to find about £5000 pa for this subsidy. These workers would be supported by three senior job support workers employed by the agency specifically for this project. Approximate cost: £5000 plus salaries for three job support staff.

4 *Rehabilitation* Five people might at any one time be attending employment rehabilitation centres.

5 *Training as craftsman's mate* This project would aim to support ten people working as trainees to become craftsmen's mates. The firm would pay the trainee an allowance, which would be supplemented by the agency. Such a supplement might range from £10 to £30 a week costing the agency £10 000. Support to the trainees might be provided by one senior job support worker sharing responsibility for placing clients in, for example, Youth Training Schemes. Approximate cost: £10 000 plus salary for one job support worker.

6 *Youth Training Schemes* Ten young people who had recently left school might be placed at any one time in Youth Training Schemes. A senior job support worker might share

responsibility for setting up schemes or placing clients, as well as finding and supporting other training opportunities. Cost: staff salary shared with project 5 above.

7 *Further education and adult education* Twenty people might at any one time be in full-time further education schemes, or spending a large proportion of their time in further or adult education. One member of staff might be employed to coordinate and provide support to these students, as well as to help potential students find places on appropriate courses. Cost: salary for one further/adult education liaison worker.

8 *Temporary work-experience* Approximately ten people might at any point be on temporary work-experience placements full-time. These trainees might be paid a nominal allowance only by the agency on top of SDA or their other allowances. A number of other people (especially the more severely disabled) might gain some work-experience part-time for a number of months while taking part in one of the other projects part-time. Finding and supporting these work-experience placements might be the prime responsibility for one senior job support worker. Approximate cost: £3000 plus salary for job support worker.

9 *Supervised work projects* Twenty-one people might be employed in supervised work schemes. Each scheme might be negotiated by the agency job finders with employers who pay one wage for each job which might be shared by one to four people, with training and support provided by agency staff. We assumed the agency might need to pay on average £40 per week per client so that each worker is paid a basic wage. The actual payment to each worker is made by the employer, agency payments being made through the employer. The agency might employ eight instructors including one full-time instructor to each of seven schemes. One relief instructor full-time could provide sickness and holiday cover with the assistance of other job support workers at times. This supervised work project might cost something in the order of £120 000 pa including payments to workers and salaries for eight instructors.

10 *Job sharing schemes* Up to 25 workers might be employed in jobs which would each be shared between one person with a handicap and one co-worker. The agency would contract with the employer to do one job. The employer would finance one wage. The agency would finance a second wage, and a supplement to the co-worker. One job support worker would also be employed by the agency to help negotiate and provide support for the schemes. The total cost of such a project for 25 workers and 25 co-workers might be in the order of £140 000 pa including wages and supplements for 25 co-workers, and the salary of one job support worker.

11 *Job attachment schemes* Twenty-four people, including some of the most disabled, might be served by this project. It would be designed for those people whose productivity may be very low. Clients would be attached to co-workers or instructors. Such arrangements might often be found, for example, in small service industries. Clients might be paid nominal allowances on top of SDA or other allowances in this project. Two kinds of scheme might be envisaged. In the first, 12 people who might be very physically disabled, or have profound intellectual handicaps, might be attached to individual co-workers. The agency would pay the co-workers a supplement to the normal wage for the job. The co-worker's productivity would be reduced on account of time spent with the client, and the agency might accept a reduced wage from the employer to compensate for this. The co-workers might be paid up to £50 per week enhancement beyond the normal wage for the job. The agency would have to contribute part of the co-worker's wage, plus the enhancement, besides an allowance to the client. Some 12 other people might show such behavioural or other difficulties that they

would need an experienced staff member each, employed full-time as an instructor, to whom they would be attached. In these schemes the instructor might be able to achieve only low levels of productivity at the job, and the employer would pay the agency only a nominal salary. The job finders would set up and support these schemes, and liaise with other professionals, such as physiotherapists and occupational therapists. The costs for such a project would include client allowances, co-workers' supplements and reduced wages paid by the employers to compensate for lack of productivity. In addition there would be salaries for two job finders/job support staff and 12 instructors. Excluding transport, these costs might total around £190 000 pa for 24 of the most disabled clients within the authority.

To the costs for these individual projects would need to be added salaries for some staff employees across the service projects, various administrative expenses and some costs for transport assistance for clients unable to travel independently. Transport assistance would need to be provided in ways that did not demean the clients as workers. Some agency staff might be contracted to provide transport to work for one or two people. Many clients would be able to get to work independently. We conceived that a vocational service might need to employ a director or coordinator, two job design/job skill training officers, and secretarial assistance. Capital charges and interest or rent, rate and service charges for office accommodation, travelling expenses and administrative expenses would need to be added.

The total staff who would be employed by this service, serving a population of 250 000, might perhaps consist of 37 staff:

1 service director;

2 job design/skills training officers;

2 job finders supporting open employment and supervised work initiatives;

2 job finders supporting workers on job attachment schemes for the most disabled;

3 job support staff supporting sheltered work groups;

1 job support worker with primary responsibility for training schemes;

1 job support worker with primary responsibility for work-experience;

1 job support worker with responsibility for further/adult education liaison;

1 job support worker for job sharing schemes;

8 instructors in the supervised work project;

12 instructors in the job attachment project;

3 secretarial/clerical staff attached to the administrative base.

In addition 12 co-workers would be involved in the job sharing scheme and 25 in the job attachment project.

Table 2 (opposite) indicates that the total cost of such a vocational service for the 215 people served at present might be in the region of £687 000 pa (£61 per person per week) as compared with the current actual cost of £518 000 pa (£46 per person per week). The costings are clearly very approximate as many assumptions have had to be made about the kind of projects which would be suitable for different people and the costs of the projects themselves. The transport bill would be very much lower if people are trained to use public transport. Nevertheless, these figures were based on knowledge of trainees in a real local authority.

Table 2 Projected costs for a vocational service for the clients served by the authority illustrated in Table 1

	Agency cost (including superannuation, etc) £
Open employment, cooperatives and supervised work (61 workers)	
2 job finders	27 000
8 instructors	65 000
Wage supplements to workers under supervision	40 000
Sheltered work groups project (50 workers)	
3 job support staff	30 000
Contribution for productivity shortfall	5 000
Training schemes (25 trainees)	
1 job support staff	10 000
Wage supplements to trainees	10 000
Student support (FE/AE) (20 students)	
1 job support staff (with other responsibilities)	10 000
Work-experience schemes (10 people)	
1 job support staff (with other responsibilities)	10 000
Allowances to clients at £4 pw	3 000
Job sharing schemes (25 workers)	
1 job support staff	10 000
Wages and enhancements for 25 co-workers (employer pays 25 disabled employees full wage each)	160 000
Job attachment project for especially disabled people (24 people)	
2 job finders/support staff	27 000
12 instructors	100 000
Wages and enhancements for 12 co-workers (enhancement up to £50 per week: employer pays agency less than full wage)	50 000
Allowances to clients at £4 pw	5 000
Central services (215 clients)	
1 service coordinator	20 000
2 job design/skills training officers	30 000
3 admin/secretarial/clerical staff	15 000
Premises and administration expenses (capital/interest charges on office accommodation, rates, service charges and supplies)	20 000
Transport (including staff travelling expenses)	40 000
TOTAL	£687 000
Average cost per client per week	£61.45

Note: The actual payment to the disabled employee would normally be made by the employer, with any agency supplement or allowance being directed through the employer to the employee. Co-workers would, however, be employed and paid by the agency.

This plan, therefore, should make it clear that the model of service we are advocating is not unthinkable. It might be somewhat more expensive than present provision, but we have tried to be generous in our estimates of costs of the new service. Moreover, this model affords its most disabled people a one-to-one relationship with either an agency worker or a co-worker full-time on the job. The experience and opportunities such a scheme might present would seem to offer great benefits for a moderately increased expenditure for each person.

Strategies for local implementation

How can people who want to develop employment services in their own areas get things going? To innovate services successfully in the present economic climate, with all the old ways of thinking about services for people with mental handicaps still around, will take commitment and imagination. The goal for local innovators will be to make things happen which, while they make most use of growth points in existing services, are also true to the principles of service design and carry local opinion with them.

Developing shared purposes

Since very few people see work as a real possibility for most people with mental handicaps it is important to generate discussion at local level on the right of people with mental handicaps to engage in paid, valued work with appropriate support. Partly this can be a consciousness-raising exercise for a small group interested in developing a service locally; but there is also a place for introducing the issue of work in wider discussions, not just with staff in health, education and social services but with employment services staff and potential employers too.

Boundaries between agencies can sometimes be so strongly defended that progress is difficult. Staff from different agencies must reach out across their boundaries if people with disabilities are to benefit. A major difficulty is that people who know about mental handicap normally know very little about employment and people who know about employment often know little about mental handicap. One function of local discussions is to build a shared fund of information and knowledge.

Clearly a central part of this whole process will be the involvement of people with mental handicaps and their families, in developing shared perceptions of the future. Potential workers and their relatives may have little knowledge (as little knowledge as most professionals) about the innovations in employment that already exist and have been described earlier; and they may also be sceptical about the ability of our public services to 'deliver the goods'. All the more reason for involving them in discussions from the beginning.

It is important to the development of a vocational service to have some early success. Small scale projects in which severely handicapped people have been placed in full-time paid and valued employment would enable lessons to be learned which would be invaluable to the future development of the service and would help to demonstrate to the sceptics that it was indeed possible. Good documentation and information about such projects should be made available to all the relevant local people so that discussion is generated, and employers, colleges and other relevant agencies see new possibilities, and would be willing to try new ideas. The person who might establish this first successful placement could be from any field of work. It might be a social worker, community nurse, adult training centre instructor, college lecturer, special school teacher, parent, psychologist, disablement resettlement officer, or other. Whoever does it has to be able to give enough time and energy. The person will need to understand the disabled person's skills and interests to help secure a job which is in line with their wishes.

Different routes for development

Although the existing day and employment services available for people with mental handicaps have not grown up around the principle of a worthwhile job for everyone, there are some clearly identifiable areas in which this concept is being developed. There are already examples where staff in training centres are planning to redevelop their roles as job finders and job supporters, away from the centre altogether; the Manpower Services Commission is interested and has at least some options which could be used to help support individual people with disabilities in jobs in open employment settings (even if people need a lot of help).

People who are interested can begin to explore worthwhile jobs for people with mental handicaps. There is no single right place to start developing services. Each person who is interested in bringing about change has to start from wherever they happen to be in the system.

Some parts of the total approach we are suggesting have already been started in different places. People involved with these growing components can combine to support each other and continue the development of those parts until they come to fruition. It is important in this entrepreneurial, opportunistic model, that the people working together locally do not lose sight of the objectives and principles of a fully developed service. Doing things because they are easy now may make it difficult to change them later.

Planning

It would be highly desirable for developments to be coordinated by a multi-agency body responsible for the development of comprehensive services for mentally handicapped people in a locality. At least one Joint Care Planning Team (Northumberland) has reviewed employment opportunities for people with mental handicaps. However, effective teams are rare and initiatives should not be delayed in their absence.

As part of their plan to develop comprehensive services, planning teams should bring together relevant personnel from the Manpower Services Commission, health, education, social services and voluntary bodies to plan the development of vocational services. A vocational planning team could be set up with membership to reflect the work oriented focus.

It should review:

- what parts of the vocational service outlined above are already available locally, what resources are available, how they can be coordinated effectively, and what gaps need to be filled;
- what advice is being given to parents on vocational possibilities;
- what schools and colleges are doing to bring vocational preparation into their courses;
- what vocational services are incorporated in hospital resettlement schemes.

Where local authorities are making the kind of employment initiatives discussed earlier (page 17), they should be prompted by planning teams to address the employment needs of people with mental handicaps.

Where new adult training centres are now being planned, consideration should be given to rethinking day services. If it is possible to appoint the staff without the buildings they can

begin to develop integrated services immediately without having to go through congregating and segregating people.

Parents

All staff who work with families of children with mental handicaps should be aware of the possibilities of future employment in adulthood and should not assume that this is out of the question. The guidance which parents receive may influence their expectations and the experiences they provide for their children with mental handicaps. Parents who are concerned about work possibilities should not be despondent if their enquiries about work are met with little enthusiasm from professionals. Parents may find themselves educating professionals who have not begun to examine the possibilities of employment.

Education

During senior school years, students, parents and teachers have opportunities to discuss future possibilities of employment when they meet to review the progress of children and also at parent-teacher association meetings. Recognising and implementing the 1981 Education Act will enable parents to put pressure on schools to orient the curriculum towards future employment. Teachers could also orient parents to work possibilities.

Leaving school is a major transition period. At least two years prior to leaving school, students, parents, teachers, and representatives from continuing education and employment, should meet to prepare the individual programme plan with a bias towards employment and a senior school curriculum of work preparation, job experience and on-the-job training. Students in schools would then follow a realistic careers course with input from all the concerned and specialist services.

Local education authorities, teachers, advisers and educational specialists should review curricula and staff training to prepare students for the world of work. This could include work or work-related experience and teaching, looking for new types of jobs and trying to find ways in which students with additional handicaps can participate fully in these courses.

Many colleges of continuing education have already started to include students from specialist schools in their classes, together with the necessary support. There is a particular role for staff to introduce students into vocational courses so that all students can gain mutually useful experiences.

Adult training centres

Many social services departments have working parties to review their day services to people with mental handicaps. The issues raised in this document could form a useful agenda for such reviews.

Staff in a number of centres have taken initiatives to develop vocational service activities outside the centres. If a centre is planning its own development in a systematic way here are some steps to consider:

Staff reorientation

In order to work out the practical implications of the principles stated earlier, staff would first need to spend time together in seminars and discussions getting a good grasp of the

principles. In this process staff will need to involve parents in training sessions, in discussion of the principles, negotiation of developments and especially in individual programme planning.

An example of a centre which has been reorienting its activities towards integration of trainees into the community is Camperdown in North Tyneside. John Fisher who took his post as manager in January 1982, had previously attended a 2½ day normalisation workshop. In February 1982, the centre was evaluated as part of an introductory PASS workshop. John attended a PASS workshop in September 1982 and then arranged for CMHERA to run a normalisation workshop for all the staff of the centre in January 1983.

The staff decided to meet together to talk about the implications of the ideas from the workshop and held two evening meetings in February. They found so much to talk about that they decided to meet regularly. To do this they arranged for some of the parents to come and run the centre for one afternoon every fortnight from April 1983. From these discussions many changes based on individual needs have emerged and these are leading to much greater integration of workers in a variety of settings. One of the earliest developments was the setting up of a Workers' Council and representatives from the Council now join these fortnightly discussions. With hindsight, it is now realised that parents should have been involved much more. A normalisation workshop for parents has therefore been scheduled for the autumn of 1984.

This example demonstrates some initial steps that could be taken in reorienting staff working in adult training centres. As staff become more committed to these principles, they will come up with ideas on how to move towards the kind of service which promotes employment in integrated settings. To begin with, staff would liaise with other service providers – business and industry. Thus staff and consumers would spend more and more time in generic settings.

There will be issues concerning changes in roles, training, salaries, titles, conditions of service as well as work base which may be encountered and would need to be negotiated. New courses will certainly be needed to train staff for such new roles.

As training centre staff and management develop more practical experience in finding integrated work placements they may allocate specific staff to work as job finders, job designers, job skills officers or job support staff. Eventually it should be possible for increasing numbers of staff to work in integrated settings.

Individual programme plans

Any planning for the future of the centre as a whole should arise out of plans for the future of each individual trainee. Discussion of individual needs within the framework of the principles provides a way of starting small and making organisational changes which are directly relevant to meeting people's needs as appropriately and effectively as possible. When needs have been identified, two fundamental questions to ask are:

How do valued citizens ordinarily have these needs met?

What are the most effective ways of meeting these needs?

The answers to these questions will guide the development of appropriate and effective methods of meeting the person's needs.

There is, in short, a lot to be done. Indeed as our own discussions have developed over the past year we have been increasingly conscious of the amount of detailed work required to bring aspirations for *An Ordinary Working Life* nearer realisation. Some of that detailed work is reflected in this paper. We recognise, however, that this is only a starting point. We hope, therefore, through contacts made by the working group and references to this paper, greatly to extend the network of colleagues interested in carrying this work forward. Through exploring the issues raised by this paper and learning from a variety of local initiatives, we can together build a common understanding of how best to meet the challenges involved in making further progress.

Notes

Community and Mental handicap Education and Research Association (CMHERA) arrange normalisation and Program Analysis of Service Systems (PASS) workshops and Program Design Sessions, all of which are excellent for staff development. Their address is:
12a Maddox Street, London.

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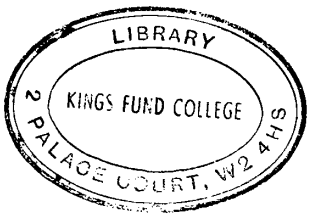

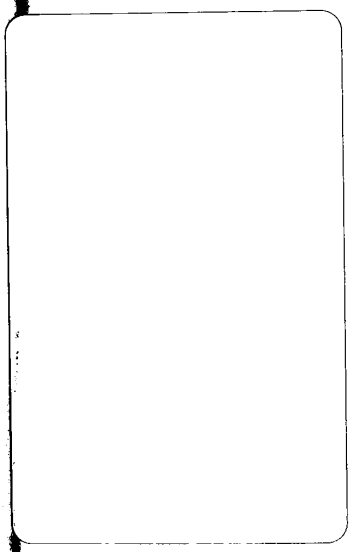

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