DOCUMENT RESUME

ED 368 137 EC 302 895

TITLE	Supporting Transition to Adulthood: A Staff Training Package for Practitioners Working with Students with Severe Physical Disabilities.
INSTITUTION	Further Education Unit, London (England).
REPORT NO	ISBN-1-85338-264-7
PUB DATE	92
NOTE	102p.
PUB TYPE	Guides - Classroom Use - Instructional Materials (For Learner) (051) -- Guides - Classroom Use - Teaching Guides (For Teacher) (052)
EDRS PRICE	MF01/PC05 Plus Postage.
DESCRIPTORS	Agency Cooperation; Curriculum; *Education Work Relationship; Family Involvement; Foreign Countries; Interdisciplinary Approach; *Physical Disabilities; Secondary Education; *Staff Development; Student Participation; Teamwork; *Transitional Programs
IDENTIFIERS	England

ABSTRACT

This staff training package was produced to complement a curriculum framework for assisting students with severe physical disabilities to make the transition to adulthood. The package is based partially on the experiences of a team from the North Nottinghamshire College of Further Education in England. Part 1 explores the concept of transition to adulthood and the various issues implicit in this process, and links staff training to these issues. It also describes the previous experiences and present needs of a group of students involved in the Transition to Adulthood project. Part 2 is a training manual presented in a workbook format. It provides an agenda for staff training, examines the educational and professional implications of transition to adulthood, and asks practitioners to evaluate their range of competencies to isolate skill deficiencies and identify further training needs. Themes emphasized in the training package include: team work at the institutional level, interagency cooperation in curriculum design and delivery, support for staff and students, multiprofessional contributions, and full involvement of students with severe physical disabilities and the support and understanding of their families. (JDD)

Supporting transition to ADULTHOOD

A staff training package for practitioners working with students with severe physical disabilities

ISBN 1 85338 264 7

FEU registered charity no. 326347

RP95A
Design and layout by
Wigwam Publishing Services

Printed by JEC Potter & Sons Ltd,
Stamford, Lincs.

CONTENTS

PART ONE

PART TWO

ACKNOWLEDGEMENTS

I should like to acknowledge and thank the following people for their help and encouragement in the production of this training package.

1. Carol Tennyson, now at Nottinghamshire Education Authority, and the *Transition to Adulthood* team at North Nottinghamshire College of Further Education.
2. The members of the *Transition to Adulthood* dissemination team: Kit Hartley, David Johnstone and Jane Lones.
3. The Project Consultant, Alastair Kent.
4. John Fish, Mike Oliver and Lynne Chapman.
5. All the participants in the activities associated with the dissemination of *Transition to Adulthood* upon whose work much of this training package has been based.
6. Merillie Huxley, HMI, and Pat Hood, Principal Officer, FEU.

Finally, I should like to offer my thanks to the young people with severe physical disabilities, both past and present, at North Nottinghamshire College of Further Education who were the inspiration for the *Transition to Adulthood* project. In particular, I should like to thank Jeremy who, despite his many disadvantages in life compared to my advantages, 'bullied' me into developing skills in the use of a word processor upon which most of this training package was typed and for which I shall be grateful all my working life.

David Hutchinson
Assistant Principal, Curriculum
North Nottinghamshire College of Further Education

ACRONYMS AND ABBREVIATIONS

CERI	Centre for Educational Research and Innovation
CPVE	Certificate of Pre-Vocational Education
CVS	Community Volunteer Schemes
DES	Department of Education and Science
DRO	Disablement Resettlement Officer
FE	Further Education
FEU	Further Education Unit
HMI	Her Majesty's Inspector/Inspectorate
ILEA*	Inner London Education Authority
LEA	Local Education Authority
OECD	Organisation for Economic Co-operation and Development
PHAB	Physically Handicapped and Able Bodied
SKILL	SKILL – The National Bureau for Students with Disabilities
TEED	Training, Enterprise and Education Directorate
YTS	Youth Training Scheme

* ILEA no longer exists

FOREWORD

In 1986, the Further Education Unit (FEU) published *Transition to Adulthood – a curriculum framework for students with severe physical disability.* This was based on work at North Nottinghamshire College of Further Education and, to some extent, signalled FEU's growing concern with the achievement of adult status for people with disabilities or learning difficulties. The earlier document continues to be a valuable source of guidance to practitioners seeking to widen curriculum opportunities for people with severe physical disabilities.

The present staff training package is based on the experiences of the North Notts. team, and on the material and contributions that accumulated around the dissemination of the first report. It is aimed both at staff who are new to this work and at more experienced practitioners. Above all, it is suitable for use by groups of staff from mixed backgrounds and, as such, takes its place alongside other FEU work which is intended to support collaboration between agencies.

There is much fashionable talk about participation. *Supporting Transition to Adulthood*, and its associated curriculum document, begin to translate that rhetoric into reality for this particular group of learners.

Pat Hood
Principal Officer

PART

❶

SECTION ONE: A user's guide

Introducing the package

Supporting Transition to Adulthood is a staff training package produced to complement *Transition to Adulthood – a curriculum framework for students with severe physical disability* (FEU, 1986)[1]. It draws on materials used in that initiative, and on the launch and dissemination activities associated with the framework.

Using the package

The package is suitable for use with experienced practitioners or those new to this area of work. It can be used by a group, working with or without a facilitator, or by individuals working alone. It would be particularly valuable as a basis for training between different agencies and institutions.

Summary of contents

Part One of the package, in addition to the User's Guide, contains background material on the philosophy of transition to adulthood.

Section Two explains the rationale of the package.

Section Three describes the background to the *Transition to Adulthood* project, gives the previous experiences and present needs of the student group, and explores the aims and principles of curriculum design for this group of learners.

Section Four explores the concept of transition to adulthood and the various issues implicit in this process. It links staff training to these issues.

Part Two is presented as a training manual, in an accessible workbook format with activities which can be supplemented with additional material according to specific needs.

Section Five provides an agenda for staff training and develops the educational and professional implications of transition to adulthood, linking these to a personal agenda of practitioner training needs.

Section Six asks practitioners to evaluate their range of competences in this area of work in order to isolate any skill deficiencies and identify further training needs as well as to develop appropriate methods for evaluating the training process.

Common themes

The *Transition to Adulthood* project and the associated dissemination process, which are described in Section Two, raised a number of themes which need to be addressed flexibly in ways that acknowledge different circumstances. The themes particularly emphasised in the training package are:

- team work at the institutional level;
- inter-agency co-operation in curriculum design and delivery;
- support for staff and students;
- multi-professional contributions;
- full involvement of students with severe physical disabilities and the support and understanding of their families.

Methodology

The materials presented in this package aim to address the common themes raised in the dissemination process of *Transition to Adulthood*. The involvement of 'consumers' in training for professionals is particularly important in raising awareness and adds an important dimension to the personal development of those responsible for the initiation and development of provision.

It is particularly valuable for professionals from a range of disciplines to train together away from 'home territory' and from the constraints of the operational policies of their services.

Support issues

The development of provision for young people with severe physical disabilities is breaking new ground for many institutions and requires a fundamental shift in attitudes, thinking and practice. The *Transition to Adulthood* project report explains that involvement in this work can be a stressful experience for many staff who may feel threatened and unable to cope with the demands placed upon them. Change is difficult, especially when staff are asked to re-evaluate methods and approaches which seem to have been successful for many years. Staff will need a considerable amount of support and practical advice if the development of new work is to be achieved.

This training package recognises these difficulties and draws attention to the following support issues which are discussed in *Planning Staff Development – A Guide for Managers* (FEU, 1987)[2].

1. Preparation

Planners should provide:

- clear statements of the objectives and potential outcomes of training to inform participants, enable them to judge the appropriateness of programmes and reduce the possible mismatch between expectations and provisions;

- advance warning to enable essential planning to take place, e.g. rearranging commitments, selection of staff and facilitating open self-selection as part of an individual's personal development agenda.

2. During training

Institutions should offer the following support during training:

- replacement cover;
- timetable reorganisation to facilitate participation;
- common timetabled periods free of commitments for all participants;
- opportunities for practice in different settings;
- mentorship: allocating an experienced colleague to give advice and share problems which includes providing training and time allowance for mentors;
- financial help/provision of resources, including reading matter, learning materials and the opportunity to make visits;
- provision of adequate training facilities.

3. After training

The following support after training will be required:

- opportunities to utilise training;
- further skills practice;
- post-training refresher/updating meetings;
- further 'cascading' of training;
- regular evaluation of the effects of training.

The support required will make demands on the institution in terms of advanced planning, provision of flexible institutional arrangements and budgeting. Without these types of support, any training programme will be less effective. The management of appropriate support should be written into any training programme at the outset as an entitlement for all staff under training.

References

[1] *Transition to Adulthood – a curriculum framework for students with severe physical disability* FEU, 1986

[2] *Planning Staff Development – A Guide for Managers* FEU, 1987

SECTION TWO: The rationale

In 1986, the Further Education Unit published a report entitled *Transition to Adulthood – a curriculum framework for students with severe physical disability.* The report, which is discussed in detail in Section Three, was based on a three-year research project undertaken at North Nottinghamshire College of Further Education.

FEU funded a three-level dissemination process which began in March 1987, consisting of:

(i) a national one-day invitation conference to launch the project report;

(ii) residential regional training workshops for staff involved in developing provision;

(iii) the establishment of networks, aided by consultancy from the dissemination team, to support those involved in developing provision.

A number of other events also took place initiated by local education authorities (LEAs), regional groups of the National Bureau for Handicapped Students (now SKILL – The National Bureau for Students with Disabilities), voluntary organisations and individual colleges.

This staff training package has been developed following the events referred to above, and the informal events which arose from them.

The GENERAL AIM of the package is to assist those involved in developing provision for young people with severe physical disability and in providing associated staff training.

The SPECIFIC OBJECTIVES are:

- to explore the various issues implicit in the transition to adulthood process;
- to set staff training in the context of transition to adulthood;
- to explore the educational and professional implications of these issues;
- to enable practitioners to identify their own training needs within the context of a curriculum developed to meet the needs of young people with severe physical disabilities;
- to enable practitioners to satisfy their own training needs.

The training package is aimed at a target audience which might include:

- practitioners in the field working as individuals or in a group;
- staff trainers;
- inter-agency staff training groups;

12

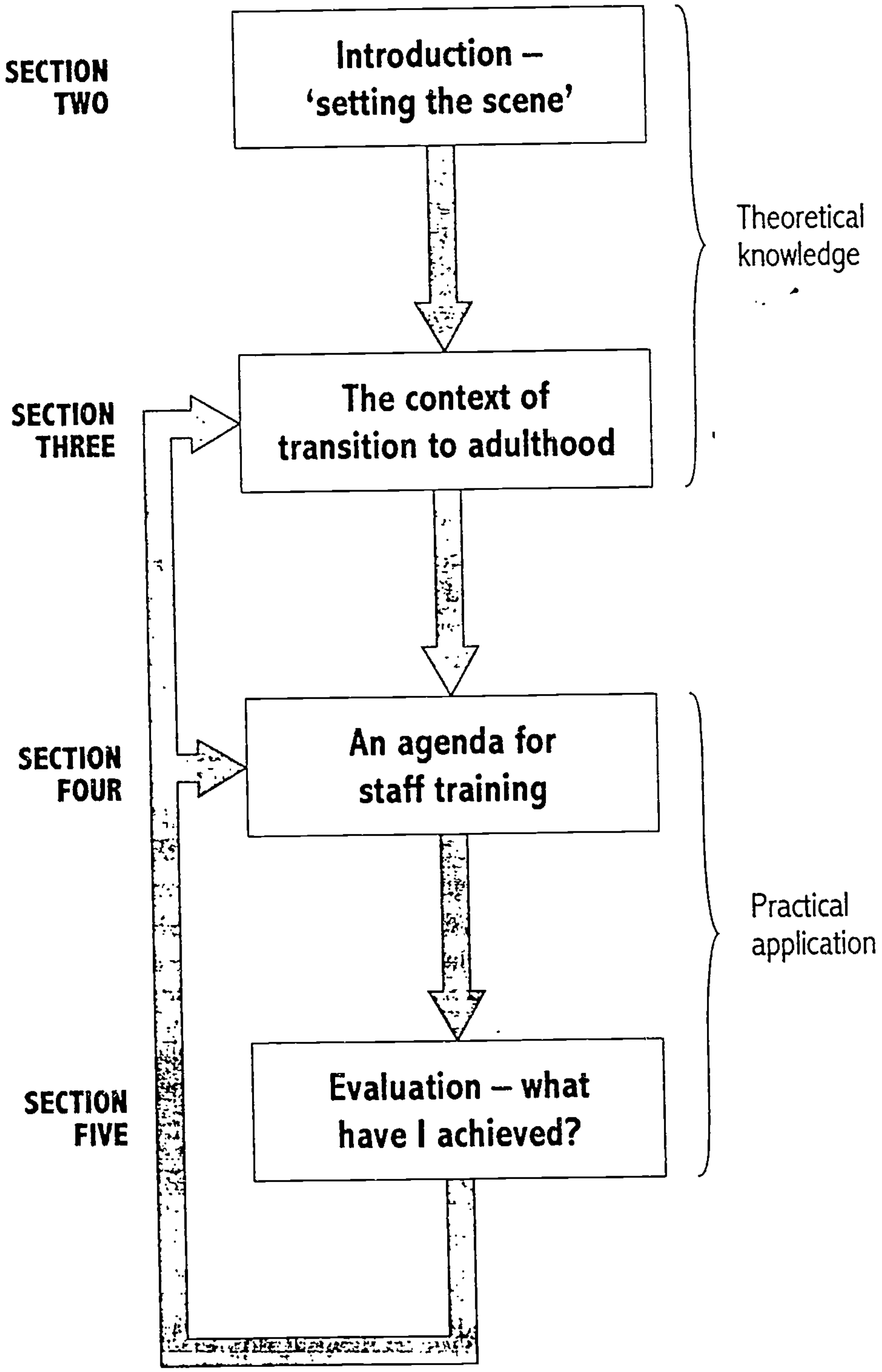
- voluntary groups;
- parent support groups.

The materials are presented in such a way that they can be used either with a facilitator or by a self-help group. The aim was to focus on practical issues and help participants find practical solutions to difficulties arising from their work.

The MODEL, illustrated in Figure 1, looks at issues of theory and practice with the purpose of increasing professional competence. By doing this, the pack aims to enhance the quality of provision available to young people with severe physical disabilities.

FIGURE 1

The model for training



SECTION THREE: Introduction – 'setting the scene'

Introduction – 'setting the scene'

Aims for the section

1. To create an awareness of the background to the *Transition to Adulthood* project.
2. To consider the previous education experiences of the student group and their present needs.
3. To identify relevant curriculum aims and some of the principles underpinning curriculum design.
4. To relate the North Nottinghamshire 'experience' to your own situation.

The *Transition to Adulthood* project was initiated by North Nottinghamshire College of Further Education and supported with funding from Nottinghamshire County Council and the Further Education Unit.

North Nottinghamshire College of Further Education has a history of providing for students with special educational needs which dates from 1969–70. The programmes of work which have been devised meet the needs of three broad groups of students:

(i) those who, with support, can integrate into mainstream full-time college courses;

(ii) those who, with support, can integrate into mainstream part-time college courses and use these as a base for building up a full-time programme;

(iii) those who cannot yet participate in mainstream college courses and who require individual programmes of experience which take advantage of the facilities in an FE college.

The response to this third group has resulted in the provision of full- and part-time programmes catering for the needs of a diverse range of people with disabilities, where neither the disability nor its severity is a barrier to entry.

In providing for the students in this third group who had severe disabilities, the college had no suitable model upon which to base its provision. The Project Director was a co-opted member of the Warnock Committee of Enquiry and was involved in the production of Chapter Ten, 'The Transition from School to Adult Life', of the Committee's Report[1] where reference was made to the concept of 'significant living without work'. During the early 1980s, this concept became more and more contentious, raising problems of definition and deeply-rooted attitudinal objections. The present economic situation is such that finding alternatives to work remains a necessity for many young people, forcing colleges to assess the role that they can play. It was a desire to develop provision for this group of learners that led staff at North Nottinghamshire College of Further Education to this initiative.

Many of the students who came into the college's *Transition to Adulthood* programme came directly from special schools which had, in many cases, provided their total educational experience. Another, but somewhat smaller, group had experienced a period of 'normality' prior to undergoing some traumatic episode in their lives which had resulted in their severe physical disabilities. With some variation, most of this second group had also experienced 'special education'.

It is always dangerous to generalise, but it was possible to discern a number of characteristics shared by members of the group, for example:

- lack of financial independence;
- an inability to accept responsibility for self-care;
- difficulty in performing simple domestic tasks;
- poor mobility skills;
- poor self-image;
- extreme passivity and acceptance of life situation.

Some of these characteristics are not exclusive to young people with severe physical disabilities, nor should they be seen as being possessed by every member of that group. It is very harmful to see such young people as a defined homogeneous group at all. They should be seen rather as individuals with many differences. Nevertheless, the descriptors reveal many of the difficulties present for these young people at the time of their transition into the adult world, a period through which all young people pass and which is generally accepted as a time of uncertainty, doubts and the need to establish a new identity and role in life. What is difficult for the majority of young people is often doubly traumatic for those with severe physical disabilities for whom the future can often be a bleak and unattractive prospect.

The descriptors might also be seen as a criticism of these young people's previous experiences. Their disabilities had been transformed into handicaps by environmental influences. The initiative aimed to take full account of these earlier experiences.

The North Nottinghamshire programme had to encourage gradual acceptance of adult responsibilities, through exposure to many different experiences and influences. Many of the students had missed ordinary formative experiences in their early lives, for example, being allowed to make mistakes and learn from them, being allowed to exercise choice, being expected to accept responsibility and being involved in making decisions which affected their own lives and the lives of others. Too often, the provision available to young people with severe physical disabilities has over-emphasised their special needs and used them as a justification for segregation. These young people have been set apart from the mainstream of society and have become objects of fear, pity or patronage. Attention has been focused on their **special** needs to the detriment of their **basic** needs and **rights** as human beings. Those rights which others take for granted – to have choice and be able to exercise that choice, to have control of one's life, to love and be loved, to take risks and accept the consequences of their own decisions. Young people with severe physical disabilities find themselves on the outside edge of society, as dependent beings.

There was no earlier obvious model upon which to base this new curriculum. Work being undertaken in parallel with *Transition to Adulthood* gave some important indicators. Bradley, in *From Coping to Confidence*[2], suggests that one of the aims of education should be to prepare young people to assume the 'adult role'. This might consist of:

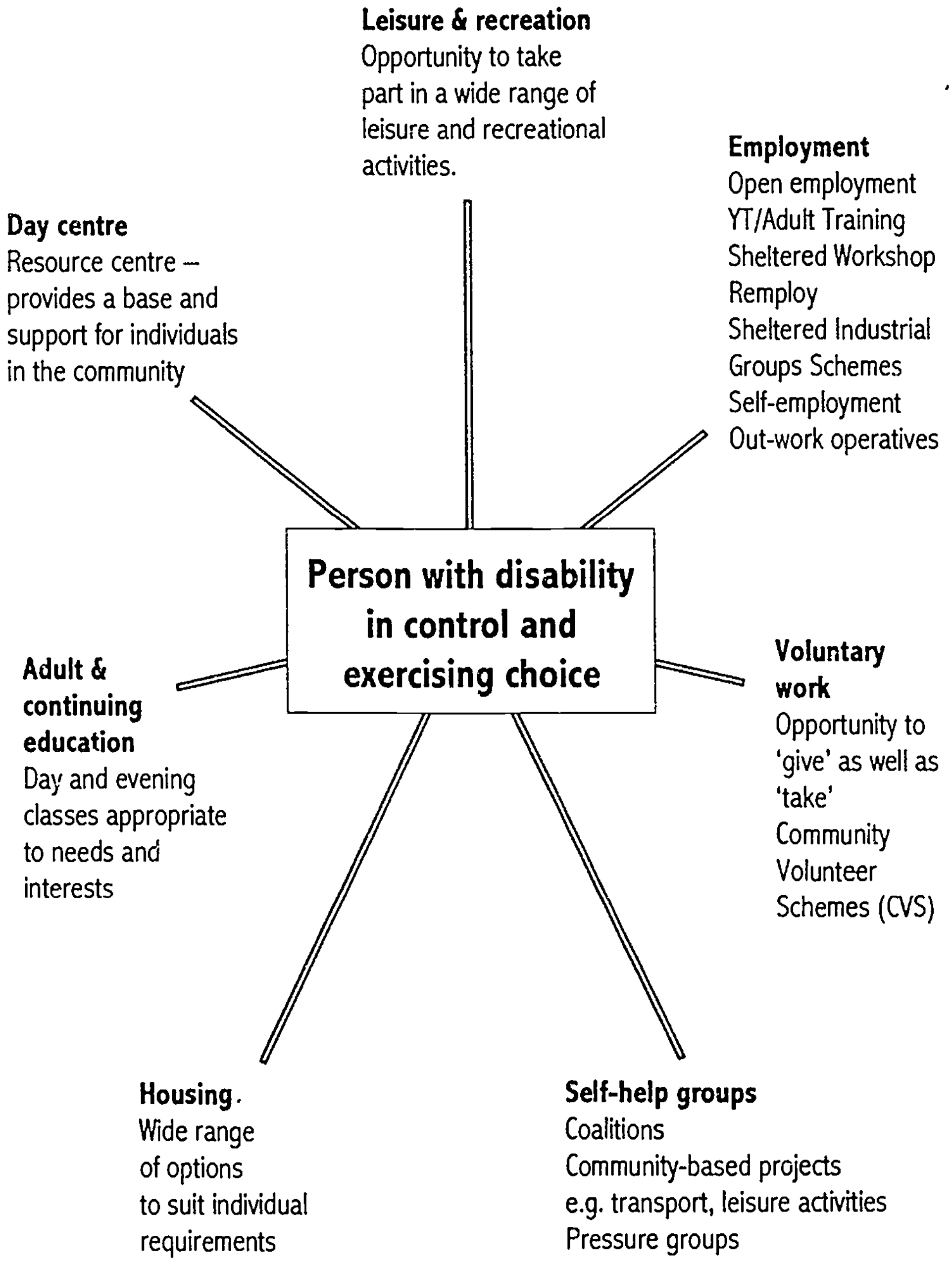
- 'Preparation for work including paid employment – this will include transferable skills that enable young people to carry out a variety of work tasks and the social skills that enable them to function effectively in the world of work.'
- 'Preparation for daily living – this involves the life skills necessary for personal survival and the social skills necessary for successful interaction with other people.'
- 'Preparation for free time – a specific input on constructive ways of spending leisure time and on coping with the possibility of unemployment.'
- 'Preparation for further education and training – special provision should be seen not as an end in itself, but as a means of facilitating students' progression on to other learning experiences.'

Other FEU publications on adult status curriculum suggested that the establishment of a curriculum framework based on transition to adulthood should be undertaken within the context of mainstream curriculum development. Themes which are of relevance to young people are of equal importance to all young people with, or without, special needs. Arising from this philosophy has been the notion of a common core curriculum, a statement of consensus about the common needs of all young people. This was, perhaps, first articulated in the curriculum framework published in 1984 for the Certificate of Pre-Vocational Education (CPVE)[3].

Developing young people's potential for independence and autonomy, does presuppose that there would be resources and facilities available within the community. The model indicated in Figure 2 summarises the outcomes and range of options which it was hoped would be available to young people on completion of the *Transition to Adulthood* programme.

FIGURE 2

A model of future need



Person with disability in control and exercising choice

Leisure & recreation
Opportunity to take part in a wide range of leisure and recreational activities.

Employment
Open employment
YT/Adult Training
Sheltered Workshop
Remploy
Sheltered Industrial Groups Schemes
Self-employment
Out-work operatives

Voluntary work
Opportunity to 'give' as well as 'take'
Community Volunteer Schemes (CVS)

Self-help groups
Coalitions
Community-based projects e.g. transport, leisure activities
Pressure groups

Housing
Wide range of options to suit individual requirements

Adult & continuing education
Day and evening classes appropriate to needs and interests

Day centre
Resource centre – provides a base and support for individuals in the community

The person with a disability is still too often seen by many professionals as the passive recipient of their professional services. The balance of power needs to be shifted to the person with disability at the centre, able to expect as their right the opportunity and facilities to exercise choice and control over their own life.

There are those in the vanguard of the disability movement who suggest that education could have an important role in creating a new self-identity for people with disabilities by introducing disability, for example, into the general curriculum. This is a means of facilitating the acceptance of people with disabilities into society. But, since this depends so much upon attitudinal change, it must be seen, perhaps, as an evolutionary rather than a revolutionary matter. What could change things dramatically, and is essential, is the development of co-operative joint planning and service delivery networks. The research undertaken at North Nottinghamshire College has shown that no matter how successful a transition to adulthood programme is, any progress made in a college needs to be maintained and extended beyond it. The system of service delivery beyond college can be characterised by ambiguity, overlap of services and by professionals who may be engaged in power politics and, motivated by self-interest, vying with each other to service the needs of clients. The result of this is disabling rather than enabling, as will be discussed in Section Four by Mike Oliver. It certainly negates many of the possible benefits of a post-school educational programme. One conclusion from the project was that, no matter how difficult it is to achieve, the only way forward is for the many service providers to work co-operatively and in a co-ordinated way to ensure that individual needs are met.

A report on the *Transition to Adulthood* project was published by FEU in November 1986[4]. This reflected the main areas of work, including:

- the background to the project;
- curriculum design;
- implementing the curriculum;
- assessment and evaluation;
- after college – what next?

This action-based curriculum research project placed emphasis on describing the experiences of the young people involved and the project staff. In *this* training pack, attempts have been made to generalise from these experiences for the benefit of others who are involved in, or might be contemplating setting up similar provision.

Some of the experiences described in *Transition to Adulthood* are those of the young people and their needs which are, to quote the Warnock Report[5]:

- 'the need for a sense of purpose';
- 'the need to feel wanted by other people and the community at large'.

Another group of experiences uses the outcomes of the project and offers these to service providers as pointers towards the way in which provision might be improved and developed. From these outcomes the lessons learned include:

- the importance of identifying need at an early stage prior to the commencement of a college programme;
- the difficulties involved in teaching young people with multiple disabilities, particularly with regard to motivation;
- the importance of a co-ordinated team approach involving, as key members, the young people and their families;
- the relevance of curriculum areas such as personal development and independence skills;
- the need for a high degree of inter-agency communication;
- the need for people with disabilities to be in charge of their own destinies by playing a significant role in deciding what services are needed and how they should be provided.

Summary

By now you should have an understanding of:

- the difficulties faced by young people with physical disabilities in the transition to adulthood process;
- the limitations placed upon their educational experiences by restrictive environmental influences;
- the relevance of person first and special needs second in the design of educational programmes.

References

[1] ***Special Educational Needs*** Report of the Committee of Enquiry into the education of handicapped children and young people (the Warnock Report) DES, 1978

[2] ***From Coping to Confidence – a staff development resource pack for further education teachers of students with moderate learning difficulties*** DES/FEU, 1985

[3] ***The Certificate of Pre-Vocational Education: Consultative Document*** CGLI/BTEC Joint Board, Joint Board for Pre-Vocational Education, 1984

[4] ***Transition to Adulthood*** – *a curriculum framework for students with severe physical disability* FEU, 1986

[5] ***The Warnock Report*** op.cit.

SECTION FOUR: The context of transition to adulthood

Introduction – 'setting the scene'

The context

Aims for the section

1. To explore the various issues implicit in the transition process.
2. To link staff training to the general context of transition to adulthood.

The transition from school to adult life is a difficult process for many young people. It is even more difficult for those with severe physical disabilities who, in addition to all the usual problems associated with becoming an adult, have to overcome further barriers in order to participate fully in society and enjoy equal access to the opportunities and challenges of adulthood.

For those with severe physical disabilities, success in moving through this transition process is often dependent upon the availability and quality of support services. A co-ordinated approach, which embraces the individual, their family and professionals from education, health, social services and training agencies on a partnership basis, is essential and should be the objective, with the aim of facilitating the individual's control over their adult life.

Transition to Adulthood was launched at an invitation conference in London, in 1987. At this conference, key theoretical issues and a conceptual framework for the transition process were outlined by John Fish, who also described the work of the Centre for Educational Research and Innovation (CERI) of the Organisation for Economic Co-operation and Development (OECD). Dr Mike Oliver, a teacher-trainer and writer on disability matters, then explored the ways in which disability is defined or conceptualised and the kinds of services which develop as a consequence. Carol Tennyson, the Project Researcher for *Transition to Adulthood*, described the project and, in particular, examined reactions to the presence of these young people in a college. These three contributions provide the material for this section.

The reader is invited to work in the way shown below, whether in a group or working alone.

Using the papers

Before reading the paper consider the preliminary questions and note down your answers.

Read the paper with the questions in mind.

After reading the paper note any modifications which you would now make to your answers to the preliminary questions and, if working in a group, discuss these with your colleagues.

Some final questions

1. What implications do the issues raised in these papers have for your professional practice?
2. What changes do you feel that you might have to make?
3. What existing competence will you have to revise/update?
4. What new competences will you have to develop?

Transition to Adulthood – a conceptual framework

John Fish

Preliminary Questions

1. How would you define adulthood?

2. What do we mean by handicap?

3. What are the main difficulties experienced during transition to adulthood?

4. How would you evaluate the effectiveness of transition to adulthood programmes?

The Paper

Introduction

The road to adulthood is an important and difficult one for many young people. For young people with disabilities there are a large number of additional barriers. A range of complicated and fragmented facilities and services face the young people concerned when they reach the age of sixteen. The North Nottinghamshire College research is an important contribution to the understanding of some of the problems which face young people with severe disabilities when they leave school.

Since 1978, CERI has been working in the field of disability, with two specific themes – integration, and transition to adult and working life.

During the period 1982–86 almost all member countries contributed to a major study of transition. The general findings are published in the report *Young People with Handicaps – the Road to Adulthood* (CERI, 1986)[1]. A number of issues were clarified by the study and the results indicate criteria by which to judge whether educational, social service, social security, health and employment programmes are promoting transition to adulthood or are perpetuating dependence and immaturity. Later CERI publications look at other aspects of transition.

Adulthood

'Adulthood' is a less than precise description of a legal and social status and of a range of individual, social and economic choices. It may be defined differently in different countries and cultures but there are common features. 'Coming of Age' can be observed in four main areas of life:

- personal autonomy and independence;
- productive activity;
- social interaction, community participation, recreational and leisure activities;
- roles within the family.

It is one of the problems of modern developed societies that each of these areas of life tends to be dealt with separately by a different department or agency.

What is needed is a conceptual framework for transition which encompasses all aspects of the move through adolescence to adulthood. Within this framework there needs to be a clear statement of objectives in behavioural terms. If these objectives could be agreed by all agencies, by professionals, by parents and, above all, by the young people themselves, there might be a more concerted effort to develop coherent approaches to the process of transition, and less confusion in areas of responsibility.

The concept of handicap

The transition phase reveals how much confusion there is in the use of the term handicap. Traditionally, it has been a label attached to the individual. Two things have become increasingly clear, namely, that it is important to distinguish between a disability and its handicapping effects, and that for the same disability these effects may vary from person to person and from situation to situation.

Therefore it follows that to categorise people by a single criterion, such as a specific disability, is wrong. It leads to stereotyping, to inappropriate expectations and to a lack of individual planning.

During transition, education, social services, health and employment agencies may use different criteria to define handicap. Some definitions are based on the help needed for the individual to be as independent as possible and others are based on the assumption that the individual remains totally dependent.

24

These differences reflect attitudes which may be crucial to individual development during adolescence.

What modern methods and technology have achieved is a lessening of the handicapping effects of many disabilities and a consequent raising of expectations. We should no longer talk about 'a handicapped person' but about 'a person with a disability'. This is not just a semantic quibble. It represents a significant change and a recognition that it is attitudes, situations and administrative decisions which determine whether disabilities are **more** or **less** handicapping.

Assessment and readiness

The process of assessment and the concept of readiness are potentially handicapping. In practice, an individual's behaviour, achievement and response to education may be very potent determinants of what is offered on leaving. Being in a special group may limit what is expected in school and these expectations may bear little relationship to what is needed in work situations.

The purpose of an assessment and the evidence on which it is based are important considerations. If the purpose is to categorise an individual then the result may be stereotyping and low expectation. If the evidence is school performance then the result may be relevant to further education but not to employment. Independent living should not be assessed without observing experience in that situation. Assessment should lead to a plan for the individual and not be a prediction simply based on past performance.

This is where the concept of readiness can be restrictive. It is often simply an expression of professional doubt. Innovations in the CERI study have shown that if you attempt to judge ability to live independently on the basis of behaviour in an institution, few individuals will be judged to be ready. However, if the same individuals are exposed to training in houses in the community, many will develop all the skills necessary to live with the minimum of supervision.

Major difficulties of transition

Many of these have been implied in the previous paragraphs – below is just a brief summary of each.

Different starting points At the end of the school period individuals may be in regular classes, special classes, special schools, hospitals and community homes. How far does the situation from which transition starts result in preconceived ideas which limit the range of possibilities that are offered to the individual?

Continuity There are three interrelated phases of the transition process – the final years of school, further education and training, and the early years of adult and working life. In each of the three phases different agencies and professions may attempt to cover different curricula. It is becoming increasingly important to develop a continuity of concern and of objectives.

Consistency Individuals and their families face inconsistent demands and attitudes. One agency may be giving support to develop employment skills while another may be awarding pensions and benefits on the basis of the individual's **incompetence**. Is it in the individual's best interests to remain dependent? There is a need for some consistency in expectation from agency to agency.

Time-scale There is no doubt from international experience that extended education and training, particularly for young people with severe disabilities, pay off in terms of employment and independence. In the United States or Sweden, an individual would normally remain in high school until 18+ and then have between two and four years vocational preparation. Compare this with the one or two years offered after the age of 16 in the UK. Adult competence is often expected from young people at the greatest disadvantage many years before it is expected of others whose education is extended.

Co-ordination The young person with a disability might well ask whether health, education and social services know what each other is doing and whether they work with voluntary organisations. Further education is accomplishing a great deal but it cannot prepare for transition by itself. There is a need for a great deal more local co-ordination, at least to the point of agreeing on common objectives.

Parents and transition It is during the transition phase that parents of young people with disabilities may become particularly concerned about their children's future. Professionals need to work with them over time to develop an idea of the adult life that is possible. Information is not enough. A new three-way relationship needs to be formed between parents, professionals and the young person concerned.

Self-presentation and advocacy We need to move away from the 'eternal childhood' model of disability toward a more positive view of adult status. New relationships will not be possible unless those with disabilities are enabled to express their views and manage their affairs.

Categorical or individual thinking We have had a tradition of people being labelled according to category of disability and then receiving a package of services whether they need them or not. In education, following the 1981 Act, we have begun to develop individual plans. The 1986 Disabled Persons Act continues this same theme. How far can we individualise service delivery? How far do we expect adult status where the individual manages his or her own resources and selects the services needed? By labelling someone 'disabled' do we automatically assume that they must be dependent on professionals and agencies?

Criteria for evaluating transitional arrangements

It is possible to look at the transition phase as a whole and to ask questions about it. These questions can be a form of evaluation and they might include:

1. What are the objectives of assessment at the end of schooling? Are they to categorise or to develop an individual plan?
2. What is the balance of the curriculum in the final school years and in further education? What is the respective weight given to academic, social, vocational and life skills objectives?
3. What information is available to young people and their families about the range of transition facilities and services available to them?
4. What continuity of concern, curriculum and objectives is there between the three phases of transition?
5. How are parents and families involved in planning and supporting their child's transition?
6. How far do transitional arrangements encourage the development of independence, autonomy and self-advocacy?
7. Do professional practices and areas of responsibility affect the development of effective transitional arrangements?
8. What financial arrangements support individuals and their families during transition? How far do they inhibit or facilitate autonomy and adult status?
9. When we aim for community provision and participation how do we define community?

Conclusion

There are four statements of intent which summarise much of what has been said. They are:

1. If one of the main objectives of transition is participation in the community then the integrative activities necessary to achieve this have to begin at an early age.
2. Successful transitional arrangements are vital if the resources devoted to special education from the early years are not to be wasted.
3. Transition needs to be looked at as a whole with continuity between the three phases.
4. All services and agencies need to work to a set of agreed behavioural objectives for the end of the transitional process. these should be the same for all individuals however severe their disabilities.

- John Fish was formerly an HMI staff inspector for special education. He chaired the committee established by the Inner London Education Authority (ILEA) which produced the report *Educational Opportunities for All?* (1985) and he was consultant to the work of CERI/OECD on its Disabled Action Programme.

References

[1] *Young People with Handicaps – the Road to Adulthood* CERI, 1986

Some reflections on disabling services

Mike Oliver

Preliminary Questions

1. What is disability and how is it created?

2. Why can services provided to people with disabilities be disabling in themselves?

3. What specific difficulties exist for people with disabilities in moving into the world of work?

4. How can services provided for people with disabilities become more enabling rather than disabling?

The Paper

Introduction

In this paper I want to suggest that 'transition' for young people with disabilities is seen as a problem, not because of any inherent deficiencies in young people with disabilities, but because of the way they are treated. To begin with, this involves the way disability is defined or conceptualised, and is followed by the kinds of services based upon these definitions. I will argue that these services further disable young people with impairments rather than enable them to develop as autonomous human beings. At this point you will note that I use the word 'autonomous' rather than 'independent' and I will have more to say about that later. Finally, I want to consider some of the ways in which services, and indeed professional interventions in the delivery of these services, can be made enabling rather than disabling.

Definitions

The idea of disability as a personal tragedy is one which is deeply embedded in the consciousness of us all and has had a profound influence both on the kinds of services provided and the ways they are delivered. However, in recent years these definitions have been challenged by individuals with disabilities and organisations run by them. These challenges have gradually penetrated the consciousness of both policy makers and service providers to the extent that alternative definitions are gradually beginning to appear in official reports and policy documents of various kinds. Here is an example from the papers circulated for this conference where it is suggested that:

> ...the degree to which a disability is handicapping depends on the situations experienced by the individual, the attitudes and expectations of others and the intervention strategies and environmental modifications which are made.
>
> CERI/OECD, 1987 [1]

This definition, therefore, sees disability as socially created rather than being merely a consequence of the impairment an individual may have. The problem is, however, that while this redefinition is acknowledged at the conceptual level, policy, provision and practice are still dominated by the conception of disability as a personal tragedy, as something for the individual to cope with. Precisely how policy, provision and practice are dominated in this way will be the subject of the next section where I will consider these issues in general, as well as specifically in the context of education.

Disabling services

A major factor in the way services disable people with impairments is through the pervasive influence of medicine and the way this contributes to a narrow definition of the issues concerned. Brisenden, writing from the perspective of a disabled person, suggests that:

> ...the problem, from our point of view, is that medical people tend to see all difficulties solely from the perspective of proposed treatments for a 'patient', without recognising that the individual has to weigh up whether this treatment fits into the overall economy of their life. In the past especially, doctors have been too willing to suggest medical treatment and hospitalisation, even when this would not necessarily improve the quality of life for the person concerned. Indeed, questions about the quality of life have sometimes been portrayed as something of an intrusion upon the purely medical equation. This has occurred

> due to a failure of imagination, the result of the medical profession's participation in the construction of a definition of disability which is partial and limited. This definition has portrayed disability as almost entirely a medical problem, and it has led to a situation where doctors and others are trapped in their responses by a definition of their own making.
>
> BRISENDEN, 1986[2]

It is not difficult to see the truth of this when applied to the educational experiences of children with disabilities. For many such children their education is interrupted by medical interventions. It is not uncommon for some of these children to have a dozen or more operations during their childhood and educational progress may be further disrupted by the intrusion of a variety of paramedical professions: physiotherapy, speech therapy, occupational therapy and the like. I am not suggesting that all medical and paramedical intervention is unnecessary, but I do think that many children are subjected to much unnecessary pain and suffering, not to cure them, but to make them as nearly 'normal' as possible.

Children have educational as well as medical needs, but the medical model pervades education and we rarely question the validity or appropriateness of medical interventions. For example, do we ever ask whether all these operations are really necessary, or if they can be done during the holidays rather than in term time? Do we suggest that physiotherapy or speech therapy could be provided after school, rather than withdrawing children from their classes? There may often be a good case for postponing an operation in favour of education.

Transition to Adulthood (FEU) makes a similar point in describing the students admitted to the project:

> Many of the students arrive in college with very negative self-image and poor self-esteem. Often they appear to have been conditioned into accepting a devalued social role as sick, pitiful, a burden of charity.
>
> FEU, 1986[3]

If children are brought up to believe, through experiencing a range of medical and paramedical interventions, that they are ill, we cannot be surprised if they passively accept the 'sick' role.

But it is not only the intrusion of medicine into education which disables children with impairments. As a society, we are prepared to evaluate the education of disabled children by different standards to those by which we judge the education of other children. Would the situation outlined in the above quote be regarded as acceptable with regard to the education of able-bodied children? Some might argue that this is, in fact, already the case, but the Department of Education and Science (DES) has responded with a whole range of measures aimed at ensuring the situation does not continue: a centralised curriculum, teacher appraisal, reform of the examination system and so on. The Secretary of State's view on special education differs markedly from this – only a few days ago he announced in the House of Commons that he so valued the contribution of teachers in special schools that he was going to increase the special schools' allowance in the new pay deal (1987).

I have already suggested that we cannot be surprised that disabled children take on the sick role, but we also need to consider why they emerge from special education seeing themselves as 'pitiful' and 'burdens of charity'. They see themselves as pitiful because they are socialised into accepting the definition of disability as a personal tragedy. Teachers, on the whole, subscribe to this view, curriculum materials portray disabled people (if they appear at all) as pathetic victims or arch villains, and education takes place in a context in which any understanding of the history and politics of disability is absent. This situation has been summarised as follows:

> The special education system, then, is one of the main channels of the world in ensuring that disabled school-leavers are socially immature and isolated. This isolation results in passive acceptance of social discrimination, lack of skills in facing the tasks of adulthood and ignorance about the main social issues of our time. All this reinforces the 'eternal children' myth and ensures at the same time disabled school-leavers lack the skills for overcoming the myth.
>
> JOHN, 1986[4]

We cannot be surprised if these children see themselves as burdens of charity given the social and educational environment in which they are brought up. Firstly, many of the traditional voluntary organisations are quite shameless in the way they reinforce images of disabled people as burdens of charity. We have all seen emotive posters of disabled children in wheelchairs imploring the general public to give money. The prime objective is to maximise income regardless of the image presented and, sadly, most of these organisations do not even realise that this is, in itself, a disabling approach. Secondly, some professionals are even employed by government agencies to act in such a way. For example, disablement resettlement officers (DROs), instead of ensuring that employers are carrying out their legal duties, are given the task of persuading employers to give jobs to disabled people. Perhaps it is a measure of our civilisation that we employ some people to beg on behalf of others; in many so-called less civilised societies, disabled people are at least accorded the dignity of begging on their own behalf.

Finally, many special schools are grateful recipients of a range of facilities, equipment and services which are provided through fund-raising activities by the local community. Often the equipment donated is unsuitable (the Snowdon wheelchair, for example) or stigmatising (vehicles with labels plastered all over the sides), but they were given from the best of intentions so we must not be ungrateful, must we? It is small wonder that disabled children are socialised into believing that they are burdens of charity.

Into work – the problem of transition

As I have argued, the special education system badly equips disabled young people for moving into the world of adulthood. While this is a serious problem, it might be redeemable if post-school services were to be enabling rather than disabling. Unfortunately, as I shall argue in this section, they are not. There is a problem with the concept or definition of transition. The 'problem' of transition, with a few notable exceptions, is usually perceived as being a psychological one for disabled individuals because they are seen as socially immature and inadequate. The real problem of transition, however, stems from our inability to organise services which are able to pass people successfully from one welfare bureaucracy to another, in this case from education to social services, while at the same time co-ordinating the input from other services, be it the health authority, the Manpower Services Commission (now the Training, Enterprise and Education Directorate – TEED), the youth or careers services. Consequently, most disabled young people get a piecemeal or sometimes non-existent service. It is now common for researchers working in this area to find that many disabled young people 'disappear' when they leave school, and are completely unknown to any of the post-school services. Whether Section Five of the Disabled Persons (Services, Consultation and Representation) Act will seriously affect this situation remains to be seen, but given the general reluctance concerning implementation, it is difficult to be optimistic.

Another problem with transition concerns the entry, or possibility of entry, into the world of work. Massie, himself disabled, makes his position clear in the following terms:

> None of us has the right to deny disabled youngsters the opportunity to enjoy a full and complete working life to the extent that their disabilities permit.
>
> MASSIE, 1979[5]

While this introduces the welcome idea of 'rights', it is also limiting in that it suggests that being disabled restricts the work that an individual can actually do. Of course, it would be absurd to suggest that blind people should have the right to be bus drivers or people in wheelchairs the right to be steeplejacks, but then I've never met a blind person who wanted to be a bus driver or anyone in a wheelchair who wanted to be a steeplejack.

The real problem with this view is that it focuses on the limitations of the individual rather than the restrictions imposed by a badly designed work environment, the negative attitudes of employers, or the limited conceptions of careers officers or DROs. This leads directly to attempts to identify jobs that disabled people can do, as with the Disabled Persons (Employment) Act 1944, where the occupations of lift and car park attendants were reserved for disabled people. Some blind people, on taking 'A' Levels at a well-known grammar school, report that they were then exhorted to decide whether they wished to be a lawyer, a physiotherapist or an audio-typist. The current fashionable work 'ghetto' for disabled people concerns computers, and many disabled school-leavers are now pointed in this direction regardless of whether they have any aptitude or desire to work in computing. My basic point is that disabled young people should be encouraged to be whatever they want to be, not slotted into some safe environment which will cause the least disruption for all concerned.

A third example of disabling services in the post-school sector concerns our ability to provide either the right kind of equipment or, indeed, equipment which works effectively. Again, if I may quote from *Transition to Adulthood*:

> Susan's main problem has been her personal care. Her urinary incontinence is dealt with by means of a stoma as she had considerable problems with her urine collection bags leaking or coming off, with the result that she is frequently wet. She has coped as well as possible, bringing in spare clothes, and using the facilities in the flat to wash and iron any that have been soiled so that she always has a clean set for emergencies. Advice has been sought from experts in the field of stoma appliances but she still continues to experience problems in this area.
>
> FEU, 1986[6]

Of course, it could be argued that the problem is Susan's inability to attach her incontinence device correctly in the first place, but the above description suggests that she is remarkably efficient in coping with the consequences of its failure. Any disabled person who regularly uses such equipment will tell you that its failure is far more likely to be due to defects in the equipment supplied than incorrect attachment.

In case any of you think that is merely a rationalisation of what is essentially a personal problem, then the MacColl Report (DHSS, 1986) should make interesting reading. The report catalogues deficiencies in the artificial limb and wheelchair services which are nothing short of scandalous. For example, the Association for Spina Bifida and Hydrocephalus claimed that 'nine out of ten of all young people with spina bifida who attend their assessment weeks are in wheelchairs which are either unsuitable, need adjustment or require further accessories'[7]. The response of the Government to this appalling situation was first to attempt to bury the report, and then to propose a number of managerial and educational changes to remedy the situation. Let me ask a question at this point: if nine out of ten of you at this conference were wearing shoes that were inadequate to your needs, that inflicted pain or were dangerous, what would happen? Would we accept a managerial or educational solution to badly fitting shoes, or would we expect heads to roll, firms to go bankrupt, media exposure and the like? None of these things has happened with regard to the situation uncovered by the MacColl Report.

A final way in which post-school services can further disable is through the setting of inappropriate aims. Look at any medical, social or educational programme targeted at disabled young people and the word 'independence' will figure large. Further scrutiny of these programmes will reveal that independence within these programmes is defined in terms of self care: the ability to wash, dress, eat, drink and go to the toilet without help. Disabled people aim to be independent but they give the word a very different meaning. Judy Heumann, a leading American activist succinctly puts it thus:

> To us, independence does not mean doing things physically alone. It means being able to make independent decisions. It is a mind process not contingent on a 'normal body'.
>
> HEUMANN, 1983[8]

It is for this reason that earlier I stated my preference for the word 'autonomy' rather than 'independence', and in the educational world we are, or perhaps should be, ideally placed to educate disabled young people for autonomy rather than independence.

Enabling services?

If we are going to provide services which enable rather than disable children and young people with impairments, then first and foremost, we must make it clear that disability and illness are not the same thing, whatever the medical model might imply. Disabled people may become ill just like everyone else, but disability itself is an ascribed social status, not an illness. To put this in educational terms, disabled children must be made to understand that they do not have something wrong with them; it is rather that society is unwilling or unable to organise itself to take into account their particular needs.

This view must be incorporated into the curriculum with an attempt to place disability in an appropriate historical, political and social context. This means that disabled children must be given the opportunity to learn and understand their place in the real world. They must be helped to understand that they have basic human rights, but, in attempting to claim these rights, they will experience personal discrimination because they are part of a socially oppressed group. Therefore they will have to fight to achieve their rights, individually and collectively by joining with other disabled people. Lest anyone think that this is an over-statement of the situation, there are disabled people who could not be here at the conference because they are not allowed to decide what time they will get up in the morning. Even if they could decide when to get up, many would not be able to get here because we do not have a public transport system which they can use. There are services in existence which give disabled people the autonomy to decide what time they will get up, and there are accessible public transport systems; the fact that they are not available to all disabled people is therefore a political and not a technical issue.

As far as professionals are concerned, they must base their interventions on the view of disability as an ascribed social status, as described above, whether these interventions be personal, social or curricular. This means that they themselves must be knowledgeable about the history of disability, the context within which it occurs, including legislation and welfare rights, and recent developments in the disability movement, notably the rise of organisations controlled and run by disabled people themselves. Above all, they must reject the personal tragedy theory of disability which leads to a desire to over-protect the children in their charge, with the inevitable consequences that these children leave the education system with low self-esteem and little or no knowledge of their place and future in the world. Such are the foundations upon which the myth of disabled young people as 'eternal' children is built.

Policy makers must look to their own services or establishments to identify ways in which they are currently disabling, whether it be because of poor physical access, negative attitudes amongst staff, or an inappropriate or inaccessible curriculum. In addition, a public commitment to the provision of enabling services must be made through the development of an equal opportunities policy. Care must be taken, through the full involvement of disabled people and their organisations, to ensure that such a policy is firm, specific and appropriate, thereby guaranteeing disabled people their full rights to participation. Such policies must stand alongside similar policies concerning race, class and gender, and not be pale imitations of these tacked on the end, almost as an afterthought.

Conclusions

In this paper, I have suggested some of the ways in which we currently disable children and young people with impairments and pointed to some of the ways in which services can become enabling. The initiative we are discussing is clearly part of the enabling process but it must be pointed out that this and similar projects are only necessary because of the disabling consequences of the education these children receive before leaving school. Such initiatives are vital in the short term but, if in ten years time we are still meeting at conferences like this and discussing them, then we will have failed to address some of the fundamental issues that I have raised in this paper. This may be unfortunate for us but it will be truly tragic for disabled children and young people with disabilities.

- Mike Oliver is Professor of Disabilities Studies at Thames Polytechnic.

References

[1] *Towards a Unified Concept of Transition: An Executive Summary* CERI/OECD, 1987

[2] Brisenden, S. 'Independent Living and the Medical Model of Disability' **Disability, Handicap and Society,** Vol.1, No.2, 1986

[3] *Transition to Adulthood – a curriculum framework for students with severe physical disability* FEU, 1986

[4] John, M. *Disabled Young People Living Independently* BCODP, 1986

[5] Massie, B. *'Significant Living Without Work' Special Education: Forward Trends,* Vol.9, No.3, 1979

[6] *Transition to Adulthood* op.cit.

[7] *Review of Artificial Limb and Appliance Centre Services* MacColl Report, DHSS, 1986

[8] Heumann, J., quoted in Crewe N. and Zola I. *Independent Living for Physically Disabled People* Jossey-Bass, 1983

The Transition to Adulthood project at North Nottinghamshire College of Further Education

Carol Tennyson

Preliminary Questions

1. What changes are likely to be experienced by young people in moving through the transition to adulthood process?

2. Are these changes likely to be different for young people with severe physical disabilities?

3. How are these changes likely to be viewed by young people with physical disabilities and their families?

4. How does meeting the needs of young people with physical disabilities in transition to adulthood affect the professionals involved?

5. As a professional, how would you define success in the outcomes of a transition to adulthood programme? Do you think the young people participating are likely to share your views?

The Paper

Introduction

The aim of this paper is to give you an insight into the everyday reality of the *Transition to Adulthood* project, focusing particularly on what it felt like to be part of it and on what our views are now that the research is finished.

The three years during which the project was implemented were certainly not the easiest three years of my life. Now that I am in a position to stand back and reflect on our experience and attempt to analyse why life was so difficult, I have come to the conclusion that it was because we were all involved in a period of great change in our own lifestyles.

It is the concept of change which I feel is central to the project and which I should like to focus on. First of all, I will examine the effect of change on three particular groups of people:

(i) students involved in the project;

(ii) parents;

(iii) college staff.

Secondly, I should like to spend a little time asking the question 'Has it all been worth it?'.

Implementation of the project was far from easy, and I think I would be right in saying that all three groups of participants would agree with me. No doubt you are all well aware that 'change' is often very difficult to come to terms with. We all develop our own *modus vivendi* and to have this questioned can be very stressful and, indeed, painful.

What are these changes? What have they meant for each of these three groups? And why has it been difficult to accept these changes?

The students' perspective

Change for the students has often meant moving from a situation where they have been protected and cared for to one where they are expected to think for themselves and take responsibility for their own lives.

But why should this be difficult? Many of the students involved in the project have had spina bifida and hydrocephalus and there is now considerable evidence to suggest that these conditions can cause neurological damage which may result in loss of motivation and passivity.

This, together with the fact that they have been conditioned by us into accepting a 'sick' role within society has meant that it has been very difficult for them to adjust to a situation where they are expected to think for themselves, to take the initiative, to negotiate their own programmes and to make decisions. Such tasks are not always easy for us but must be infinitely more difficult for those students who have spent 18 years in a society which has succeeded in convincing them that they should passively accept our benevolence and be grateful for it. It is hardly surprising that the ideas of self-reliance and self-determination are difficult to come to terms with.

The parents' perspective

Many of the parents have needed as much, if not more, support than the students, to come to terms with the changes affecting their sons and daughters.

Many have devoted their entire lives to caring for their disabled child or children. A course like *Transition to Adulthood*, which encourages the independence of their offspring can be very threatening. I well remember one mother who had been very supportive to her daughter whilst she had been in college, suddenly becoming very alarmed when we suggested that we would like to teach the girl to catheterise herself, not because she didn't think she was capable of doing this but because, as she said, 'It's the last remaining thing that I have to do for her – what will I do then?'.

There have also been those parents who have supported our work with the students but who have balked at the idea of their sons or daughters handling their own finances. Again, not necessarily because they don't consider them to be capable of this, but because the benefits and allowances have long since become an integral part of the family budget. It is hardly surprising that they should find it difficult to accept these changes.

The staff perspective

The majority of lecturers in a college of FE are used to working to a syllabus and preparing students for an end of course examination. From past experience we knew that this was not an appropriate teaching strategy for this particular group of students.

Staff have had to be particularly innovative and resourceful in their attempts to motivate the students. Very often this has meant standing back and reassessing their whole approach to teaching. It has meant accepting a facilitating role as opposed to a directive role. It has also meant accepting that we don't always know best.

Quite recently, we asked the second-year *Transition to Adulthood* students to find themselves a work experience placement. One boy who uses a wheelchair expressed a wish to work in a garage. We discussed this amongst ourselves and came to the conclusion that, although the boy had very good mobility skills, this would not be an appropriate placement. However, after hearing our arguments he remained determined to 'have a go'. He approached several garages whose reaction was similar to ours but did eventually find one that was willing to give him a trial period and he actually spent a very happy and successful term helping with MOTs, changing wheels, carrying out minor repairs, etc. With every justification, he was able to turn round and say 'I told you so'. Obviously we don't always know best and it is hardly surprising that professionals who see themselves as experts, will find it difficult to accept this.

However, I wouldn't want you to think that the past three years have been all gloom and doom. They certainly haven't. Although we have had our problems we have also had some very happy and rewarding times.

Has it all been worth it?

There have been many times throughout the past three years when we have asked ourselves this question.

Looking back now, I am sure that I speak for all the **staff** concerned in saying that yes, most definitely it has been worth it.

At the start of the project, I was told by a fellow professional that she very much doubted the wisdom of our work, that the students would be far happier going straight to a day centre where all their needs would be catered for. I didn't agree with her then, and I certainly don't agree with her now.

Over the past few years, we have seen the students develop into more confident, more self-reliant, more positive young adults. Let me give you a few examples of what we consider to be success. For us:

> **Success** is watching students gain in confidence to the point of being able to knock on the Head of Department's door and demand an audience – something that many staff would think twice about doing.
>
> **Success** is finding out that two students who have led very restricted social lives have arranged each Saturday to take themselves off to watch Mansfield Town play football.
>
> **Success** is receiving a letter from County Hall asking us for information about a petition regarding withdrawal of care assistants – organised completely without our knowledge.
>
> **Success** is discovering that two students reported missing from Cookery had taken themselves off to the pub for a lunchtime drink instead.

These examples, together with the benefits we, as staff, have gained in growing as a team and in individual personal development, have more than convinced us that it has been worth it.

And what about **parents**? Do they think that it has been worth it? Although some would, I think, still have reservations, the majority have expressed their thanks for helping them to plan for the future whilst they are still fit and able, rather than letting it ride until they are so old or so frail that they can no longer cope and their sons or daughters have to be taken into care – which in reality can mean a long-term placement in a geriatric ward.

Finally, what about our main concern, **the students**? Do they think it has been worth it? I think the answer is a resounding yes. Having experienced being in control of their own lives there are very few who would want to hand back this control to someone else.

Perhaps my most vivid memory of the past three years is of sitting in the staff room with my colleagues at the end of the summer term wondering whether we were doing the right thing, wondering whether it really was all worth it. There was a knock at the door and I opened it to find David, who is featured in the project report.

'I'd just like you to know,' he said, in his usual brusque manner, 'that I'd never have done it without you lot.'

Those words meant a lot to us then and I hope they will inspire you to take up the challenge to implement such a course in your own areas. I don't promise you an easy time but I do promise you that it is very worthwhile.

- Carol Tennyson was Project Researcher for the FEU/Nottinghamshire County Council *Transition to Adulthood* project. She is now Inspector for Post-16 Special Needs in FE, in Nottinghamshire Education Authority.

Summary

By now you should have an understanding of:

- the concept of transition to adulthood;
- the theoretical framework of transition to adulthood and some of the concepts/issues involved;
- the consumer's view – heard in the paper by Mike Oliver;
- the need for a model of future provision which places the young person with severe physical disability at the heart of the programme.

PART

2

SECTION FIVE: An agenda for staff training

Introduction – 'setting the scene'

The context of transition to adulthood

An agenda for staff training

Aims for the section

1. To explore the educational and professional implications of the issues underlying transitions to adulthood.
2. To enable the practitioners to develop their own training needs.

There are a number of issues which have been highlighted by the *Transition to Adulthood* project and its subsequent dissemination process. These need to be taken on board by those who work with young people with severe physical disabilities if they are to enable these young people to be in charge of their own transition to adulthood. This should be the primary focus when working through this section of the package.

The reader is encouraged to identify their own personal agenda for training. For those working in a group where, perhaps, a team is responsible for the delivery of services, the team can prepare its own agenda.

The following model indicates a number of possibilities.

AN AGENDA FOR STAFF TRAINING

- ☐ Handicap and disability
- ☐ Adolescence
- ☐ Adulthood
- ☐ Parental perspectives
- ☐ Meeting individual needs
- ☐ Developing and supporting the curriculum in an inter-agency setting
- ☐ Post-college provision
- ☐ Your own issues (please specify)

Please tick the areas which you wish to explore

The activities which follow are based upon the issues identified in Figure 3. These have arisen as significant during the dissemination process of *Transition to Adulthood.*

Where an activity is shown as (individual/group) this is an indication that it can be used in either mode. Where (individual) or (group) follows an activity this is intended to indicate to those of you working in a group those parts of the activity which should be attempted in either an individual or a group situation. Those of you working alone should ignore these descriptors.

THE ACTIVITIES

Issue 1 – handicap and disability

Activity A (individual)

Write down your definition of handicap:

Write down your definition of disability:

Activity B (individual)

Look at the following photographs and then note down your immediate response to the question 'Is this person handicapped?', together with any key words which spring to mind as you look at each photograph. (Use the table on page 46.)

◀ Photo 1

▼ Photo 2

46

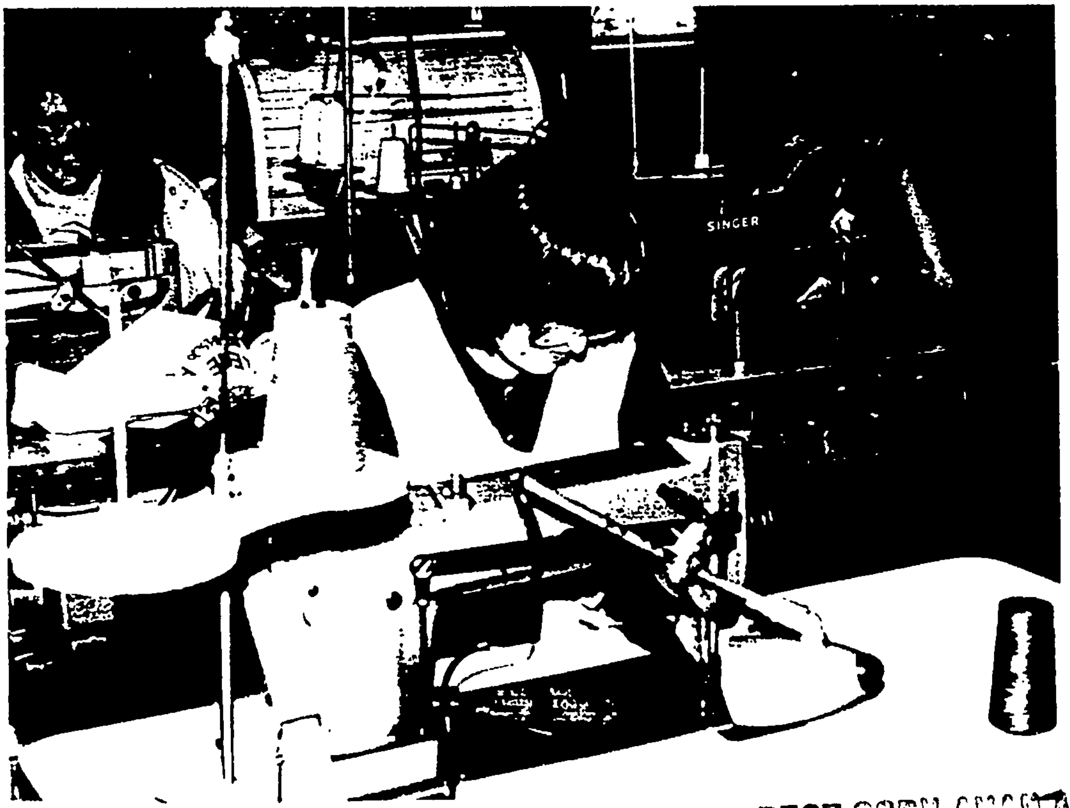
◀ Photo 3

◀ Photo 4

◀ Photo 5

▲ Photo 6

▼ Photo 7

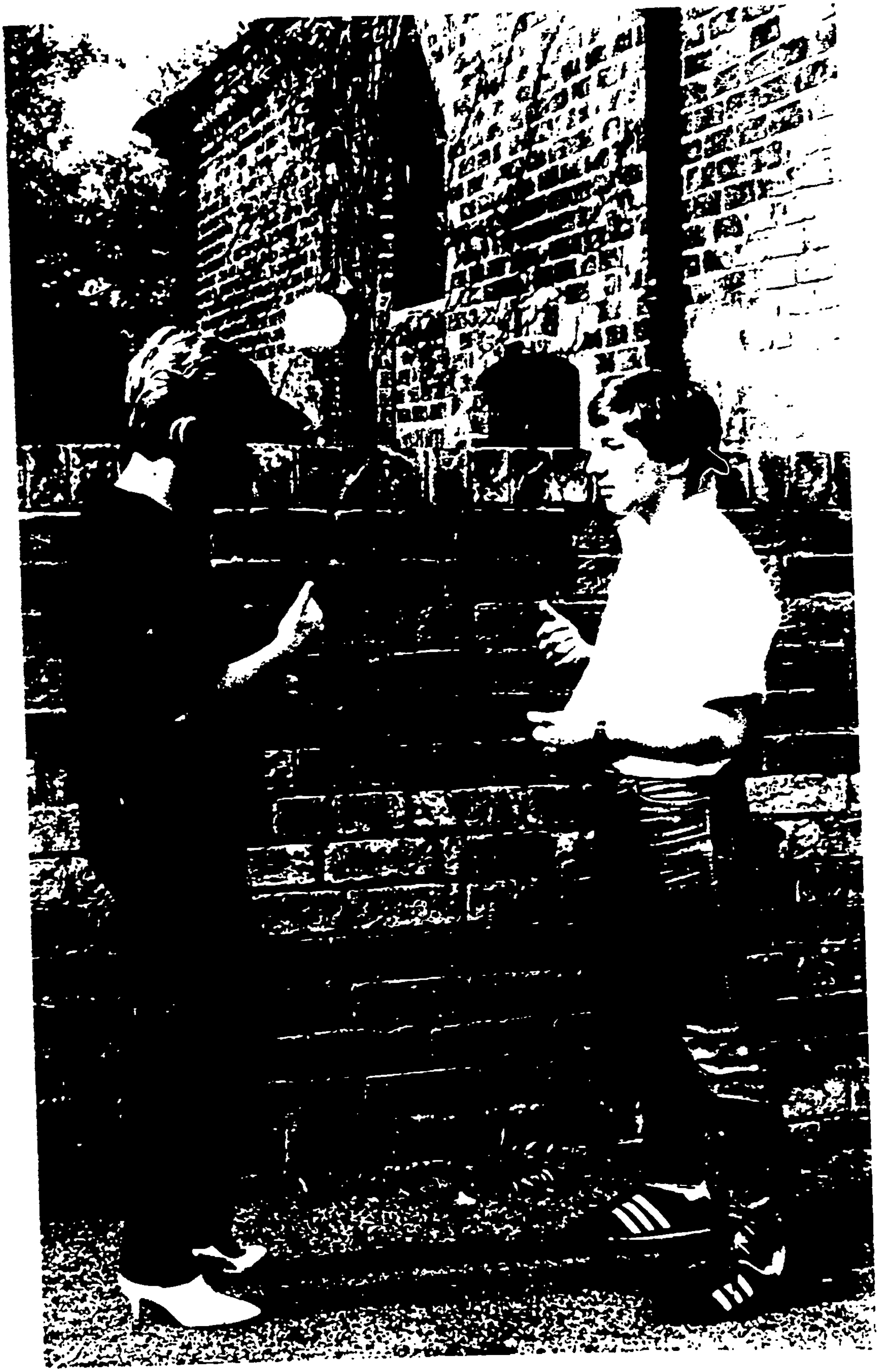


48 BEST COPY AVAILABLE

Photo 8

Photo 9

Photo 10



▲ Photo 11

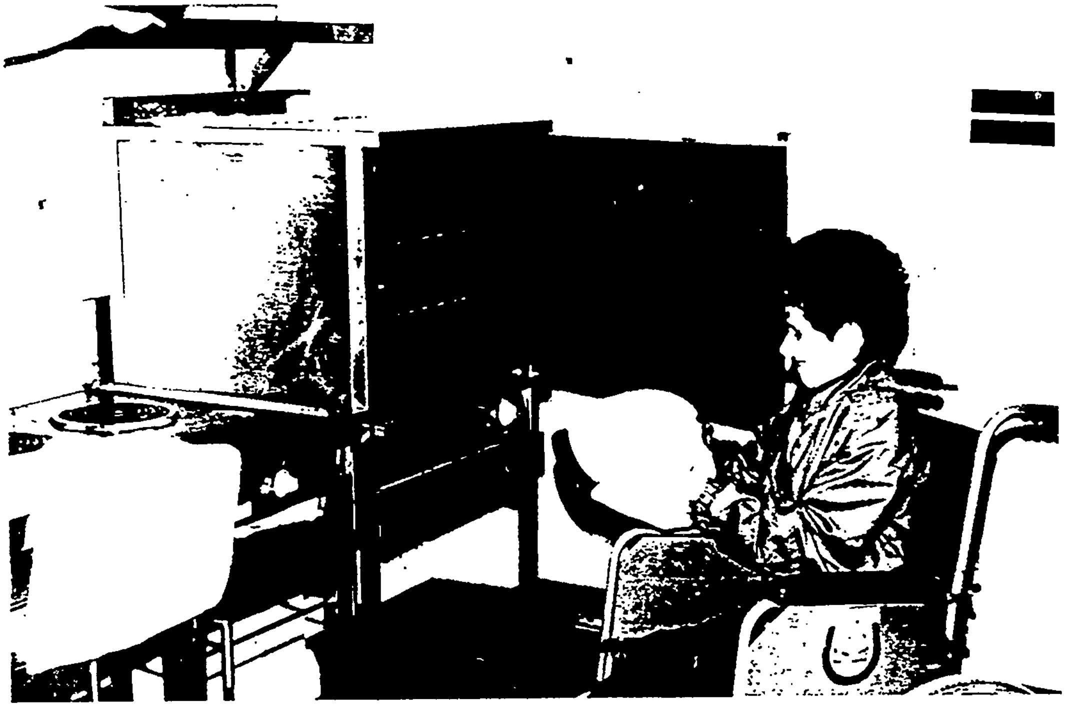


Photo 12

Photo 13

▲ Photo 14

▼ Photo 15

52

Photograph	Is this person handicapped? (Yes/No)	Key words
1		
2		
3		
4		
5		
6		
7		
8		
9		
10		
11		
12		
13		
14		
15		

Activity C (group)

1. Each person should share with the rest of the group their definitions of:

- Handicap
- Disability

2. As a group, attempt to arrive at a group definition of the two terms. (If you cannot agree see page 101, *Transition to Adulthood* [FEU, 1986] or more recent FEU publications.)

Activity D (individual/group)

1. As an individual, read the following quotations which have been taken from papers presented to an OECD conference on the 'Handicapped Adolescent'.

(i) 'What makes the handicapped "special" are the attitudes and reactions of others who are not handicapped; and the greatest harm to the handicapped child or adult stems from this socially engendered impairment of daily life, self-concept and future – not from functional impairments themselves.'

(ii) 'Many disabled young people grow up with a socially communicated sense of stigma and doom, and socially generated expectation that handicapped children have no real future as adults. Special provisions, specific educational strategies, vocational and rehabilitative training may go far in compensating for disabilities as well as supporting young people in their difficult transition to adulthood. However, unless the "hidden agenda" of stigmatisation and its negative social and psychological effects are dealt with openly, provisions and strategies risk falling short of attaining their aim of helping disabled youth to live an independent and as full an adult life as possible.'

(iii) 'Social psychological literature abounds in research and data on the importance of self-image in the development of the individual, his identity and the adult life he comes to lead. It has been shown that the concept of the self is forged by the image of oneself reflected by others. It is evident that the self-image held by disabled youths and adults has had to come to terms in one way or another with the prejudices and stigmatisation of non-disabled people. Gliedman and Roth write: "If one thing is clear from the autobiographies of the handicapped, it is that the first hazard many face is the demoralisation that can result from having one's competence as an individual constantly challenged while one is growing up – not because one actually is incompetent but because the able-bodied think one is".'

(iv) 'Gliedman and Roth talk about the "theft of the future" of many handicapped youth. Those who remain perpetual patients because of severe disability do not develop socially – they remain stuck in time, citizens of a therapeutic state where there are only good patients and bad patients, not grown-ups and children, and where cradle-to-grave institutions take care of them for life.'

(v) 'In the customary institution he is a passive receiver of help and assistance. When living freely and independently the disabled person, like all others, has to ask for service. Our investigations show that many disabled people starting their integrative lives find it difficult to exchange the passive role of a receiver for the active one of ordering services. We found that nurses and service assistants have the same problem although the direction is here reversed. A well-educated and well-trained teacher or nurse who is familiar with his/her role of thinking and acting for the disabled will have considerable psychological trouble when he/she has to take his/her place as a service assistant to the disabled.'

2. Each one of the quotations makes important points about attitudes, both for young people with disabilities and for professionals who work with them. Re-read each quote and note down what you feel to be the main points of each one.
3. Do you agree with the points being made?
4. As a group, discuss the following statements and explore the implications these have for your own and other people's professional practice.
   (i) 'It is not the disabling condition which is crucial, but the perception that people hold about it.'
   (ii) '"Special" services can in themselves be disabling.'
   (iii) 'Professionals and individuals with disabilities need to change if they are to shift the balance of power.'

Issue 2 – adolescence

Activity A (individual)

Adolescence is generally regarded as a 'difficult' time for all young people. In this activity, you are asked to investigate the process of how 'normal' people acquire their adult identity and make the transition from childhood to adult life.

1. **Initially, think about your own adolescence and how it felt to be 16 years of age. To help you, please note:**
   - **(i) the year in which you were 16**
   - **(ii) whether you were at school or work**
   - **(iii) your family situation**
   - **(iv) what you were wearing, e.g. style of clothes, shoes, hairstyle, etc.**
   - **(v) what you did on a typical Saturday night!**
   - **(vi) what were the things you did that your parents/guardians didn't really like?**
   - **(vii) what you felt about the opposite sex**
   - **(viii) anything else that you can remember about this period of your life**

Activity B (group)

1. As a group, share your memories of your own adolescence and then make a list of what you agree on as being the four main preoccupations of adolescence:

   A =

   B =

   C =

   D =

2. Having agreed on a list, reflect on your four main preoccupations and discuss within the group whether any of these preoccupations will be different for young people with severe physical disabilities. If you think they will be, note the differences.

Activity C (group)

Having undertaken Activities A and B, you should now be able to consider how much more difficult adolescence is for young people with severe physical disabilities.

1. Look at the four main preoccupations of adolescence which you identified in Activity B and, in your group, discuss the particular problems young people with severe physical disabilities might face. List these in the table on page 51.
2. As a group of professionals, identify all the possible ways of enabling young people to overcome these problems.

Problems faced during adolescence by young people with severe physical disabilities	Ways in which professionals can enable young people to overcome their problems

58

Issue 3 – adulthood

Having looked at adolescence, we will now consider 'adulthood'. In some cultures, the transition to adulthood is clearly marked by 'initiation rites' or 'rites of passage'. Each individual, therefore, is well aware, often almost to the minute, of the time when they become an adult. Western culture does not have this and consequently the achievement of adult status is less clearly defined. Indeed, for some young people, there is an 'agreed' extension to adolescence, i.e. continuing education at college or university.

Activity A (individual)

Consider the following questions and please note your answers.

1. **At what time in your life did you consider yourself to be an adult?**

2. **Why (i.e. what features of your life at that time signified your achievement of adult status)?**

Activity B (group)

1. **As a group, share your individual responses to Activity A and then make a list of what you agree on as the main indicators of adult status.**

   A =

   B =

   C =

   D =

   E =

   F =

   G =

   H =

2. **Now discuss ways in which it might be more difficult for young people with severe physical disabilities to attain some of these indicators. Note these in the table on page 53.**

The main indicators [illegible] of adult status	Difficulties of achievement for young people with severe physical disabilities

Activity C (individual/group)

So far we have been considering, through an examination of adolescence and the achievement of adulthood, what might be seen as emotional difficulties which young people with severe physical disabilities might experience in their transition to adulthood. These, of course, are in addition to the difficulties which arise simply from day-to-day life. These are rarely experienced by able-bodied people and certainly not to the same extent, e.g. access to buildings, mobility, going to the toilet, eating, taking medication, dressing/undressing, and managing time. Professional workers will need to be especially alert to these difficulties, and will have to use initiative and resourcefulness to enable the young person to achieve as much autonomy as possible. This activity, therefore, is a vital one and concerns these important issues.

1. Write down the professional role that you play in the young people's transition to adulthood.

2. Within your role what do you do/have to do that:

(i) might alleviate the difficulties of adolescence and facilitate the achievement of adulthood for young people with severe physical disabilities?

(ii) might enhance the difficulties?

(iii) how can you maximise on (i) above and minimise on (ii)?

3. As a group, share your individual responses and then make a list of what you agree are the priorities for the development of your professional roles.

Issue 4 – parental perspectives

Activity A (individual/group)

Exploration of earlier issues has established that adolescence and the achievement of adult status are fraught with difficulties for young people, but this is especially so for those with severe physical disabilities. It is important, however, for professional workers to remember that this period of a young person's life is also stressful for their family. A young person cannot be seen in isolation from their everyday living situation. It is too easy for the professional to label the family as over-protective and a hindrance to their own work with the young person.

This activity is designed to explore the sorts of conflict that can arise in the family at this time, and to develop effective ways of working.

1. Each of the following situations contains potential conflicts.

Situation 1

James Green is 18 years old. At the age of eight, he was involved in a road traffic accident and suffered severe brain damage.He was awarded considerable damages which were put in trust for him.

As a result of the accident, he walks with an unsteady gait, and although of 'normal' intelligence, has a severe speech impediment which makes his speech extremely difficult to comprehend.

After his accident, James attended a special school for children with physical disabilities as a weekly boarder, returning home to his family at weekends. His parents are divorced and James' mother has two younger children still at home.

Since starting a college course, James has been increasingly unhappy at home. He feels that his mother is holding him back, and that the time has come for him to make a break. His mother, however, is convinced that James cannot cope on his own.

James contacts a social worker and asks her to visit his mother and attempt to resolve the situation for them. How can James and his family be helped to come to terms with his growing need for independence?

62

Situation 2

Jane Brown is 19 years old. She has had spina bifida since birth. She uses a wheelchair and is doubly incontinent.

Before starting college, Jane attended a school for children with physical disabilities as a day pupil. She lives at home with her parents and younger brother. She also has an elder sister who is married. Jane's mother takes complete charge of Jane's personal care – she gets her up each morning, bathes her, changes her appliance, dresses her, puts her to bed, etc.

Jane receives mobility and attendance allowances, but personally does not have any dealings with these. She has always appeared to be quite happy. She was a popular pupil at school and a member of the local Physically Handicapped and Able Bodied (PHAB) club, where she has become very friendly with Stephen, who himself uses a wheelchair as a result of cerebral palsy. Stephen is extremely intelligent and has found employment as a computer programmer. Recently, Jane's parents have noted a change in her and they have become quite concerned about her. She is very quiet, spends a lot of time alone in her room and seems very unhappy with life in general. Jane refuses to discuss the situation with her parents, saying that she is all right and that they are imagining things. They, however, feel that her relationship with Stephen is at the root of the problem and their fears are confirmed when Stephen visits Jane at home and they announce to her parents that they intend to get married.

What difficulties do you envisage for the couple? Can you offer any suggestions to help them with these difficulties? How can Jane be supported in making a decision about her future life? How can her family be helped to accept and support her decision and look at the consequences for their family unit?

Situation 3

Stuart Wilson is 21 years old. He has been disabled since birth with cerebral palsy. He is confined to a wheelchair and has only limited use of his hands. He has a slight speech impediment. He is of 'normal' intelligence, quite mature and has a bright personality.

He attended a residential school for children with physical disabilities. He left school at 18, and since then has lived at home with his parents and younger sister and has attended a college of further education as a day student.

Stuart is about to leave college. He is aware that he is unlikely to gain employment. However, he is adamant that he will not attend the local Social Services day centre and is equally adamant that he wants to leave home. His parents are very caring and recognise his desire to be independent, but are doubtful about his ability to cope and are also very concerned about how he will pass his time during the day.

Stuart and his parents make an appointment to discuss their difficulties with Stuart's college tutor. What choices are open to Stuart? How can he be supported in becoming more independent? How can his family be supported in feeling less anxious about his future?

Choose one situation (more if you have time) and attempt to highlight the main issues and provide some ideas about how conflicts might be solved. Those of you working in a group situation might like to have a number of your group acting out the situation in role play with the rest of your group as observers. At the end of this activity summarise your findings in the following table.

Areas of conflict	Possible solutions

Activity B (individual/group)

1. Read through this moving account presented by a parent during one of the Transition to Adulthood dissemination workshops. Note down your reactions to the questions on page 60.

Is there life after 19? A parent's perspective

Two years ago I asked this question at a case conference which was discussing my son's immediate educational needs. The professional reaction was one of such shock and dismay that I felt positively churlish for asking it – I was reassured that the 'winds of change' blowing through special education were opening up new horizons for post-19 young people.

Two years later, I can now answer my own question. Yes, there are new possibilities for many young people, but for my son and those like him, there is neither educational provision nor any other suitable alternative.

He belongs to that minority of handicapped – 'the ineducable, the unemployable, the impossible' (forgive the most unprofessional terminology) – in other words the severely multiply disabled. He suffers from a combination of severe physical, sensory, intellectual and emotional disabilities which render him immobile, almost blind, intellectually impaired and emotionally unstable – about to be launched into a potentially hostile, unsympathetic and hazardous society.

In preparation for this transition from the environment of a special school he has spent the last six months in a leavers' unit for post-16 adolescents attached to his present school. It is residential, Monday to Friday, the intention being to remove them during the week from the home to achieve the maximum level of personal independence. The result to date has been a complete emotional breakdown, the worsening of a stress-related physical illness, and, far from loosening the bonds between my son and his parents, it has made him more dependent than ever on us. He is now isolated, withdrawn, anxious, depressed, guilt-ridden, on constant medication and under constant medical supervision. In less than three months he will be returned to our care – his education at an end and facing an unhappy and uncertain future – no longer the responsibility of any agency but ourselves; the professional agencies can wash their hands of him. They are under no obligation to do anything more for him or us.

You may wonder what he wants and what we would like for him in the immediate future. HE is quite clear – he wants to remain at home with us. WE are quite clear – we want him at home for as long as he wants to remain with us. At the moment we ask only for the necessary day-care and support services to make this possible and allow him some independence from us, and to allow us to continue to work and look after David. We would like an appropriate day provision which would continue to offer the educational opportunities he still needs, and at the same time, offer him a stimulating, enjoyable and rewarding lifestyle in which he could make friends outside his immediate family circle.

What have we been offered? First, residential placement – a very tentative offer which, in view of David's wishes, his emotional instability and our wishes, is a non-starter. Furthermore, I have no intention of placing my son in any kind of residential institution while society, government and the professional services still haven't decided what to do with the profoundly handicapped – whether to retain residential homes or to replace them with small residential units and integrate the handicapped into the community.

Having turned down residential provision we have investigated the day provision available in my particular borough. We have to date followed up two possibilities.

One, a placement on a two-year Youth Training Service (YTS) course for Post-19s with special educational needs, funded by Manpower Services (TEED) but managed by the Local Education Authorities (LEAs), or placement in a day centre funded by Social Services. David was interviewed in March regarding the YTS placement or rather 'interrogated' under intense pressure. The prevailing attitude demonstrated by the officer in charge was that David would present the staff with major, unprecedented problems of care and supervision – placing an intolerable burden on them. David would have to be prepared to 'adjust', 'cope', 'do his best', 'work very hard', 'act like a man', 'push himself'. Even then they had reservations that the course could offer him much anyway, as it was designed for the mobile, the sighted, with some degree of numeracy and literacy and very much orientated towards work experience. This produced in all of us the most negative reaction. (My, fortunately, unspoken response is far too impolite to repeat here.) However, as we have not heard any more since, we can reasonably assume that this also is a non-starter. Further investigations have revealed that, in any case, as the funding is managed by the LEA, the onus would be on us to convince them that funding for David would be worthwhile – whatever that may mean.

We come to the final option – a day centre for the disabled – the 'adult nursery' so aptly described by a student in ***Transition to Adulthood***. In theory he would be looked after and occupied between the hours of nine to five for five days a week until he is 40 and then, presumably, as remission for good behaviour, he would only be entitled to two days a week. In practice, I suspect he could easily be left to his own devices to vegetate in front of a television set or wander aimlessly around the place in his wheelchair.

This is the reality of post-19 provision for my son. May I make one final point? Apart from the shock of the discovery that there is nothing suitable for my son in the immediate future, the situation is made increasingly worse by the realisation that I can no longer insist that suitable provision is offered because any provision is now discretionary and furthermore is divided between different agencies. In my borough there is a superb double-act between Social Services and Education in which neither will assume responsibility of funding while there is any chance of passing the buck to the other agency. One finds oneself dealing with a confusing number of individuals whose roles and responsibilities are never defined. I am quite sure that this is deliberate and the object of the exercise is to confuse and mislead a multiplicity of 'monkeys' to prevent any access to the 'organ-grinder'.

In conclusion, I would like to remind you that my son is being denied the further educational provision which is freely available to any 'normal' 19-year-old with no strings attached – the opportunity for acquiring leisure and other life skills which are offered to the less disabled and the normal experiences of adult life which most of us have enjoyed.

Reference

The above case study appeared in ***Uneasy Transitions*** Falmer Press, 1991

(i) How can the relatively private world of 'parenthood' be assisted in working in the 'public' domain of professionals with its prejudices and frequently contradicting pieces of advice?

(ii) How can the situation be improved where parents feel that they need to 'fight' to obtain advice, information and help?

(iii) How can professional workers be helped to understand the emotional and physical strains that can be involved in physical care in a family setting?

(iv) How can professional workers be assisted to respect parents' views rather than merely tolerate them?

(v) How can parents be made to feel part of the future for their children with severe physical disabilities and be included in the consultation/exchanges of information passed between professional workers?

(vi) How can the wishes of people with profound disabilities be discovered when they may not be able to speak for themselves?

(vii) How can professional workers be helped to understand the intensity of the parent-child relationship where the child has a physical disability, with the mutual dependency that can be present?

(viii) Can parental apprehension and anxiety about the long-term provision for the young person with severe physical disability be overcome by setting up 'parent workshops' or 'letting-go programmes', or are these patronising?

(ix) Can you think of alternative support activities?

Issue 5 – meeting individual needs

Activity A (individual/group)

The *Transition to Adulthood* project report states:

> 'When students arrived at the college, there was no suitable model upon which to base provision. Our initial response was to take on board the Warnock concept of "significant living without employment" and offer individual programmes of experience, based largely upon catching up on missed education and extension structures topped up with a measure of recreational and creative activity.'
>
> PARAGRAPH 8

1. **How does this situation relate to the one prevalent in your local college?**

2. **What are the obstacles to young people with severe physical disabilities being accepted as fully participating members of the college with as much legitimate right to be there as any other student?**

3. **How can these obstacles be removed, overcome or circumvented?**

Activity B (individual/group)

1. **The following case study is a description not of an individual, but of a fictional person made up of characteristics from a range of young people with severe physical disabilities involved in the *Transition to Adulthood* project.**

Janet aged 18 – where next?

Janet was born with spina bifida and hydrocephalus and had a shunt fitted at birth to control the hydrocephalus. She uses a wheelchair and is doubly incontinent. She had been at a residential special school for most of her school years and returned home at the end of this period to live with her mother and younger brother, her father having left home when she was aged ten.

At 16, Janet appeared verbally confident, but was reported by her school to be functionally illiterate. Her level of attainment in numeracy was also very weak. She was said to be independent in self care but considered to be very lazy and needed constant reminders to empty her appliance. Janet's social worker reports that life in Janet's home is a struggle, money in particular being a problem. Whilst Janet has a good relationship with her mother, it is one based very much on her dependency. Janet's life outside the home is confined to a weekly visit to a local PHAB Club and she lists her main activities as watching TV and playing her records.

In many ways, Janet's educational experiences were fortunate in that she entered a nursery unit at her school when she was aged two and a half and she was able to remain at school until she was aged 18, since the school had a 16+ unit. At 18, Janet left school and moved into special provision in a local college of further education. When she joined the course, staff found it very difficult to work with Janet as she did not seem to be interested in any of the activities offered to her and was content to sit for long periods of time doing nothing. Specific assessments carried out at the time she entered college showed that:

1. Janet was not financially independent and was not aware of the allowances which she received.
2. Janet had difficulty in performing simple home skills, tasks such as cutting, peeling, chopping, opening tins, making tea/coffee, etc.
3. Janet could not accept responsibility for her own personal care needs.
4. Janet had, apparently, a low self-image and, whilst ostensibly happy, really lacked confidence.
5. Janet had limited mobility skills and was entirely reliant upon others to move to and from her home and, since the family had little money and no transport, this rarely happened.
6. Janet was very passive in many aspects of her life and accepted without question what was done for, or to her.

What would you regard as Janet's curricular needs in enabling her to make the transition to adulthood. You might find the following headings useful:

(i) Preparation for work

(ii) Support for daily living

(iii) Support for leisure opportunities

(iv) Preparation for further education and training

(v) What are the needs of your own group of young people?

Activity C (individual/group)

The *Transition to Adulthood* project report states:

> 'The curriculum is intended to develop the students' potential for independence in all spheres of adult life and place them in a position to accept responsibility, exercise choice and be in control of their lives.'
>
> PARAGRAPH 16

To achieve this with people who are often inexperienced financially and personally, and who may be socially dependent, who often have a low self-image, appear generally passive and accepting, requires a willingness to take risks.

1. What do you think should be the parameters of risk taking?

2. How do professionals maintain a proper balance between opening up new activities and protecting young people with severe physical disabilities from the most traumatic consequences of their inexperience or inability?

3. How far is it legitimate to raise issues which you are unable to see through to their resolution?

4. How would you feel about issues which put you in the position of taking sides between the young person and their parents?

5. How can a programme operate which facilitates risk taking with severely disabled and potentially dependent young people? Identify the key components for its success.

An effective programme for managing risk taking	Key components for success

6. What support would you expect from your senior managers and how might this be provided?

Elements of support	Ways of providing support

7. What information would you expect to give to senior managers?
How might this be given most effectively?

Information for senior managers	Ways of giving information

74

8. What information would you expect to give to the parents of young people? How might this be given most effectively?

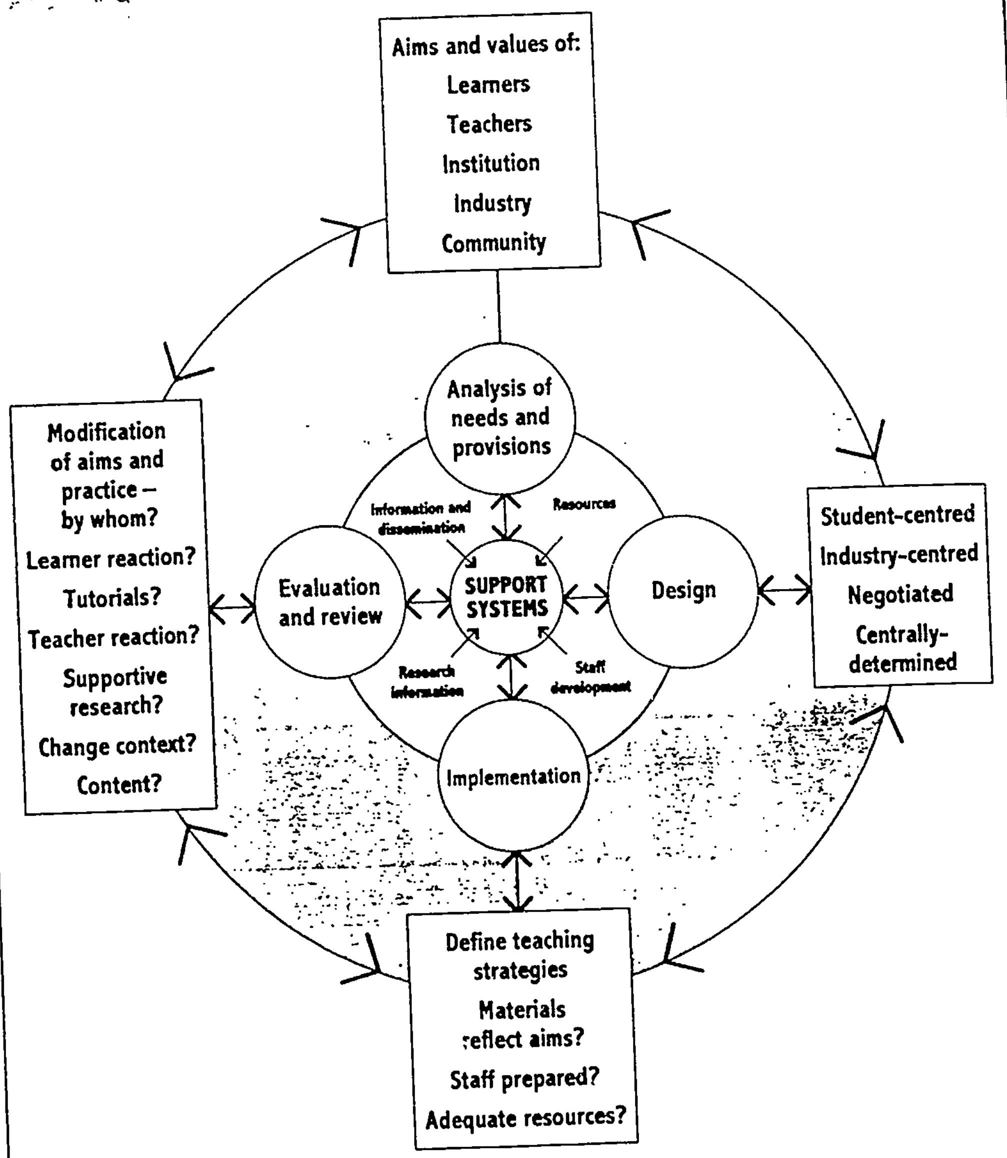
Information for parents	Ways of giving information to parents

Issue 6 – developing and supporting the curriculum in an inter-agency setting

The *Transition to Adulthood* project used, as a starting point, the FEU model of curriculum development. This is shown in Figure 4.

FIGURE 4

Curriculum development model



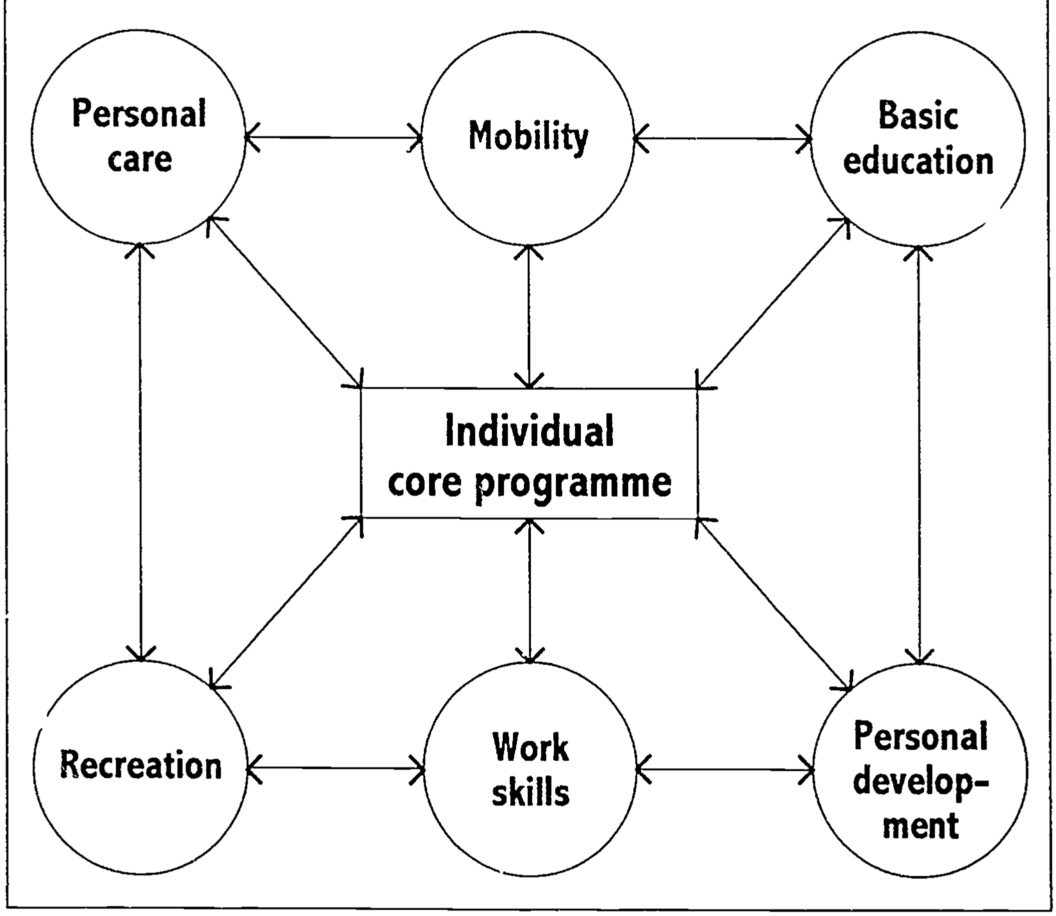
INNER CIRCLE – elements of curriculum
OUTER CIRCLE – elements of curriculum development

Activity A (individual/group)

The *Transition to Adulthood* curriculum framework included a core framework of interrelated modules which, grouped together, made up an individual programme as indicated in Figure 5.

FIGURE 5

The core programme



1. Draw up a similar core programme designed to meet the assessed needs of your own group of young people with severe physical disabilities.
2. What support will you need in order to develop your programme?

Activity B (individual/group)

1. Look at Figures 4 and 5 again, and decide where you are most active professionally. Try to decide on the links that you need to establish with other agencies.

   Draw this network of links below.

2. You may decide that there are gaps. The staff development pack, *From Coping to Confidence* (DES/FEU, 1985)[1], outlines a framework for collecting and communicating useful information on support agencies in Module 7. This framework has been developed further during the *Transition to Adulthood* dissemination process. Try to complete the 'Useful contacts' pro forma on the following page for yourself and note where the gaps are in your network.

FURTHER EDUCATION UNIT

Transition to Adulthood Regional Workshop

USEFUL CONTACTS

Local	**Name, Address, Telephone no.**
LEAs	
Schools	
Training and Enterprise Councils	
Social Services	
Health Service	
Voluntary organisations	
Self-advocacy groups	
• Leisure/recreation	
• Employment	
• Housing	
• Care	
• Technological support	
• Other	

Regional	**Name, Address, Telephone no.**
SKILL – The National Bureau for Students with Disabilities	
Regional Advisory Council/ Regional Curriculum Base	
TEED – Training, Enterprise and Education Directorate	
Voluntary organisations	
FEU regional officers	
Others	

National	**Name, Address, Telephone no.**
Department of Education and Science	
Her Majesty's Inspectorate	
Further Education Unit	
Department of Social Security	
Department of Health	
National Council for Educational Technology	
Voluntary organisations	
Funding organisations	
Others	

Activity C (individual/group)

A principle established in the *Transition to Adulthood* project was that for a college to provide relevant provision for young people with severe physical disabilities, staff must have up-to-date and comprehensive understanding of the work of other services and agencies:

> 'No matter how difficult it is to achieve, the way forward is for the many different service providers to work together to ensure co-ordination between them so that each individual who is in need of help can benefit from a multi-disciplinary service.'
>
> PARAGRAPH 173

1. **How do staff gain knowledge of, and develop, the working relationships necessary to support young people with severe physical disabilities through a college programme and on into adult life? Write out your views below.**

Essential knowledge of working relationships	**Methods of obtaining/developing these**

2. **What appear to be the barriers to inter-agency co-operation in your working situation?**

3. How many of these are real obstacles?

…………………………………………………………………………………………

…………………………………………………………………………………………

…………………………………………………………………………………………

4. How can apparent 'barriers' be overcome? Write down your response below.

'Apparent' obstacles to inter-agency collaboration	Strategies for overcoming these obstacles

Issue 7 – post-college provision

Figure 2 in Section Two of this package suggests a model of future need with the disabled person in control, exercising choice. However, the *Transition to Adulthood* report states:

> 'In setting up a college-based *Transition to Adulthood* course for severely disabled young people, it is necessary to accept that no matter how much progress is made in college, it is essential to establish co-operation and joint planning with those who will be working with the students in the future if progress is to be maintained and extended.'
>
> PARAGRAPH 157

BUT

> 'Jealousy and resentment between the different agencies involved with disabled people are often deeply entrenched and extremely difficult to break down. "Who pays for what" often results in essential facilities or care being postponed or withheld indefinitely whilst the "professionals" argue the case amongst themselves.'
>
> PARAGRAPH 159

AND

> 'One particular problem experienced by many of the students we have met is a sense of isolation and bewilderment as to which of the service providers they should turn to for help.'
>
> PARAGRAPH 174

Activity A (individual/group)

Faced with this situation:

What practical steps would you take to enable young people with severe physical disabilities to gain access to necessary facilities and resources when they leave college? You might find the pro forma on page 76 useful.

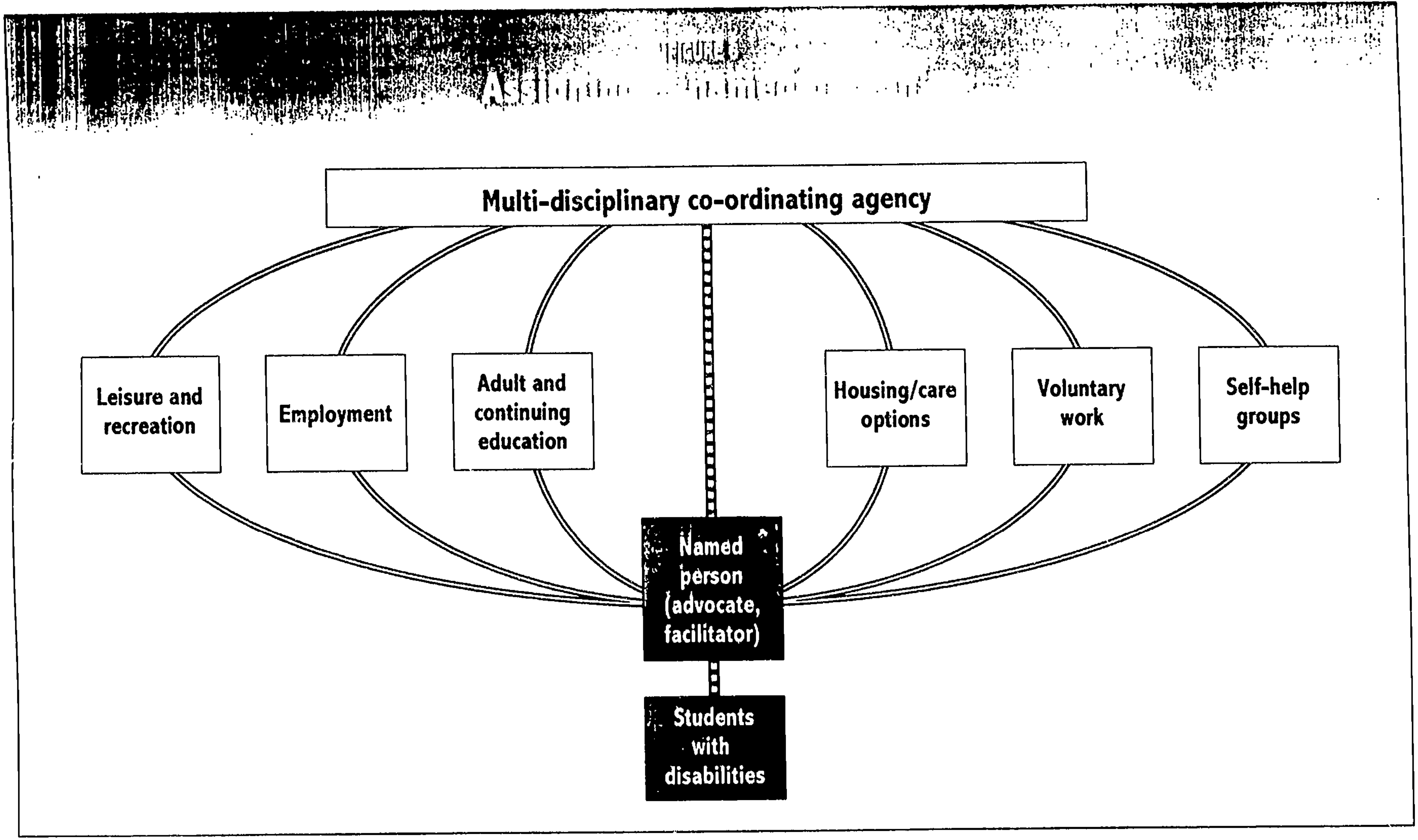
Activity B (individual/group)

The *Transition to Adulthood* report addresses the problem of the confusing and competing array of services and states:

> 'This problem could be alleviated by assigning a "named person" to the young person and their family who could act as an advocate to encourage them to formulate ideas about their needs and help them find the necessary resources. A jointly-funded, multi-disciplinary agency could also be useful in linking the many different professionals and resources that are available. This would help fill the gaps which inevitably result from separate provision.'
>
> PARAGRAPH 174

Figure 6 describes the model put forward in *Transition to Adulthood.* How can you ensure that a 'seamless robe' of provision is developed in your area? Draw up an action plan for co-ordinating local provision, using the guide on page 78.

Facility/resource to be achieved	Present obstacles	Steps to remove obstacles and free facility/resource	Who will take these steps?


Multi-disciplinary co-ordinating agency
Leisure and recreation
Employment
Adult and continuing education
Housing/care options
Voluntary work
Self-help groups
Named person (advocate, facilitator)
Students with disabilities

Action plan for co-ordinating local provision

1. What is your intended outcome? What do you want to achieve?

2. The plan

3. What are you going to do about developing the plan:

   (i) by next week?

   (ii) by the end of a month?

   (iii) by the end of six months?

4. Who are you going to involve in the development of the plan?

5. How are you going to involve the young person and their family, as partners, in the development of the plan?

6. How will you evaluate the effectiveness of the plan?

References

[1] *From Coping to Confidence – a staff development resource pack for further education teachers of students with moderate learning difficulties* DES/FEU, 1985

SECTION SIX: Evaluation – what have I achieved?

Introduction – 'setting the scene'

The context of transition to adulthood

An agenda for staff training

Evaluation – what have I achieved?

Aims for the section

Practitioners should:

1. identify their range of competence in the context of the development of a curriculum framework for young people with severe physical disabilities;
2. isolate any skill deficiencies and the need for further training;
3. develop appropriate tools for evaluating the training process.

A self-evaluation task sheet

1. What skills do I need to possess in order to develop a curriculum that is responsive to the needs of young people with severe physical disabilities?

Skills

(i)

(ii)

(iii)

(iv)

(v)

(vi)

(vii)

(viii)

(ix)

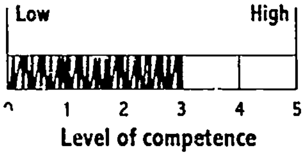
(x)

Other skills

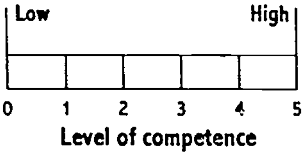
2. How competent am I in the use of these skills? (Use the method indicated below, marking off where you feel your level of competence to be. An example is given.)

Example

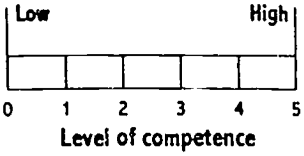
Skill area e.g. meeting individual needs



(i) Skill area



(ii) Skill area



(iii) Skill area ....

Low High
☐☐☐☐☐
0 1 2 3 4 5
Level of competence

(iv) Skill area ....

Low High
☐☐☐☐☐
0 1 2 3 4 5
Level of competence

(v) Skill area ....

Low High
☐☐☐☐☐
0 1 2 3 4 5
Level of competence

(vi) Skill area ....

Low High
☐☐☐☐☐
0 1 2 3 4 5
Level of competence

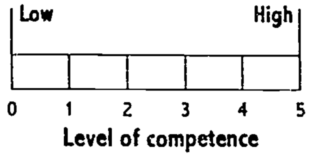
(vii) Skill area ....

Low High
☐☐☐☐☐
0 1 2 3 4 5
Level of competence

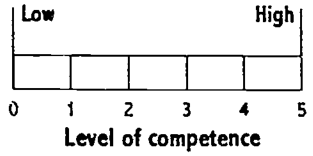
(viii) Skill area ....

Low High
☐☐☐☐☐
0 1 2 3 4 5
Level of competence

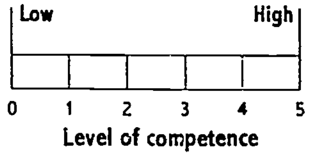
(ix) Skill area . . . .



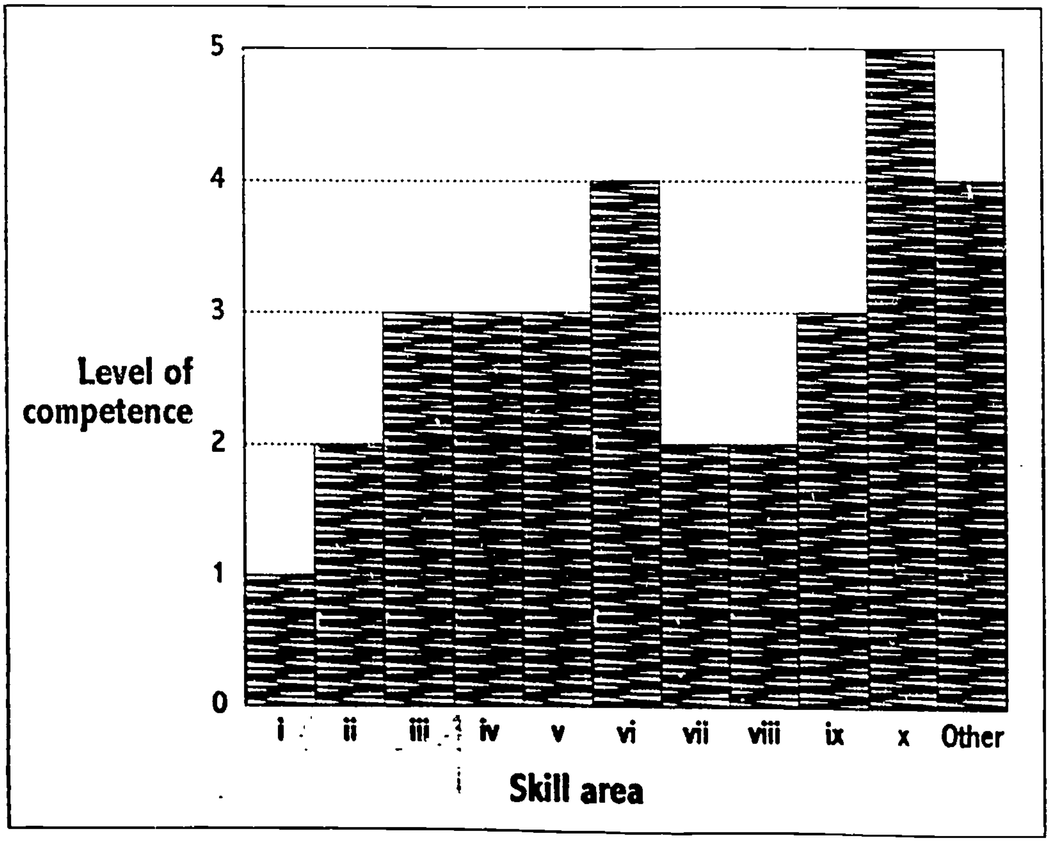
(x) Skill area . . . .



Other skill area . . . .



3. When you have completed the above activity you might like to convert the results into a profile of competence as shown in the example below.



4. For those of you working in a group, you might share results and draw up a profile of group competence. This can help to identify people who have a high level of competency in a particular skill area and so can be called up to contribute to training activities. It also provides a very useful way of identifying the balance of skills in a team.

5. When you have drawn up your profile, identify those skill areas which you feel require further training activity. Any area with a score of less than 3 should be included in your list. Prepare a priority list showing the source and method of further training.

Priority list for further training	Source and method of further training

For a final activity in this training package you will now consider an example of a programme which was designed to be responsive to the needs of young people with severe physical disabilities. This programme was developed during a residential workshop organised by the author in collaboration with the Spastics Society. The inter-agency group responsible for the development of the programme consisted of:

- further education lecturers from maintained and voluntary colleges;
- teachers from maintained and voluntary schools;
- physiotherapists;
- social workers;
- care staff;
- day centre staff;
- careers officers;
- medical staff.

Each of the groups attending the workshop had, over a period of two days, undertaken a series of activities similar to the ones contained in this training package. As a final activity, they were asked to identify a group of young people, describe their current situation and plan a programme designed to facilitate their transition to adulthood.

Read through the programme now and at the end of this activity answer the questions which appear on page 89.

The programme

Introduction

After a school-leavers' case conference four young people decided that they wanted to live in the community.

The students

Four young people aged 17+:

- with severe physical disabilities;
- of 'below average' intelligence;
- with communication difficulties (good comprehension but poor expressive ability);
- using electric wheelchairs;
- in a residential establishment (maintained by the Education Department).

Their ambition was to move into a purpose-built group home in the community, with Social Services support and help from other relevant agencies.

Aims of the programme

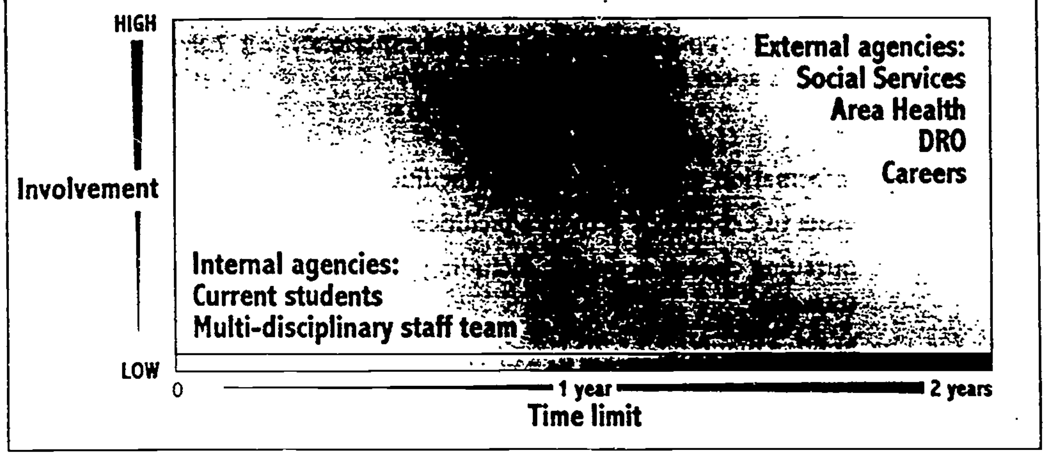
For the young people to approach the future with realism and to develop skills in order to live a life which is appropriate for young adults.

Objectives of the programme

1. To involve the young people at every stage in the design, implementation and delivery of the programme.
2. To carry out training in the following identified areas:
   - language and communication;
   - daily living and life skills;
   - mobility;
   - inter-personal relationships;
   - leisure;
   - employment.
3. To carry out training in these areas for a period limited to two years after which the young people would move into the group home.
4. To reduce the amount of training involvement as the programme develops (see Figure 7).

FIGURE 7

Training involvement



Specific training activities

Language and communications:

- a comprehensive language programme appropriate to daily living situations;
- access to micro-technology.

Daily living and life skills:

- personal care and hygiene;
- physical management;
- household tasks;
- kitchen assessment;
- medication management;
- financial awareness and money management;
- shopping;
- health and safety in and out of the home;
- decision-making and assertiveness training;
- awareness of law and order and legal rights;
- providing information on local community services and facilities.

Mobility:

- wheelchair skills;
- wheelchair availability and maintenance;
- providing information concerning environmental controls and opportunities to experience them;
- providing information on transport, including own transport, and providing the opportunity to plan and experience this.

Inter-personal relationships:

- social skills;
- sexual relationships;
- providing information on counselling and sources of help;
- providing opportunities for practical experience, e.g. role-play and trial periods spent in the group home.

Leisure:

- information on activities/leisure facilities/clubs available in the area;
- visits to experience activities/facilities;
- pursuing chosen activities, including planning, costing and arranging transport;
- holiday planning.

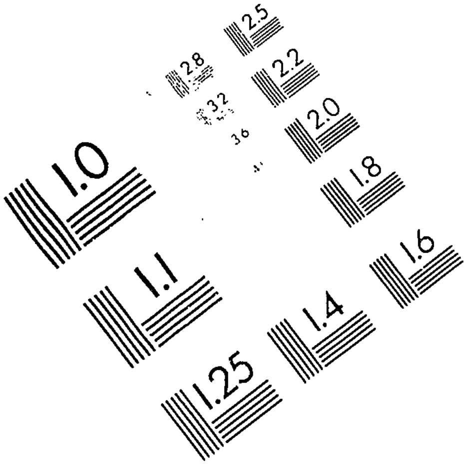
Employment:

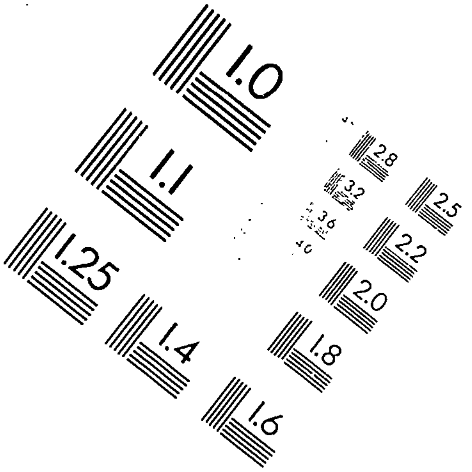
- undertaking assessment for work;
- visiting and experiencing different work situations;
- providing information on support in employment;
- where to find help in getting employment;
- the implications and benefits of earning a wage.

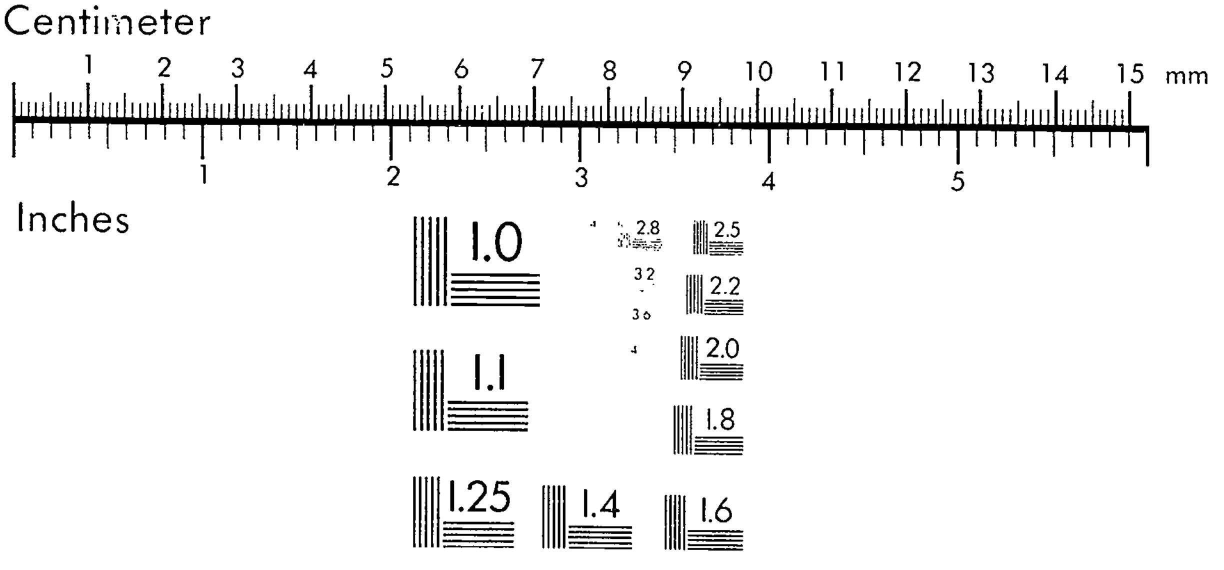
AIIM

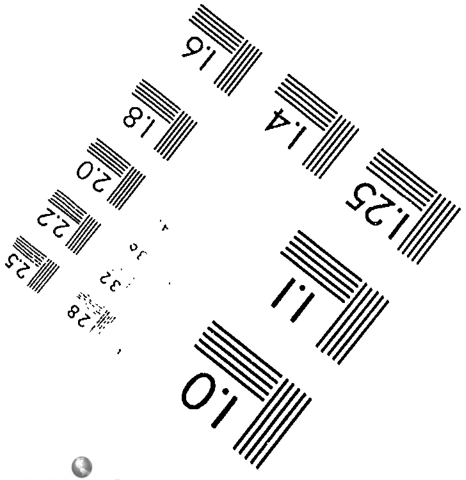
Association for Information and Image Management

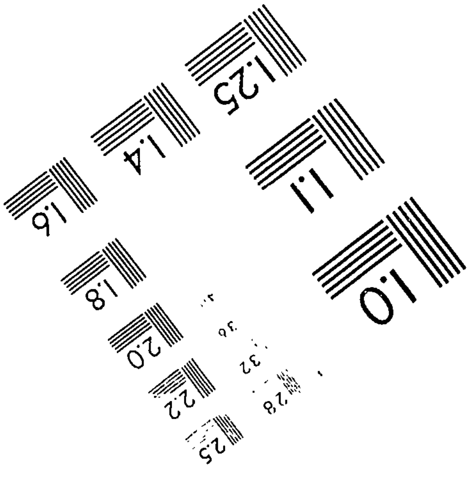
1100 Wayne Avenue, Suite 1100
Silver Spring, Maryland 20910
301/587-8202











MANUFACTURED TO AIIM STANDARDS
BY APPLIED IMAGE, INC.

Having read through the programme, answer the following questions noting your reactions. If you are working in a group, share your views with the other group members.

1. How relevant is the programme in meeting the student needs described?

2. Is the programme capable of meeting all the students' needs? If not, which needs cannot be met and why?

3. Can you identify the support you will need from within your own institution in order to implement the programme effectively?

4. Can you identify the external agency support you will need in order to implement the programme effectively?

5. What skills are needed to develop, implement and evaluate the programme?

6. What implications do such programmes have for staff development, for 'specialist' teams, and other college staff?

7. What implications do such programmes have for training between professionals from different services?

A coda

Since the publication of *Transition to Adulthood* in 1986, work in related fields has continued. A recent OECD/CERI project, the *Disabled Action Programme*, looked at the role of inter-agency collaboration in the development of young people with disabilities as they move into adult life.[1]

In 1988, following an invitation from the DES, FEU became involved in a new CERI action programme *Supporting Active Life for Young People with Disabilities*. The outcomes of this work have been published by FEU in the *Working Together?* series[2].

To end this training package there follows a reminder of the issues identified by *Working Together?* As you read the following, drawn from the various bulletins and reports in the *Working Together?* series, please consider how these relate to the institutions or services for which you work. What implications do they have for your own professional practice?

- Services for young people with different disabilities do not share information, strategies or resources and so provision is duplicated and expertise lost. People with more than one disability may also find that this lack of co-ordination results in a poor service.
- Transition is not understood as a legitimate process and so schools, further education, higher education, employment, etc. operate independently, as though young people come from nowhere and disappear at the end of their time in that phase. Few links backwards and forwards are made, and record-keeping practices reflect this.
- Institutions or services within a phase do not often co-operate officially and so curriculum development or other work is carried out in FE colleges which either duplicates work being done in neighbouring colleges or could be carried out much more effectively as a co-operative effort. Much laborious 'reinventing the wheel' takes place, as does under-use of valuable resources.
- Developments are all too often separate so that strands of work which could combine, such as the development of aids and adaptations which enable individuals with a disability to gain access to microtechnology and the development of teaching and learning programmes, do not come together and maximise their potential.
- Information is fragmented to such an extent that this is a positive barrier to young disabled people being able to make decisions in their own lives. It is only on the basis of having a range of high quality, up-to-date information available and accessible that young people can be instrumental in the planning of their progress through the transition to adult life. For example, even though there are many ways in which

99

preparation for, and entry into employment can be achieved, too many young people with disabilities follow the one track into training or employment that is made known to them by professionals, without being aware that other opportunities exist.

- Professionals themselves rarely have access to comprehensive information.
- Parents, and their legitimate role and involvement in the lives of their children, are often disregarded or marginalised. In an attempt to precipitate young people from childhood into adulthood, it is often forgotten that it is only at the end of the transitional process that young people undergo the major separation from their parents. During the adolescent period, the separation process is still going on and parents, as well as young people with disabilities, need to be supported if the outcome is to be a genuine transition. Too often, young people with disabilities are catapulted into premature adulthood by anxious professionals.
- Support for young people with disabilities ends abruptly with the gaining of initial employment, and it is widely perceived that a substantial number of young people fail to sustain work because appropriate support has not been continued beyond the getting of a job, either for the young person or the employer.

References

[1] ***Disabled Youth: The Right to Adult Status*** OECD/CERI, 1988

[2] ***Working Together? – aspects of transition for young people with disabilities and their families*** A series of studies carried out for the UK contribution to the OECD/CERI Disabled Action Programme, FEU, 1989

Other useful FEU publications include:

Developing self-advocacy skills with people with disabilities and learning difficulties (RP449), 1990

Learning Support – a staff development resource pack (RP454), 1989

New Directions – a curriculum framework for students with severe learning difficulties (RP221), 1988

Working Together? – aspects of transition for young people with disabilities and their families (RP510)

This is a series of publications which can be purchased individually or as a package. The series includes:

Enabled to work – support into employment for young people with disabilities, 1989

New technology, disability and special education needs, 1989

Self-advocacy and parents: the impact of self-advocacy on the parents of young people with disabilities, 1989

FURTHER EDUCATION UNIT

Objectives

The objectives for which the Further Education Unit (FEU) is established are to promote, encourage and develop the efficient provision of further education in the United Kingdom and for that purpose:

a) to review and evaluate the range of existing further education curricula and programmes and to identify overlap, duplication, deficiencies and inconsistencies therein;

b) to determine priorities for action to improve the provision of further education and to make recommendations as to how such improvement can be effected;

c) to carry out studies in further education and to support investigations of and experimentation in, and the development of, further education curricula and to contribute to and to assist in the evaluation of initiatives in further education;

d) to disseminate and publish information, and to assist in the dissemination and publication of information, about recommendations for and experiments and developments in further education.

Address

Citadel Place, Tinworth Street, London SE11 5EH
Telephone: 071 962 1280
Facsimile: 071 962 1266