

After School - What Next?

**Developing multi-agency
transition policy and practice**

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Summary

- The lack of effective and co-ordinated support for people with disabilities and their families during transition from childhood to adulthood has been noted by researchers and other commentators. This had led to the recent interdepartmental government guidance *Making Connections: A guide for agencies helping young people with disabilities make the transition from school to adulthood* (1997).
- Transition can be seen as a period in time, a set of processes, and as experiences for young people and families – all are important in determining what support is needed.
- In identifying goals for transition activity it is vital that the complexity of needs and circumstances are properly taken into account.
- Agencies and professionals need to look beyond their own role and specialist boundaries.

The needs of young people and carers

- Flynn and Hirst's (1992) research showed that young people with learning disabilities who are going through the transition to adulthood need information, involvement in decisions, support in making choices and, as they move towards adulthood, a range of services and supports. Research and experience shows that the aspirations of young people with disabilities tend to be essentially the same as those of people without disabilities.
- Parents and carers also need focused support during the transition period. The shift from reliance upon support from school towards what people perceive as an uncertain future in adult services is often very difficult for families to manage.

The need for joint policy and practice

- The range of agencies and professionals with some part to play during the transition period necessitates joint working. This is made difficult, and even more essential, by the range of requirements, constraints and circumstances faced by local agencies.
- In order to achieve key objectives in transition the involved agencies need to give collective attention to: co-ordination of support, assessment and planning during transition; the allocation of sufficient and appropriate resources for assessment and individual planning (this should be creative, person centred and outward looking); the provision of comprehensive, timely and user friendly information for young people and their families; coherence and clarity in eligibility and resource allocation.

Developing joint policy and practice

- Local agencies should provide support for joint working at a strategic level - for example including transition in Children's Service Plans and Community Care Plans and providing a context which enables joint work. Senior policy makers can also support specific initiatives to facilitate joint practice.
- Key components of joint policy would appear to include: agreement in respect of definitions of transition; a shared understanding of the central aims and functions of a transition process; agreement regarding the key stages and phases of activity; specification of roles; detailed protocols in some key areas.
- Joint policy is likely to be limited in its effectiveness and fragile unless it is accompanied by support mechanisms. These might include: a multi-agency steering

group; structured activity within the involved agencies to deliver on their parts of the policy; arrangements for confidence building and conflict management.

- Though this guidance focuses mostly upon ways to provide better support in transition, joint attention is clearly needed to identify and address key service gaps and incoherence in provision.
- Though joint policy and practice is vital to achieving effective support for people in transition, those involved must keep focused on the actual experience of young people and their families. Responsiveness and relationships are at the heart of good transition work.

Introduction

Recent years have seen an increasing awareness of the importance of the period of transition from childhood to adulthood for young people with disabilities. Work has been undertaken by the OECD/CERI (1986) Council for Disabled Children (1993), Further Education Unit (1994), Social Services Inspectorate (1994, 1996) and others. This has highlighted the importance of co-ordinated, coherent support during the last years of school and the early stages of services and opportunities for young adults. Other work (NDT/SPRU 1992) has focused upon the aspirations and needs of young people as they leave school and become adults.

As well as focusing attention upon the importance of transition, practitioners and researchers have pointed to the frequent lack of effective support for young people and their families during this period. Fragmentation of policy, of agency and professional roles and underdevelopment of suitable practice are seen to underlie problems in achieving appropriate support.

This guide

This guide will focus upon the development of effective multi-agency and multi-professional transition policy and practice. It is written primarily for those agencies and workers struggling to turn their commitment to improvement into practical transition activity.

We believe this focus will help agencies to deal with the complexities and difficulties posing obstacles to coherent and effective support for young people and their families.

Policy and practice

These guidelines are intended to complement the work of the Council for Disabled Children, Values Into Action, National Development Team and others (see appendix 3). These projects offer useful information and support

for families and young people and more of the content of good practice.

This publication concentrates a great deal upon systems and process. We make no apology for this as it is our experience that in a context of fragmented responsibilities, such a focus is necessary. From experience, however, we would offer an introductory word of caution. The construction of jointly agreed policy and process is no guarantee of achieving the right outcomes in transition. There are dangers that an over focus upon agreements and systems can deflect attention from the need to keep firmly focused upon the actual experiences of young people and their families and to see transition practice as dynamic and developing.

It is the experience of many involved in developing transition practice that the 'soft' elements are crucial. The advice and suggestions in this guide relating to relationship and confidence building, sharing of information, and collective reflection upon practice are every bit as important as the policies, procedures and protocols.

The need for evaluation

As the development of transition policy and process is at an early stage in this country so too is evaluation of agency effort and outcomes. The advice and tools set out below emerge from informal review of current activity, including the author's own recent experiences leading transition development in one area. In order to ensure that we are really making progress towards better transition we need to undertake structured evaluation of process and outcomes. It is crucial that such evaluations focus strongly upon the actual experiences of young people and their families.

What is transition?

In a recent paper: *Rites of Passage; Transition to Adult Life for Young Disabled People* (1996), Philippa Russell, the Director of the Council for Disabled Children quotes John Fish and Jean McGinty (1992).

“It is a phase or period of time between the teens and the twenties which is broken up educationally and administratively. During the transition phase there are changes of responsibility from child to adult services, from school to further and higher education, and from childhood dependency to adult responsibility.

It is a process by which the individual grows through adolescence to adulthood and achieves a balanced state of dependence and independence which a particular community expects of its adult members”.

The OECD study that Fish and McGinty drew upon identified three critical stages for transition to adult life for young people with special needs:

- the final years at school
- further education and vocational training or preparation for work and/or independent living
- the early years of employment and independent living.

(OECD/CERI 1986)

It is also important to recognise that transitions are experienced by people. That they have emotional and psychological effects. This is not simply a technical process via which, if agencies develop the right systems, an efficient transfer from childhood to adulthood takes place. Agencies and their staff need to consider what it feels like to go through this kind of transition and respond accordingly.

Young people and their families may experience the transition from childhood to adulthood in different ways, depending upon many factors. This period may be a very positive experience as young people make a set of steps towards adulthood, taking on the roles, status and opportunities associated with this. For families, this can be a time when a young person’s development towards adult status is celebrated, looked forward to and planned for.

Unfortunately, however, for very many people this period can be one of fear, uncertainty, disappointment, dislocation and even trauma.

In developing approaches to support for people in transition it is particularly important that these various ways of perceiving transitions are considered.

Goals of transition

Academics, professionals and other commentators have attempted to conceptualise some goals for transition between childhood and adulthood:

The 1986 study from the OECD and the Centre for Educational Research and Innovation suggests four groups of goals for young people in transition to adulthood, around:

- employment, useful work and valued activity
- personal autonomy, independent living and adult status
- social interaction, community participation, leisure and recreation
- adult roles and relationships including marriage.

Clearly, for many young people with disabilities focused support, which goes beyond the vocational guidance generally available to older students without disabilities, will be needed to help them in these transitions.

Service related changes in transition

In thinking about the transition phase we tend to think about the later school years, perhaps from 14 (especially since the 1993 Education Act and the associated Code of Practice) through to a period sometime after a person has moved on to adult activities and opportunities. It is becoming clear, however, that the later

school years and leaving school are only part of the period of transition for young adults.

During this period, when a young person is moving towards adulthood, there will be changes in the services and supports they may use:

- In the later school years there will be changes in curriculum including, for example, work experience, careers work, more attention to personal and social development in adult environments.
- Changes of worker. For example, social worker, community nurse, speech or physiotherapist, from paediatric to adult medical services etc.
- Changes in family finances - including introduction of some benefits and of charges for some services.
- Changes in the places where some services are provided and the personnel providing them. For example from school to college,

or day service, or employer. From children's to adult short term support or leisure opportunities.

- Changes in the sections or departments responsible for the main services received. For example from education to social services. From children's sections of social service departments to adult sections.
- Changes in the general nature of services. For example from a mainly educational focus to broader aims within adult services.
- New ways of doing things within services. For example changes to arrangements for accessing services, the times they are available, what happens within them etc.
- Changes in legal status - as young people acquire adult rights.

It doesn't take much imagination to consider how bewildering such a set of changes can feel for a young person and their family.

The needs of young people and carers

Young people's needs

In their research looking at the lifestyles, aspirations and circumstances of teenagers and young adults with learning disabilities, Margaret Flynn and Michael Hirst (1992), conclude that:

“Young people with learning disabilities, whose lives and situations are changing, need information, involvement in decisions regarding their lives, reassurance that the options available to them as young adults will be at least as good as those they are leaving behind, or help to cope when their aspirations become ever receding possibilities”.

and

“In an ideal scenario, young people will be helping to identify their own needs and make choices, social workers will be helping to identify sources of support, and packages of services will provide a seamless web of provision during the transition to adulthood”.

This study gives useful insights into the kinds of lives young people with learning disabilities wish to lead, and some of the powerful obstacles in their way:

“The better we know people with learning disabilities, the more we discover that their aspirations, values, wants and pleasures fall within the range of desires common to most of us”.

“We uncovered a disquieting paucity of evidence of a long term commitment to person to person support centred on young people, coupled with shortfalls in efforts to attend to people's aspirations for their own homes, close relationships, and employment”.

Tidsall (1996), after researching transition planning suggests that:

“Over and over again, young disabled people have listed what they want. They want accessible housing, employment, transportation, services and communities. They want to participate, to be included, to be independent, and to have control of their own lives. Young disabled people do not always state the exact same list but why should they be expected to? Even when disabled people construct the lists (which I suggest they should), the debate could continue endlessly about the proper list of transitional goals. How many of us, labelled disabled or not, fulfil any list of transitional goals provided within the literature?”

Why should young disabled people be expected to follow a set list many people never meet?”

Tony Ryan has recently undertaken a Department of Health funded exploration of issues relevant to young people and their families as they move from school to adult life. He notes the complexity involved:

“Any device or process which has the objective of successfully supporting people who have learning difficulties through this transitional phase in their lives, must first address exactly what transition means to it's beneficiaries. Transition in the lives of people who have learning difficulties can not be defined singularly or as a set of distinct service goals. Life is not like that and the lives of the people who participated in the project were not like that. Transition, as characterised by expectations and aspirations, was viewed by some of the respondents as being about a whole series of things in their lives, some of these things were seen as being interrelated. So transition can be many different things relating to housing, education, work as well as sexuality, independence, status and self esteem” (Ryan 1998).

Carer needs

In the 1993 CDC/King's Fund study, conducted across several local authority areas, a Parental Enquiry identified a number of issues and concerns for parents:

- Parents were very reliant on schools for information support and advice, including from other parents.
- Some were concerned about where they could turn to for similar support after school.
- Parents were aware of the lack of coherence of transition policy and practice.
- Parents were very concerned about what they saw as service reductions and decline.
- Services were not seen to be sensitive to the population and ethnic make up of the areas.
- Parents were given little opportunity to make choices in provision or chances for their children to try options.

- Transport was seen as a major barrier to independent activity.
- Few had regular contact with social workers.
- Parents knew little about transition processes.
- Most had low expectations about what would be available after school or college.
- The importance of post school assessment was not well recognised - some felt it was of no use because there were no services to result from this.
- Single parents in particular found it difficult to attend meetings which they considered were arranged for the professionals convenience.
- Many had concerns about how they would cope when their children left school.

(Adapted from CDC/Kings Fund 1993).

Clearly these findings present real challenges to those attempting to develop effective support for families in transition.

Research and experience suggests that there is a lot of overlap between the needs of families/carers and those of young people, but also some significant differences. The 1992 Flynn and Hirst study pointed up some of the differences:

“We recognise that most parents require assistance with the work of caring for people with learning disabilities in the family home. Indeed, home care and support services, including day time opportunities, may be crucial to the well being of carers and to the continuance of care giving. Yet young people with learning disabilities have needs of their own - not least drawing away from reliance and dependence on their families. A mark of their genuine acceptance in our society is found in real relationships they enjoy with ordinary people. The dilemma for carers and service providers generally is that their presence may inhibit the development of such relationships. Given that people with learning disabilities are vulnerable to exclusion, isolation and abuse, focused efforts have to be made to introduce them to networks in local communities”.

Ryan (1998) notes that, in his research:

“Parents and carers also had different expectations about the transitional years. Some parents had very limited expectations.

Expectations which may have been shaped by traditional service outcomes, traditional attitudes about people with learning difficulties and the prevalence of carers needs over the needs of service users. Other parents, and carers, however, identified training, further education and work as defining their expectations. Rarely did parents and carers concur with the views of young people themselves about issues of independent living and only one addressed issues of sexuality.”

The dilemmas around differing expectations and goals are real and have to be carefully addressed. Russell (CDC 1993) notes the crucial partnerships needed in transition and concludes:

“The most important partnership is the triangular one between young people, their parents and professionals. During transition this partnership should give greater weight to the young person’s views and work to increase his or her autonomy”.

Things that can go right

For some people and their families, the experience of transition can be positive. It would seem that the chances of things going well may be increased when:

- Transition processes place the young person and their family at the centre of planning for the future, taking proper account of needs and aspirations as they define them.
- The process and stages of transition are explained to people at the right time and in the right way for that person/family.
- People have consistent, friendly and available people to answer questions and support decisions and choices.
- Transition activity is co-ordinated between all key agencies and professionals, avoiding confusion, duplication and overlap for young people and their families. The contributions of the different agencies and professionals offer coherent and complementary support for young people coming into adult services.
- Transition related work starts well in advance of school leaving, allowing good preparation and planning with the person, the family and the various agencies and

workers so that a person's needs and choices are fully explored and developed.

- The process and activities of transition allow and support young people to develop skills and interests that they can continue and further develop after school leaving.
- Options to be taken up on school leaving are designed around the informed choices and needs of the person, crucially including support for access to non-specialist and non-service opportunities.
- A range of options and choices are available to the young person on leaving school.
- Post school educational or vocational options allow young people to build careers.

Things that can go wrong

For some families, the experience has not been good. Some of the poor transition experiences described by families and young people may occur when:

- The main service agencies and workers responsible for young people as they move towards adulthood do not work together effectively.
- The service agencies do not properly involve the young person and their family in transition activities and planning.
- Services, agencies and professionals providing opportunities for adults do only superficial, brief and 'last minute' assessments of the needs and wishes of the young person and their family. This leads to fitting people into existing provision which does not adapt itself to meet specific needs, or placing people on waiting lists for such provision.
- Service agencies appear to have low expectations of young people and are not creative in looking for options and opportunities designed around their needs.
- Vital information does not get passed over to young people and their families making it very hard for them to make informed choices.
- People who have been very important to young people and families suddenly seem to disappear.
- Important activities or services are suddenly withdrawn.
- People are suddenly transferred to new activities, services or professionals without adequate preparation.
- New services or provisions are found to be inferior, strange or even unacceptable.
- So many changes happen all at once, and no one seems to be co-ordinating this.
- New ways of doing things, or getting services, can remain strange and unexplained. For example new charges for services, new freedoms for adults .
- Educational and vocational opportunities on leaving school are unavailable or limited to temporary courses not clearly linked to career aspirations.
- Fragmented and uncoordinated post school provision creates problems of reliability affecting both young people and their families, for example around family working arrangements.
- Workers and professionals involved with families are unable to communicate appropriately and/or are unaware of important cultural, religious or other issues which need to be taken into consideration.

The need for joint policy process and practice - system fragmentation

The introduction to the recent Government interdepartmental advice on transition, *Making Connections* (1997), notes that the publication is the result of a meeting between the Prince of Wales and officials from several departments:

“To discuss the difficulties young disabled people were encountering in obtaining appropriate services from agencies during the transition period. These difficulties seemed to be due to a lack of collaboration between the agencies involved”.

The agencies involved might well have something to say about this - not least that resources may also have a part to play! Having made this point, however, it is clear that there is much room for improvement in transition support, and that this can only come from the co-ordinated effort of the various professionals and agencies.

In order to maximise the chances of good transition experiences for young people and their families it is clearly crucial that the key agencies and professionals develop co-ordinated policy and processes and that these are supported by the necessary organisation, resources and management. The Council for Disabled Children (1993) noted that:

“A large number of different agencies and professionals contribute to individual transitions, often in a fragmented and uncoordinated way. There is no certainty that their contributions will be consistent and compatible. It is impossible for a single department or agency to help an individual to achieve all the goals of transition”.

This co-ordination can be difficult to achieve given the varying requirements placed on the participating agencies by law and by local

policy and also given the different resource and other constraints being faced. Agencies and professionals are also likely to find that their operational systems, time scales for action, even language differ.

As has been noted no one agency has been given sole responsibility for supporting young people and their families during transition. Various pieces of legislation place requirements upon a range of agencies and departments, including:

- Chronically Sick and Disabled Persons Act 1970.
- National Health Service Act 1977.
- Education Act 1981.
- Disabled Persons (Services, Consultation and Representation) Act 1986.
- Children Act 1989.
- Local Government and Housing Act 1989.
- National Health Service and Community Care Act 1990.
- Further and Higher Education Act 1992.
- Education Act 1993, and the associated Code of Practice on the Identification and Assessment of Special Educational Needs.

NB: A comprehensive list of relevant legislation and policy appears in *Making Connections* (1997).

What do young people and their families need from joint working?

A previous section outlined some of the needs of young people and their families during transition, and some of the things that might go right or wrong for them. At this stage it is useful to consider, in more detail, what joint transition policy and practice should offer and some ways in which this might be achieved. How can we reach a situation where things mostly go right for people?

Aims and objectives of joint working

We would argue that there should be a number of key aims for joint transition practice:

- Dislocation and trauma for young people and their families should be minimised, consistency and continuity maximised, over the immediate school leaving period and for some time after.
- Young people and their families should be included as full partners in the process of transition assessment, planning and other activity, and empowered to play this role.
- The involved agencies should operate joint transition processes which lead to the meeting of the maximum possible of identified needs and aspirations through the coherent and effective use of their collective resources.
- Agencies should seek to avoid overreliance on specialist services in meeting needs, where ever possible using their specialist resources to facilitate access to mainstream opportunities and provisions.

In order to achieve these aims, joint attention will need to be given to:

- Co-ordination of support, assessment and planning work.
- Coherence and clarity in eligibility, resource and service allocation methods.

- The allocation of sufficient and appropriate resources to assessment and planning.
- Creative, person centred and outward looking assessment and planning approaches.
- The provision of comprehensive, timely, user friendly information for young people and their families.

Co-ordination of support, assessments and planning

One problem that often occurs during transition is that young people and their families are faced with a number of professionals providing support, undertaking assessments or involved in service changes and transfers. The worst case scenario for families is when these involvements are uncoordinated and fragmented, where information being collected is duplicated and overlapping, and where involved professionals are unclear about each other's involvement and roles. Those on the receiving end often say that they would like a single person to connect to during transition.

Given the number of service transfers taking place, and the organisational and resource factors in operation it is, of course, difficult to make things as coherent as would be desirable for young people and their families.

There are some practical measures that can be used to increase the chances of a coherent assessment.

Co-ordination of assessment can be aided by nominating a lead worker for an individual/family during key stages of transition, ensuring that: assessment planning and support work is co-ordinated through this person; this key worker keeps the young person and family informed and acts as a point of contact and information.

Given that transition extends across the usual boundaries between child and adult services it

may well be that there needs to be a transfer of responsibility at some stages. The crucial thing is that such transfers are kept to a minimum and are managed according to agreed systems, ensuring the maximum continuity.

Agencies in some districts are nominating workers or small teams to focus on transition.

Philippa Russell (1998), in reviewing developing practices around transition notes:

“One growing trend I have noticed, which I think is positive, is the appointment of (or re-designation of) care managers with particular responsibility for managing the planning and transition arrangements between children and adults’ services. These care managers liaise with schools etc. They ensure that relevant information is available and that they are well equipped to take a significant role in the transition planning arrangements”.

The National Development Team (1997), exploring concerns and practice around health issues in transition, noted some attempts to achieve greater coherence.

“A School Leavers Assessment Team run from a social services department has done a lot of good practice-based work with individuals, involving social services and careers.

Some localities had a Transition Officer, or a Co-ordinator of Transition Planning, in post.

Linkworkers in the project suggested that:

- A dedicated post is needed for transition planning, but to work with others, not solo
- The Transition Team needs a common purpose, an agreed focus and commitment
- Transition groups should include people with learning disabilities and carers
- The Team should include a manager responsible for ensuring, for all assessments, referral to the right person.”

Advantages of these types of arrangement are suggested to include:

- Consistency of contacts for young people, families, and other professionals.
- Increased likelihood of consistency and continuity in assessment and planning.
- The development of key skills and knowledge about service systems and provision.

There are many variations on this theme. In one district, for example, care managers take on

this key role, commissioning assessments from other professionals and agencies as appropriate. In another district there are separate social services and health nominated transition workers. These workers work closely together to avoid confusion, undertaking separate but complementary roles.

Example – Integrated Assessment Project

This project has been developed by the Oxfordshire Joint Commissioning Reference Group for Children with Special Needs.

“At 14+ the Integrated Assessment is designed to incorporate the requirements of the Education Act 1993 for a 14+ Review and Transition Plan, with the need for Social Services to make an assessment of a young person under the Disabled Person’s Act 1996, sections 5 and 6, and a desire to inform adult services (Health and Social Services) of the Future Needs of a young person with disabilities who will be requiring the support of medical or social services when they reach 18 years, so that plans can be made”.

Contact: Marian Roiser, Joint Commissioning Reference Group for Children with Special Needs. Hernes House, Hernes Crescent, Oxford OX2 7PS. Tel. 01865 316699.

In some districts, organisational and management arrangements may mean that professionals from the same agency are not jointly managed. There are also relatively autonomous professionals such as GPs and consultants. In such situations it can be helpful for nominated workers to gather together assessments for action planning. In Stockport, for example, a specialist community nurse plays this role in respect of health provision.

Eligibility and resource allocation systems

Many people involved in transition have expressed frustrations about fragmentation, incoherence, uncertainty and what is sometimes seen as the last minute nature of resource and service allocation.

Many young people and their families are left confused about what services they are eligible for from the various agencies and what other opportunities might be available to them.

Unfortunately is also not uncommon for workers from the involved agencies to be uncertain about the other agencies' policies. In one district, for example, copies of an information booklet for families outlining adult services and opportunities were quickly snapped up by representatives of childrens' services for their own information!

There are often grey and overlapping areas in terms of eligibility and provision. Part of any transition process should be to clarify these issues for those involved and to provide clear information to young people and families.

In so far as the timing of resource allocation is concerned this can in part be a consequence of the positive development of a wider range of service options in some areas in recent years. With further education courses, for example, the college timetable may well not fit neatly with the urge to agree service options and opportunities early in transition.

Problems may also, however, occur around agencies and parts of agencies failing to co-ordinate timescales for assessment and service allocation.

Another problem that some workers involved in transition have noted is late decisions on resource allocation linked to authority budget cycles. With budgets not decided until April, some have reported that it can be the summer before service proposals receive funding decisions. Often people have left school not knowing what they are going on to. This can lead to a very worrying and frustrating wait and may lead to last minute scrambling for alternative options. It is also very difficult, in these circumstances, to properly introduce people into the new services and opportunities they will be moving on to.

Unfortunately there also seems to be a danger that this last minute process can lead to conservative decision making to avoid anxiety. It seems common that more innovative, creative options are more likely to be subject to these last minute decisions. This can lead to people opting for a 'safe' option at an earlier stage.

It would seem that to avoid the problems of anxiety and the tendency towards conservative decision making, transition systems should allow for decisions on resource allocations to

be made well before the last minute. At the same time decisions should not be made early just as a matter of convenience or to allay worry. There needs to be sufficient flexibility to allow people to change their minds.

Agencies in some districts are attempting to reduce the types of problems outlined in a range of ways, for example:

- In some districts agencies are co-ordinating the production of care plans flowing from joint or complementary assessments. This can reduce the fragmentation and confusion for young people and their families and help facilitate more coherence in the timing of offers of service and resources, especially if linked to a co-ordinated resource allocation system.
- Agencies in some areas are attempting to ensure that offers of major components of service are made well in advance of school leaving. In one county, for example, the social services department have set themselves the standard of offering services to young people with disabilities at least 6 months before a person's 18th birthday.

Resources for support, assessment and planning

One of the difficulties facing agencies seeking to offer improved transition support is that improvement will usually require some resources. There are many arguments for investing resources in transition, including:

- There is enough experience now to convince us that failure to target effort in the transition phase may well condemn young people and families to a difficult, for some a traumatic, time in their lives.
- It could be argued that education and children's services have not properly completed their task if they don't invest in helping young people to build upon their education and development as they move into adulthood.
- If adult service agencies fail to invest in this period they may well increase the possibility of difficult relationships with young people

and their families for many years within adult services.

- Effort to support access to non-specialist options may avoid young people becoming unnecessarily dependent and free up resources for others.

Perhaps the most important requirement is to allocate workers with appropriate skills to offer consistent involvement, at a reasonably intensive level over a substantial period.

Workers involved in transition assessment and planning need to get to know the young person and their carers well, over a reasonable period of time so that their real needs and aspirations can be properly identified. Young people and their families, in a bewildering period of change, are quite likely to be cautious and wary in the early stages. Brief assessments, by someone who does not know the person or their family, are unlikely to really allow them to offer considered views in a relaxed environment.

One issue thrown up for service agencies is the danger that age eligibility arrangements for assessment or services may make it difficult to offer what young people and their families need when they need it. A good example of this is the eligibility for assessment of disabled people under the 1990 NHS and Community Care Act at age 18. For many young people, this will be too late for assessment work to begin if good transition planning and support is to be offered. Social service departments will therefore need to ensure that either there are clear arrangements for their children's services to be undertaking assessments at an earlier stage, or that adult services have resources available to begin earlier assessment. An alternative is to establish workers or teams to span the age range. Bolton Community Healthcare NHS Trust have a Health Transitions Team within the Learning Disability Service which co-ordinates and provides health care across the age boundaries

If getting to know a person is a prerequisite for them to be able to effectively communicate their needs and aspirations, the assessors must spend time with the person, and in a range of settings and situations. This is time consuming work.

In one district, for example, attention to the needs of people in transition has led to the redeployment of some resources to allow the adult care management team to offer intensive and consistent assessment and planning with young people, currently over an 18 month period prior to the young person coming into adult services.

In some districts, agencies have managed to allocate some support worker time to assist the professional assessment staff. This can be very valuable in undertaking some of the time consuming work assisting young people and their families, for example in the exploration of options and choices.

Creative, person centred planning

Agencies should develop assessment and planning methods that offer young people and their families a real opportunity to influence the process, and which are more likely to produce creative outcomes. After exploring transition planning with young people with learning disabilities Ryan (1998) notes:

“It is recognised that the reforms concerning transitional planning, which formed part of the Education Act 1993, have been useful in promoting systematic planning for young people who have learning difficulties. However, there do exist some question marks over the processes themselves. Traditional ways of planning with people who have learning difficulties have two failings.

First, the ways in which they work may exclude many people who have complex needs. Second, they fail to get hold of the complex and unique ways in which people with learning difficulties view transition and aspire to adult life. Local authorities need to devise plans and systems for planning which place people themselves and their families at the centre of the planning process, as well as developing new, less formal ways of enabling people to define their aspirations.

The focus of the transition appears to be on curriculum based activities and has an emphasis on social development and skills. Whilst it is recognised that this emphasis plays an important role in preparing young people for the adult world, particularly in terms of decision making and preparation for work, it should also be noted that transition, for the people themselves, might

be about accessing services and achieving outcomes.

Without access to housing, support, and the very things that can come from such independence such as status, dignity, relationships and self esteem, will people ever make the transition to what they perceive as adult life?"

To be really successful, transition planning needs to go beyond the traditional methods employed in many assessment processes. In some districts, agencies and professionals are experimenting with the use of person centred planning approaches such as Essential Lifestyle Planning, Personal Futures Planning, PATH, and others, (Sanderson et al 1997). The challenge is to adapt the assessment and resource allocation systems of the agencies to these approaches.

It is also important to remember that introduction of new techniques and approaches to planning must be accompanied by training and support for staff.

Communication is likely to be a difficulty with many young people. This may be because they do not communicate with words. Transition planning and assessment needs to take this into account, and ensure that various resources are called into play to help. This might involve using others who know the person well to help, it might also involve using those with specific skills in this area such as speech therapists. In some places 'Total Communication' approaches which apply a wide range of methods are coming into use (see Appendix 3).

Communication may also be an issue where a person and their family do not have English as their first language. In many areas the population of young people with learning disabilities who come from ethnic minority communities is increasing. Assessors need to call forth assistance with these families and are likely to have to allocate more time to gather information. In addition to communication, cultural and religious issues are likely to assume a greater importance with some families.

Creative planning - example

In one district, care managers have been allocated substantially more time for planning with people than previously. This has

supported efforts to make the transition process more of a partnership.

Some care managers have taken the transition files they use and given them to the young person and their family. They have used creative approaches to try to make sure that the process of exploration of possible futures is more owned and understood by the young person. Pictures, video, symbols and objects linked to options that are being tried or looked at have been used.

Also, in this district an external consultant has been employed to work with the care managers in developing the application of Essential Lifestyle Planning approaches.

Speech therapists are being used as consultants by care managers working with a group of young people who do not use words to communicate. The idea is to develop care managers' skills and identify approaches to effective communication with the individuals being planned with.

Workers able to communicate effectively with people who do not have English as a first language are part of the transition team.

Contact: Martin Routledge, tel: 0161 911 3848.

As noted above, existing systems for planning and review have been found to present problems for young people in influencing the assessment and service planning process. Reliance upon traditionally organised school review meetings, interview type assessment sessions and other similar approaches, are unlikely to allow young people with learning disabilities a proper opportunity to influence their own transition.

Some possible approaches to empower young people within these processes include:

- good preparation before meetings and follow ups from meetings
- adapting the methods and format of planning meetings to facilitate better involvement
- shifting from the over use of formal planning meetings to methods more likely to be able to involve young people

- ensuring the curriculum in the final years assists the development of decision making skills specifically around planning for the future
- the use of advocates
- using external groups to facilitate self advocacy.

Empowering young people - example 1

Transition Into Work

“Was developed between the Vocational Support Team based at the Knoll Resource Centre and the Loyne School in Lancaster as a three year plan, it’s principal aim being to help students to:

- make the step of leaving school easier for the individual and his/her family
- identify at an early stage individual needs, wishes and expectations
- offer informed choice, by enabling individuals to sample a variety of options such as work, college
- to make plans with the individual and his/her carers for the future
- to enable individuals to become more confident.

The Knoll works together with the Loyne School to ensure that those students who have an interest in a vocational future and are due to leave school in the next two years will be given the chance to increase their understanding of the differences between school, college/training and work situations.

The program’s four modules cover the theoretical concepts and will attempt to enable individuals to identify what work is, and examine different cultures. We compare the expectations of school and work, investigate options available on leaving school, involving careers advisors and other professionals.”

Contact: The Knoll Resource Centre, tel: 01524 846058.

Empowering young people - example 2

Lambeth school leavers project

“This project was set up to promote self-advocacy amongst young people with learning difficulties in their final years at special school and enable them to enter adult life and make informed decisions and choices. It also sought to promote the concept of self advocacy and empowerment of people with learning

difficulties amongst parents, carers and school personnel and to enable young people with learning difficulties to play a meaningful part in their social services assessment and ensure that their wishes and preferences were central to the assessment.

Many young people with learning difficulties have little available to them when they leave school, while others go to college but find that once their course is over they have no other opportunities for development. The project set out to inform young people, age 16-21, of the options available and to support them in making choices. Work was carried out with young people in their last two years at school, as well as those who were preparing to leave college. People with learning difficulties were fully involved in the planning and work of the project. Project information was produced in ways that were accessible to people with severe learning difficulties, involving extensive use of photographs, pictures, videos and drama activities. Pictures used were representative of the people in terms of ethnic origin, and care was taken to ensure that activities were culturally appropriate.”

Contact: Mark Gilbert, Director, Lambeth Accord, 336 Brixton Road, London SW9 7AA, tel: 0171 274 2299.

The historical experience of people with learning disabilities leaving school, especially people with severe disabilities, is to transfer from a specialist and segregated children’s system into a similar one for adults. The period of transition offers a real opportunity both to young people and to service agencies to break out of the historical dependence on meeting people’s needs and aspirations almost exclusively within specialist services.

This is a time when opportunities to open up new possibilities exist. If service agencies can respond creatively to young people’s needs, both in their planning systems and through deployment of their resources, inclusion within real community life and opportunities can be achieved. For this reason good transition policy and support should include, as a central component, ways of looking beyond specialist service options.

Previously the typical agency response to more need or demand has been, where possible, to develop an additional specialist service - a day centre or short term support unit, for example. In recent years some exceptions to this rule have started to develop. Supported employment

is probably the foremost example of using resources in ways which do not try to encompass people within specialist options but seek to enable access to opportunities alongside non-disabled people. Initiatives in supported living where the provision of accommodation and support are separated are another positive development of this type.

Clearly, there is a long way to go towards a situation where resources are primarily targeted at supporting ordinary lives. In the Flynn and Hurst study (1992) quoted above, the authors point out that:

“Ordinary lives often require extraordinary supports and far reaching reforms. At the time of the study, these did not touch the lives and circumstances of severely disabled young people with multiple service needs. Beyond their immediate family circle, extraordinary supports were largely absent from their lives. They spent more of their time indoors than getting out and about and many were reliant on parents and others for varying degrees of assistance; their lives were often quiet, fairly solitary, and suggestive of limited personal relationships. Although some went to a social or youth club, much of their social contact revolved around their regular weekday placements. We wonder to whom, apart from parents, they can look for guidance, affirmation and inspiration. Their circumstances and the lives of many other young people in the study sample are a reproach and a challenge”.

It could be reasonably argued that developing transition planning processes without first developing new services and resources is likely to lead to frustration and cynicism. On the other hand, better assessment and planning can, if there is accompanying agency commitment to follow through the outcomes of this work, go some way towards shifting this situation.

Example - shifting from dependence upon specialist services

In one district, assessors have been allocated significantly more time for transition planning than previously. This allows them to get to know people better and to consider possibilities and options which time pressures previously made impossible.

In addition, the tools and guidelines that they are using encourage them to discover the existing networks that people have, and to

explore ways of developing these. Having done this they are asked to look at how services and resources from the learning disability service can support this. Finally, if it is necessary, they look at what specialist options might be needed.

Care managers bring service proposals to a panel of resource managers and are encouraged to identify needs and aspirations which the current configuration of specialist services cannot properly meet. The managers then strive to shift the use of existing resources in these directions, or to make bids for additional resources.

A review of the transition outcomes for people in the last year shows fewer people entering traditional learning disability services.

One example of the effects of this process has been the shifting of resources towards assistance for people seeking to develop relationships and leisure activities. A number of initiatives in this area are now taking place within the district.

Those involved in transition work within this district remain rightly cautious and concerned about next stage transitions for people who have gone on to further education or vocational training, but feel that they may be seeing the beginnings of a sustainable shift in opportunities for school leavers. Contact: Martin Routledge, tel: 0161 911 3848.

Philippa Russell (1998), poses the dilemma that shifting from use of ‘traditional’ services such as five day a week day service provision can present real problems for families where reliable alternatives have not been generated. She suggests also that there are public policy issues which may influence transition planning, for example:

“Welfare to Work and the New Deal will help some young disabled people into work, but they may seriously disadvantage some others because they cannot attain the expected targets within the anticipated period of time, or they cannot work full time.

Some disabled people will never be able to work full-time because of their levels of disability. For this group disability benefits will be absolutely critical in supporting them and in hopefully enabling them to work part-time or at least to pursue valued and constructive day

opportunities. There is great concern that the review of the benefit system may overlook the crucial underpinning role of financial assistance with additional daily living costs. Some parents and young disabled people are now saying that they won't even contemplate work in case that failed and they lost their benefits."

These issues and dilemmas clearly need to be seriously considered when agencies are developing opportunities and alternatives to traditional services.

Providing information about services and opportunities

Young people and their families must have sufficient information, provided in the right ways and at the right times, to be able to make informed choices, and to influence the process of assessment and planning.

Some of the key questions for agencies to answer here are:

- What information is needed?
- Who needs it?
- When is it needed?
- How should it be provided?

What information do people need?

Broadly speaking young people and their families need information in order to help them to be full partners in transition, and to influence the outcomes of the process.

They need to know:

- what happens in transition - stages, personnel involved, assessment and planning systems, rights
- what options might be available on school leaving and how to influence and choose between options
- key differences between children's and adult services and experiences.

Example - information needs

In one district, guidelines for care managers stress the importance of provision of

information to young people and their families.

"In order to reduce the difficulties associated with transition, to help people make the right choices, and to ensure good planning, it is crucial to provide young people and their families with relevant information about adult services and opportunities. In part this can be done by direct tasting or exploration of options, in part it involves giving specific information, in part it is about being available to answer questions.

It is important to bear in mind that people's minds are often swirling with new, and often anxiety provoking information during the process of transition. It is therefore important that information is provided in manageable chunks, and in different ways, and that care managers and others make themselves available to respond to enquiries outside of formal meetings.

Some of the information that people will need includes:

- information about the range of service options and possibilities
- information about the process of transition itself and the roles played by different people and workers in this
- information about the key differences between children's and adult services
- information about charges and costs in adult services.

This is not an exclusive list, of course, and not all of this information is necessarily best provided by the care manager. Having said this it is the care manager's responsibility to make sure that people do get this information. It is also important that care managers are not passive in this process, simply responding to enquiries, because people often do not know what they need to ask," (Oldham LDS 1995).

Contact: Martin Routledge, tel: 0161 911 3848.

When is information needed?

It is clear from experience that different people want, and are best able to receive information at different times and stages. Some young people and families want to start thinking about the future after school leaving very early in the school career, others do not wish to do this until quite late.

The implication for those providing information is that they have to be flexible enough to respond to these differences. Having made this point, the development of the 14 plus

transition system makes this a logical point at which information should start to be transferred in a systematic way.

Agencies and professionals have a responsibility to try provide information to young people and families and to assist them during these years even if families might be understandably reluctant to contemplate the changes.

Broadly speaking it would seem useful to build up information provision. This could move between general information about developments and changes in the final school years and the broad range of options in adulthood, towards very comprehensive and detailed information for option selection as school leaving comes near.

How should information be provided?

Consideration should be given to the media for information transfer, appropriate forums, and who is best placed to provide information.

Media - These might include written information (booklets, pamphlets, etc), audio and video tape, person to person. It is important to provide a range of material as people will make use of different types. There are good examples of:

- short leaflets introducing adult services or the transition process
- longer booklets with detail about process and adult options
- audio and video tape material
- newsletters.

Philippa Russell, 1998, suggests the usefulness of transition guides, written by young people, parents, voluntary organisations etc.

Example - Transition video

In Oldham a joint agency transition group have commissioned the production of a video. The video shows both the process of transition and the range of service options available to people as they leave school. The transition group feel that there are several advantages to the use of video:

- Families can look at the material in their own time, replaying any parts that they need repeating. This can be a useful supplement to direct discussion with involved professionals.
- Young people and families are able to get an overview of the range of services and opportunities, helping with breaking down the mystery of the services and facilitating choice.
- The video graphically demonstrates the aims of transition work, bringing some coherence to the work of the various involved professionals, in partnership with families.
- There seems to be some symbolic importance to showing child and adult services on the same film, demonstrating the continuities and the need for progression.
- The video can be used at various stages of the transition process and in different forums.

Contact: Martin Routledge, tel: 0161 911 3848.

There are also examples where young people and parents have worked to produce videos. Russell, 1998, notes:

“Where parents and children work together, the finished product is genuinely user friendly and is sure to convey the intended messages”.

Forums - A wide range of forums might be used and these can often complement each other:

- In transition and other planning meetings. Consideration needs to be given to what information can be practically transferred at these meetings. There is likely to be a need to provide outline information and to build on this in follow up or pre meeting sessions of various kinds. Russell, (1998) notes:

“One useful way of meeting families and at least making introductions is of course for social services to attend more transition planning meetings. Nationally there is ample evidence that hard pressed local authorities are often not represented at the fourteen plus review (even though it is a golden opportunity to meet families and young people who will inevitably make

future demands of social services). One or two authorities like Oxfordshire have managed very well but they have had a dedicated integrated assessment transition project”.

- In separate information days and evenings. Several districts report that they offer this type of information session. There is a great deal of variation, from one off once a year lecture type presentations to multiple sessions, held at different times, with translations, creative presentations, good opportunity for question and answer etc. Russell, 1998, suggests:

“Annual transition fairs (with a wide range of voluntary/statutory providers displaying their wares, having people to talk about options and usually including some kind of workshop or seminar). These are very useful in rural areas or indeed in localities where it is hard to get parents and young people together, because they concentrate activities and the annual date is in everybody’s diaries”.

Russell also notes the potential role of the Careers Service in running seminars or workshops, giving options and passing on information.

- Via transition courses. In some respects these can be seen as a development from information sessions. In some areas there are structured sessions, offering cohorts of school leavers/families detailed information about process and service options, in order to complement individual assessment/planning and to provide opportunities for mutual support and self-help.

Example -Transitional Support Group

This group, run jointly by a social services group worker and a parent partnership officer in Gateshead, was set up to provide information and support to families going through transition:

“The idea of a transition support group is to help parents have access to the information they require and to help them become more aware of the options that are available to the young person. It is often helpful to meet and talk with other people who are experiencing similar circumstances, and parents/carers can often support each other more successfully”.

Over 10 weeks sessions were offered on:

- Introduction and overview of the transition

process.

- Children with Disabilities Team.
- Careers Service.
- Further Education Colleges.
- Day Care Provision.
- Post- School Support and Opportunities.
- Employment Opportunities.
- Crossroads Care Scheme (support for carers).
- Benefits.
- Voluntary Organisations - An Overview of Opportunities.
- Health Overview.
- Leisure and Social Activities.
- Social Services Assessments.
- Farewell buffet.

Contact: Sue Barker, Gateshead Social Services Department, Prince Consort Road, Gateshead NE8 411J, tel: 0191 490 1616 ext 238.

Personnel - Various people may provide transition related information: teachers, health or social services staff, careers officers, other professionals, voluntary organisations or advocacy groups, parent partnership officers etc. There is a crucial need for consistency in information provision, in order to avoid confusion and uncertainty. It is very important that key agencies and professionals share information themselves, and agree on approaches to providing this direct information. It is possible that these arrangements may need to vary and be flexible from situation to situation. The relationships between young people, families and different professionals and workers will often influence who is best placed to communicate what information.

Structured and co-ordinated presentation of information

Experience suggests that there are advantages to be gained in providing information in a co-ordinated, structured way. There can be little worse for a family, anxious about the future, to

be hearing significantly different things from different professionals. Joint groups should look at the stages of the final school years and give attention to offering information at each of these stages in a progressive way, acknowledging that people do not fit neatly into the stages, and that different methods and approaches are likely to be effective for different families.

As noted above there are some examples of this being offered via transition or careers courses for young people and families. It is also important to connect concrete information, gained through experience and observation, with information presented in specific information sessions. Thus it is likely to be useful to link any opportunities for practical option exploration, visits, etc to the organised opportunity to reflect upon these.

Young people and families, faced with a large amount of new information, will need the opportunity to go away and reflect, to consider questions they have, and then be able to ask these. The availability of someone to consult with over a significant period of time is invaluable.

Developments to date

Progress to date in achieving effective multi-agency policy and practice

The positive news is that, in many districts, people from different agencies are working to build better transition practice. There are examples of practice likely to improve the transition experiences of people with learning disabilities and their families. These include examples of:

- joint operational policy and process
- increased coherence in assessment, planning and resource allocation
- systems for the effective transfer of planning and individual information
- ways of better including and involving young people and families
- methods for achieving smoother transfer between various services
- attempts to achieve coherent support in transitions that take place after school leaving.

The general situation however, appears to be that many districts possess pieces of the jigsaw without managing to put together the whole picture. It would also seem to be the case that good practice is fragile.

Our experience and information to date suggests that with some notable exceptions, there has been relatively little progress at local

strategic levels in producing joint transition policy within which operational managers and staff can easily produce coherent process and practice. We hope that the recent Governmental advice will be of help to senior policy makers at the local level.

Examination of initiatives reveals that they often emerge from the development of key relationships between middle ranking representatives of agencies, or professionals with some significant degree of autonomy such as head teachers. Often local arrangements develop as professionals recognise the obvious needs of students and their families.

In some cases agreements are ad hoc and informal or do not reach senior management levels for ratification.

While these middle management and professional coalitions have many benefits there are also draw backs. Interagency practice often remains dependent on key players, significant resource issues cannot be tackled, joint work often remains partial rather than comprehensive or coherent.

For the time being it may be that in many areas these alliances of managers and practitioners are likely to remain the main initiators of joint work. We would urge these groups, however, to take every opportunity to use their links to senior policy making and resource forums in order to ratify and extend multi-agency commitment to joint work.

Strategic policy

The 1993 CDC/Kings Fund review found that:

“Middle management was not well informed about policies, particularly for interagency work. At the same time senior management needed to be informed about the issues and gaps in provision in order to develop such policies”.

The 1994 report by the SSI *Growing Up and Moving On* recommended within it's Key Messages the need for:

“Complementary and cross referenced children's services plans and community care plans to address the specific needs of disabled young people and their families during the transition from children's services to adult settings”.

and

“Joint commissioning between SSDs, education departments, health authorities and others, to ensure that providers of services can respond to the locally assessed needs of disabled young children”.

A recent review of the policy context for learning disability services (Community Care Development Centre 1998) notes that:

“A central strand to Government thinking is the emphasis on partnerships. The Secretary of State regularly talks about “breaking down the Berlin Wall between Health and Social Services. The White Paper proposes placing a statutory duty of partnership on public bodies and brings local authority representation into health service organisations. Discussions are taking place within the DoH with regards to the development of pooled budgets and a consultation paper is expected soon on joint working between Health and Social Services”.

Given the policy exhortation for authorities and agencies to link their planning in areas of overlapping or complementary responsibility it is of concern that in an area such as transition, relatively little progress seems to have been made. Philippa Russell, (1998) for example, notes that:

“Few Children's Services Plans focus on transition (although they are supposedly linked to Community Care Plans)”.

development of local joint policy in support of their managers, professionals and staff efforts to improve transition practice.

Senior policy makers, within agency planning and decision making forums can:

- Develop a general policy context which creates the conditions within which joint process and practice can develop effectively. This might include general support for joint agency co-operation and coherence via joint strategies, joint commissioning, integrated assessment, agreements on agency roles and responsibilities etc. Health Improvement Programs and Joint Investment Plans could include content supportive of transition improvements.
- Take specific initiatives to facilitate joint agency transition process and practice. For example: Social service departments could include transition initiatives within Community Care Plans, Children's Service Plans and specific service strategies. Health and social services purchasers can include transitions within their strategies and contracts with providers, health providers within their business plans. Careers Agencies may include transition policy within Service Level Agreements. LEA and school planning can incorporate joint transition initiatives. Agencies can co-operate in allocating resources for transition development (see below).

Possible developments

We would urge senior policy makers to use the *Making Connections* initiative to launch the

Example of a strategic initiative

Hampshire Social Services Committee have accepted a Policy on Transitional Arrangements for Young People with Disabilities. Components of this policy include:

- Information for Service planning.
- Information about services.
- Co-ordination of services.
- Assessment care planning and review.
- Organisation and management.
- Monitoring and review.
- Service development.

As well as establishing the policy position of the Social Services Department, this report linked each of the implementation components with the roles and arrangements established with the other agency partners.

Amongst the strategic issues identified in the Hampshire report was the need for:

“Co-ordinated planning between the Social Services Department, the Health Authority, the Local Education Authority, and the Further Education Funding Council to manage boundaries, funding and support for further education. Agreements will need to be reached with the assistance of the Careers Service and Employment Services over employment and training opportunities. Local Housing providers and Health services may need to contribute to plans for independent accommodation. All agencies will need to agree the equipment, adaptations and support that may be necessary to enable a young person to access a service”.

The report also points out the need for achieving clarity about available budgets:

“Presently, considerable difficulties arise in establishing clarity over budgets that can be accessed for young people. Children Act budgets are available, as are limited aftercare funds. This age group has entitlement to the Disabled Living Allowance in their own right from age 16, and to STG monies from adulthood. Those involved in assessment and service planning from a young person’s 14th year, need to have established the source of funding from Health, Social Services, Education, FEFC or voluntary organisations and to be aware of how these services will continue to be funded, if appropriate, once the person reaches the age of 18”.

In support of this strategy, Hampshire have:

- Specialist transition workers in each area who take responsibility for the strategy.
- Transition care management budgets.
- Transition information packs.

Contact: Moira Swann, Commissioning Manager, tel: 01962 847263.

Developing Operational Policy

Supporting operational policy development

One of the challenges facing those attempting to devise policy is the difficulty in finding the time and resources for the development effort required. Senior policy makers can support this in a range of ways. Examples include:

- the allocation of existing resources such as Policy Development Officers and research resources
- secondment of staff for project development
- use of joint finance funding for development posts

Approaches to developing operational policy

Agencies involved in the purchasing and providing of services for people with learning disabilities are organised in a variety of ways. Looking at adult social and health services, for example:

- Some operate specialist care management teams, others are generic (sometimes with workers with a special interest).
- There are a range of purchasing arrangements in terms of who holds purchasing power, levels of delegation etc.
- Management of service provision varies with some organisations more specialised than others.
- The balance between providers - social services, health, independent sector varies.
- Policy making systems vary greatly both at strategic and operational levels.

For these reasons, it is not appropriate to be over prescriptive in offering ideas for the development of transition policy and process. Having said this, there are certain constants across districts - first of these is the needs of

young people and their families, and their common experiences of transition. The ideas and suggestions within this section are offered as approaches that are being tried in some places and which seem to offer the chance of better outcomes for people.

Most of the approaches have not been operating for long periods and there has been little formal evaluation. Having said this, however, those involved are working on this and are motivated and encouraged by the responses they are getting from people they spend time with and consult.

Which agencies and workers need to collaborate?

One of the dilemmas in developing co-ordinated transition policy and process is that potentially, managers professionals and workers from many agencies need to be involved. Some people will need to be involved in the policy and process development, others in the operational delivery of the policy. Decisions about key participants will have to be made locally.

There are some partners who are likely to need to be involved in some way on the continuum between consultation and significant involvement.

Social services - purchasing and providing managers (adults and childrens sections) Operational managers and fieldwork staff including - social workers, care managers, representatives of provider services (day services, short term support, supported accommodation, occupational therapists supported employment staff etc).

Health - purchasers and providers. Operational managers and fieldwork staff including: community nurses (specialist and non-specialist), speech and physiotherapists, GPs, consultants.

Education - including LEA representatives, FEFC, managers and staff from schools and colleges (e.g., SENCOs), educational

psychologists, learning support teachers, home tutors, parent partnership workers.

Careers staff- often special needs careers advisors, but including other advisors.

Training/employment agencies - employers involved in both open and supported employment, Training Providers, TECs, Department of Employment staff.

Independent sector organisations and workers - including management and operational staff as above, advocacy agencies etc. Particularly important are groups representing people with learning disabilities and carers.

It should be stressed that although many of those involved will inevitably be specialist managers and staff, it is vital to look outward towards non-specialist services and opportunities, such as housing providers, leisure and community services, non-specialist health staff etc.

We have noted above that the best context for effective and sustained joint policy and practice is likely to be one where local strategic policy makers have taken steps to produce a policy environment which promotes and aids joint operational work.

People with learning disabilities and their families, however, cannot wait for the perfect policy context before practical steps are taken to help improve their transitions experiences. Similarly, service agencies need to be developing more productive partnerships with young people and their families in the short term, in order to increase their own effectiveness and efficiency.

Written agreements

It is important, wherever possible, to go beyond de-facto informal agreements because experience in many areas has shown these to be extremely fragile to changes in key personnel. In addition, the commitment to formal joint policy and the process of producing this, often helps to gain wider ownership and commitment to the agreements. As will be emphasised below, the detail of policy and process is

important in ensuring clarity and coherence of effort.

Written specification of policy, process and roles can also assist agencies and professionals to focus upon any resource allocation and organisational arrangements they may need to make in order to deliver on their agreed tasks.

Without this level of specificity, there is a danger that joint effort will founder through lack of sufficient internal planning and preparation.

Review of the development of policy and process around the region suggests that the initiative or impetus may come from different sources. Some of these have included:

- Reviews of existing process via individual agency or joint research
- Workshops or conferences focusing upon transition
- Campaigns by carer or service user groups, sometimes supported by voluntary organisations.

Example – Researching transition needs and issues

A health care trust serving two London Boroughs, with funding from the NHSE, is undertaking intensive local research in co-operation with other agencies.

“This two and a half year project, which began in October 1996 is studying services for disabled school leavers. It is based in Optimum’s community paediatrics department but is overseen by a multi-agency project team which includes key representatives from local Social Services and Education departments.

The project focuses on disabled young people leaving school in Lewisham and Southwark. It includes people assessed as having a range of moderate or severe disabilities, including physical disabilities, sensory impairments and learning disabilities. The research aims to explore the role of inter-agency transition planning in improving services for these young people. Key underlying principles are:

- a qualitative approach to evaluation which gives a central place to users’ experiences and views of services
- an acknowledgement of specific issues affecting disabled young people from minority ethnic groups, who form up to 40%

of school students in the locality.

We are also exploring ways of consulting disabled people about the research at all stages. To assess the quality of transitional planning and liaison by health and other services, and the effectiveness of interagency co-operation”.

For further information contact Ruth Cohen or John Khan, Young Adults Transition Project, c/o Central Lewisham Health Centre, 410 Lewisham High St, London SE13 6LL, tel: 0171 771 4443.

Example – joint investment for development

In West Cheshire, Joint Finance funding was used to second a senior Careers Service manager to the social services department. This project worker had the following objectives:

- develop a model of transition for young people with disabilities which incorporates the requirements of the Code of Practice under the 1993 Education Act
- set up a system of procedures which would ensure smooth transition
- liaise with all relevant agencies including Education, Health, Social Services, Careers, Colleges and the Further Education Funding Council
- establish a pool of information about available resources and options which would be available to the young person and their families or carers
- once procedures have been established the Co-ordinator would provide training to all relevant agencies
- to ensure that there was a process in place by which future changes could be implemented.

Contact: Jean Smith, tel: 01606 557328.

In those areas which have made progress in developing joint local operational policy and process, such initiatives have often been followed by some form of joint working party, with an agreed and clear brief, and with representation from key partners.

The level and degree of joint commitment which can be achieved will vary greatly depending upon local circumstances. Some groups have found it helpful to start with reasonably achievable tasks in the short term that will not produce great resistance or prove too difficult. Success can then be built upon to build up the levels and detail of transition activity and the degrees of jointness involved.

Content of operational policy

Operational policy should reflect key local objectives in respect of transition which have emerged from working party or other joint deliberations.

Some key issues need to be considered in framing the content.

Which groups of young people should be included?

One important early decision to be made by those organising transition processes is to determine which groups to include within the process. Agencies in some districts have focused upon all young people with disabilities. Others have concentrated upon young people with learning disabilities or with severe learning disabilities. There are a number of factors which might be taken into account in making this decision - much is dependent upon local circumstances and possibilities.

There seems to be a clear danger that young people labelled as having mild or moderate learning disabilities are less likely to be the recipients of structured, multi-agency transition support. Where specialist services for people with learning disabilities are under severe resource pressure there is often a tendency to limit the supports and services provided to people from the potentially large group of people with ‘lesser’ disabilities.

Another reason for this kind of response to these groups is a fear that location of services for them within learning disability provision can lead to lack of involvement and support from the range of generic services and opportunities that they need.

One possible approach is to develop a system which offers all young people with learning disabilities structured transitions support but where the nature of some aspects of the process and involvement of various agencies and professionals varies.

Joint agreement regarding the central aims and functions of transition activity

This is important because agencies and professionals are often starting from different perceptions as to what constitutes transition, and what are the important objectives to be pursued. For some the focus may be upon achieving educational or vocational continuity or smooth transfers of responsibility between agencies or professionals. Others may see reduction in confusion or maximisation of informed choice for young people and families as the central aim. Young people and their families are likely to see provision of suitable services as a major objective.

There may need to be some exploration, negotiation and compromise to ensure coherence in policy and practice. Establishment of clear aims and objectives will also make it possible to produce operational arrangements in pursuit of these.

Example of joint objectives

In one district a multi-agency transition policy starts by identifying the key objectives for the joint transition process. These include:

- ensuring effective interagency planning and collaboration
- ensuring good quality assessment work exploring all opportunities and making clear plans
- to provide good preparation for adult life experiences and opportunities
- making the person going through transition central to planning, avoiding fitting a person in to existing services
- ensuring effective partnership with parents, for the period of transition and for the future
- ensuring continuity of support, avoiding the loss of learning and needs, and reduce the

trauma of change

- making sure that people have real choices
- ensuring that staff from different agencies learn from each other in order to provide the best support for young people.

Contact: Martin Routledge, tel: 0161 911 3848.

Stages, phases and activities of transition

In order to operationalise any transition process there must be some precision in specifying the stages and phases which will form the focus of joint action and specific roles. Agencies and professionals are then able to focus their planning and practical arrangements around these phases.

Example of transition phases

In one district the stages of transition relating to people with severe learning disabilities were agreed to be:

- 14 plus review - the beginning of significant transitions activity involving a range of tasks - seeking an opinion under the Disabled Person's Act (1986); beginning to explore vocational options with Careers; social services to provide outline information on adult services (including video, and information pack); development of curriculum; outline planning information on numbers and needs passed through to adult services.
- Age 16 - annual review used to begin more significant transfer of information re adult services and options. This will include presentations via information sessions involving a wide range of providers. Referral to adult care management service (assessment not yet activated). Curriculum further developed, links to adult service options pursued where appropriate - e.g. careers, supported employment, further education.
- Age 17/18 - care manager allocated and assessment work begins using agreed process, including period of getting to know the young person and family; joint planning

of assessment tasks and time scales (including young person and family and other involved professionals); significant period of information sharing and option exploration generation and review of service proposals. In school curriculum further developed to support preparation for adult life, in closer association with adult providers where appropriate.

- Age 18/19 - service and opportunity proposals finalised, referrals for services or opportunities pursued. Setting up of transitions arrangements - phased transfer to post school activities, getting to know providers and services, making specific plans for service use or goals relating to activities and opportunities, ensuring that necessary supports are in place to facilitate service use.
- Post school - co-ordinator allocated to continue to support family and young person for at least two years after transition. Allocated worker dependent upon transition destinations. Possibility of further transitions during this period.

These arrangements are adaptable to young people who choose to go into further education or another option before 19. There is a danger, of course, of structuring transition to encourage staying on to 19 when this may not be the right option for some people.

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Specification of roles

Given the complexity of transition and the number of agencies and professionals potentially involved, there are serious dangers of overlap, duplication, or gaps in activity. Without joint agreement on roles, service effort can be inefficient, interagency and inter professional conflicts more likely, and the young person and their family left confused. Experience suggests that it is helpful to specify in some detail who will do what and when, and how these contributions will be co-ordinated.

This clarification of roles also helps the individual agencies and workers in determining/adjusting their own organisational and resource arrangements in support of the collective transitions effort. The importance of this should not be underestimated. Focused transitions work often requires shifts to the methods and culture of agencies and professional groups.

Where appropriate, specification should include roles for agencies, departments, sections of departments, and specific workers or groups. Role specification might be incorporated within a joint transition policy or in associated protocols or guidelines where the necessary detail requires this.

Procedures and protocols

Why procedures and protocols?

Some elements of the transition process are particularly complex and require detailed clarification of roles responsibilities and activities for each stage, expanding upon general policy agreements. Within those districts operating or developing joint transition policy, procedures and protocols of two kinds have often been developed:

Joint procedures and/or protocols - between all or some of the partners in order to ensure sufficiently detailed clarity of agreed roles and tasks, and how these will be actioned. For these elements specification of systems, structures, tools to be used, key events and timescales are important. It is likely also that these joint arrangements will need to be kept under review and updated (see steering groups below).

Internal procedures and protocols - within agencies and parts of agencies in order to ensure that teams are in a position to effectively carry through on their commitments

In this section we will focus upon the first type. The agency checklist in Appendix 1 offers guidance on agency/team tasks.

Some examples of areas which may require procedures/protocols

Systems for the transfer of planning information

Effective sharing of information is crucial in planning and delivering effective transition practice. The types of information that need to be shared include general planning information and specific information about individuals.

1) General planning information

This includes the transfer of information from children's to adult services in order for those services to plan ahead. Education, social

services, and health services for children should be providing information on numbers of young adults coming through, and some profile of the needs that are emerging from assessments while young people are in school. There should to be a system for this, with specification of the information to be transferred, nominated responsibilities for providing, receiving, and using information, and agreed time scales.

This information can enable adult services to plan to meet the future needs of young adults. This is particularly important when there are patterns of changing, new, or substantial needs coming through. In one authority, for example, there has recently been a bulge in the numbers of young people from South Asian communities coming up to school leaving. In another authority significant numbers of students with complex health care needs are projected to leave school in the next few years.

This information can be useful in demonstrating the importance of the development of joint practice or role clarification within adult services. For example, in one district the emergence of significant numbers of school leavers requiring non oral feeding has provided impetus for providers of social care and nursing services to develop joint protocols to ensure effective support for these young people.

There is a need for co-ordination of the collection and transfer of this type of information. It is common for no one agency or part of an agency to have all the relevant information.

It is also very important when collecting the information, to make sure that young people placed outside of a district for their education or in a mainstream school are not missed.

2) Information about individuals

As well as the general planning information there should be systems for transfer of information in respect of individual young people. As has already been stated continuities of various kinds are vital in transition. The

transfer of key information at important stages is a crucial aspect of this.

There are various types of information and several phases for information transfer. The most important information sources are the young person themselves and their parents/carers.

Information is collected throughout the school years on educational achievement and needs (culminating in the Record of Achievement). Various professionals may be involved with an individual including social workers, health professionals, careers officer, educational psychologist, etc.

As a young person moves through the final years of school it is very important that those assisting people and their families in transition have access to and use this information. Many families complain that they seem to have to start from the beginning with new professionals such as care managers who come into their lives, or even have to give the same information over and over again to different professionals. There are also concerns that in many cases, when young people transfer into adult services their experiences, skills and aspirations seem to be unknown to those working with them.

Some of the key stages and opportunities for collating and sharing information are the school review stages, including crucially the 14 plus review, the requirements of the Disabled Persons Act 1986 and the assessment for adult services (see below).

Clarity of roles and activities associated with the 14 plus review

These include:

- who attends
- production of the Transition Plan
- roles in achieving planned goals
- following up plans in later reviews.

Most LEAs have produced local procedures and protocols. The roles for other agencies within the 14+ transition planning process often require greater local clarity and detail to avoid the danger of their involvement failing to have real purpose and outcome. The partners need to

achieve agreement on roles and activities both within the review process and for follow up action in succeeding years. Experience suggests that the roles of adult services are often underdeveloped.

A system for monitoring progress of groups and individuals at different stages of transition should be part of these arrangements. Agencies in a number of districts have agreed systems of meetings to track progress of individuals and groups and to monitor agreed activity.

Arrangements in respect of the Disabled Person's (Services Consultation and Representation) Act 1986

There should be clarity regarding the arrangements whereby LEA's 'seek an opinion' under the Disabled Person's Act 1986. This is in order to determine whether a young person will be considered to be disabled and therefore eligible for assessment for services under various pieces of legislation. The partners need to be clear about:

- the timing of this process
- who will be the nominated officer(s) with social services
- when a response can be expected
- how this information will be used.

Social services need to ensure coherence between children's and adult services in respect of definitions of disability and eligibility for assessment under the NHS and Community Care Act 1990 (see below).

Post 14 arrangements between children's and adult sections of social service departments and health services

It is important that the respective services and managers agree arrangements and processes which clarify who will take what roles post 14. For example:

- will adult services have any role in the 14+ planning process or is this left entirely with children's services?

- what will be the arrangements for transfer of responsibility, for which young people, at what stages?
- how will services ensure continuity in meeting important needs?

Arrangements for assessment under s 47 of the 1990 NHS and Community Care Act and for co-ordination of assessment and service planning in the final school years

This includes:

- assessment methods and timescales
- roles of agencies and workers
- co-ordination of planning and assessments
- eligibility criteria - clarity and coherence between the agencies
- care/service planning and resource allocation processes - clarity and coherence (including any application for FEFC funding)
- arrangements for transfer between services - introductions to adult services, phased transfer etc.
- systems for identifying patterns of service deficiency.

Example – co-ordinating systems

In one district, the joint agency Transitions Action Plan for 1997/8 includes a task for all agencies to agree key elements of the assessment/planning process for students leaving in summer 1999 (amendments to the 1997/8 process). Components of this would include:

- assessment planning meetings -timing, key functions, attendees etc.
- role of school reviews
- arrangements for contributions of key professionals/professional groups to assessment/planning process (children's SSD, adults SSD, schools, careers, LEA, speech therapy, physiotherapy, nursing,

other health, college, other)

- practical arrangements between school and assessors/planners (information, tasters, transport, timings etc)
- arrangements for turning assessment outcomes into service offers
- arrangements for bringing students through into new services and opportunities.

“It is proposed that these amended arrangements, once agreed, be written up for all participants to ensure clarity, with timescales clearly set out. Each agency/professional group will need to ensure that the arrangements are supported by internal organisational and support systems” (Oldham LDS 1998).

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Agreements in respect of key operational issues

Joint action to support people in transition inevitably throws up practical issues which need to be jointly resolved. It may well help if those developing and managing joint processes make some decisions about how some of the most common issues will be handled. Examples include:

- Staffing and other resources for transition tasks. In order to allow agencies to facilitate option exploration while continuing with their normal work there will be resource implications. Agencies may wish to consider who will accompany and support students and the appropriate balance - school staff, care managers, college or social services staff, etc. In dealing with this issue some forward planning seems necessary. For example, agencies might identify time periods when option exploration within their services are likely to be taking place and adjust their use of resources accordingly. Alternatively there may be some time periods when making resources for option exploration is easier than others.
- Agreements and arrangements need to be reached about who will provide transport to facilitate option exploration, and any issues of payment for this. Transport has been found to be one of the factors which can

hinder and reduce chances for exploration of choices in many districts.

- Similarly agencies need to be sure that appropriate insurance arrangements are in place, and that there is clarity of responsibility for students safety during option exploration.
- Co-ordination of activity- all the agencies involved with students in transition have their own programs of work, staff roles, priorities and timetables. It is very important that there is some co-ordination of assessment and planning work. At the planning level this is about ensuring a level of coherence, for example, linking college link experiences, school arranged work experiences, careers advice, and involvement from any social services supported employment service. Very important also, however, is the practical planning level. Teachers responsible for final years curricula and arrangements, and those from other agencies need to plan together to ensure that their arrangements fit together.

There is potential for some chaos if significant numbers of people are trying to make arrangements for students to spend time in various activities without this co-ordination.

Arrangements for transfer between specific services

Where people are transferring between services with a similar function, but which are operated by different agencies or sections, there is a need

for organised support to ensure smooth changes and avoid trauma.

Examples would include where young people are moving from a short term support service operated by children's services to one run by adult services, or between a foster placement and an adult placement. In some districts structured arrangements are made between the responsible agencies, which might include, for example:

- clear agreements on referral systems and timing
- clarification of worker roles in the transfer
- phased introductions for young people and families
- provision of good information about differences between services and systems.

Post school transitions

This includes clarity of roles in supporting young people who move from school into a range of post school options. Crucial here is agreement between the key agencies and professionals - care management, Careers, adult/further education tutors, employers etc., as to who will provide what support in which situations. Without this clarity, young people are likely to experience incoherent, fragmented support leading to lost opportunities in pursuing career and other goals (see below).

Beyond school leaving - comprehensive and coherent post school services

Agency roles after school leaving

Successful transition for many young people will depend upon coherence between the services and interventions of different agencies and professionals both as they move towards school leaving and after they have left. This applies to the links between many agencies. Two of the key areas where coherence is crucial are:

Health and social care

One of the clearest examples of the need for coherence is between health and social care services. Issues around appropriate health and social care roles can be very important to young people moving through into adult services. An example of this would be where a young person with significant health care needs (perhaps involving challenging behaviour or complex nursing needs) starts to use adult services, such as short term support or supported employment. In order for the person to make best use of the social care facilities there may well be a need for various health care inputs.

This may involve equipment, staff training/monitoring and direct intervention by health staff. For young people and their families it is very important that the involved agencies are clear about how they will co-operate to provide the best support for young people in these situations.

For many people with significant health care needs and their families this is a source of great worry during transition. While a young person has been at school there has often been intervention from a school nurse, and from on-site therapists. As this support ceases there are fears about the competence of adult services to meet the health care needs.

The National Development Team has recently been looking at health care for young people with learning disabilities, aiming to identify issues and concerns, good practice and ways of improving transitional planning. At a conference in November 1997 the project team reported the concerns that they had found within the eight localities taking part in the project.

The main concerns were much the same in all localities. They included:

- The loss of co-ordinated health services which were previously available through the school and Child Health Services.
- The loss of knowledge and understanding of the young person and his/her disabilities.
- The loss of childhood respite services with the capacity to respond to a young person's extensive health care needs.
- A lack of findable, usable and up to date information about what services and benefits are available.

The project identified examples of developing methods for building knowledge and awareness of the health needs of people with learning disabilities in the Primary Health Care Team and Community Health Services.

“The National Development Team, with others, has developed a Personal Health Record *Advocating for Health Personal Health Record*. Copies of this personal booklet have been piloted in some of the localities in the project and elsewhere. The feedback suggests they bridge the gap between the information needs and points of view of young people with learning disabilities, their relatives, professionals and other people who support them.

A Primary Health Care Co-ordinator working with carers, schools, GPs and several other disciplines, including audiologists and chiropodists to improve services for people with learning disabilities. Achievements include:

- connecting up the voluntary sector and GPs
- piloting the use of Personal Health Records and
- helping primary health care teams identify people with learning disabilities.

- The work has brought enormous differences in the practice of primary health care teams, particularly because individual professionals have welcomed the possibility of interesting work.
- Learning disability trained health workers working in partnership with general practices to develop appropriate preventative health plans for people in their practice population who have a learning disability.
- A Community Nurse visiting day centres, looking into what health screening people with learning disabilities are receiving, and identifying problems.
- A 'Well Women' initiative included women with learning disabilities and breast screening had been arranged for them".

Further education and vocational training

As has been noted above, many young people now go onto further education courses (including residential colleges) or into employment training on leaving school. Many of these people go through further transitions after completion of courses and training. The development of these further education opportunities in recent years has clearly offered great benefits to many young people.

Russell, (1998), however, raises a range of concerns expressed by many families who feel that:

"they may be offered a good package of courses, but when their son or daughter arrives there are difficulties. Support is not always available. Some tutors are reluctant to tolerate behaviour difficulties or certain special needs. FE colleges do not have access to educational psychologists, speech therapists etc. as of right as do schools. Some will buy in expertise, others are reluctant to spend money on such services. The pressure to achieve results and perform well in league tables may make some colleges less tolerant of diversity.

Social services may be reluctant to provide transport and there can be arguments about provision of aids and equipment.

There is not always clarity of agreement between the FEFC and social services departments about payment of the social (residential) care element in specialist

college placements. Placements may be lost because of local wrangling.

Young people with behaviour difficulties may actually be excluded. Exclusions from the school system are accompanied by very clear regulatory frameworks which schools must follow, with appeals procedures clearly in place. Young people excluded from college are in a much more difficult position.

Statements are discontinued when a young person enters the FE system. This also means that neither students nor parents can appeal to the SEN tribunal which is available to young people and their families when still at school".

Without co-ordinated and coherent support for young people undertaking such post school education and training there are dangers that they will have real difficulty in using these experiences as part of a career plan.

There are many examples of young people going onto courses or training without clarity as to their purpose, and leaving these experiences with no clear progression route. These experiences call for the relevant agencies and professionals to clarify and co-ordinate their support for these young people. Some of the key players here are care managers, careers advisors, college based careers staff, employment services, supported employment services, FEFC representatives.

These professionals need to negotiate their respective roles in assisting young people to plan their careers and the support to be offered during these immediate post school years. For many young people, a combination of options may be taken up on school leaving and it is again vital that the involved professionals co-ordinate their support.

Developing post school options and services

Tidsall (1996), asks:

"But what is the point of the professional expertise, resources and time put forward through interdisciplinary meetings when opportunities are so limited? At worst the meetings may be directing attention and

resources away from substantially solving the problem.

Too much is being done on changing the individual young people and too little is being done on widening the present dearth of post school opportunities. Too much is being done professionally and too little is being done politically. Professionals working with the young people need to act politically, to challenge local environments”

Ryan (1998), describes transition outcomes for people involved in a recent study within six local authority areas. His description poses dilemmas around the question “Planning for What?”

“For most of the participants of this project, at least, the money and status associated with employment which they aspired to, had eluded them. The majority either attended or were planning to attend college, with some having their part time college week ‘topped up’ with attendance at day or training centres. Five of the participants were attending or had recently attended residential schools. It is, therefore, fair to say that despite the planning which has been brought about by the legislative changes, not a lot of change has occurred in relation to providing people who have learning difficulties with access to real employment and choice in their lives. The failure of systematic planning to deliver these kinds of outcomes for people, is not, of course, the fault of such planning itself, but rather more about the context within which transitional planning takes place. Corbett and Barton regard individualisation, in the absence of a framework of equal opportunities for people who have learning difficulties, as failing to recognise the external factors such as discrimination in the workplace (Corbett and Barton, 1990, page 37). In this sense it is such a framework that we should all be striving to achieve.

However, in the absence of such a framework the growing supported employment movement offers real choice to people who have learning difficulties. Six of the participants of the project were being supported in such a way, in real jobs. Although the supported employment movement has grown steadily in recent years, the existence of schemes is reliant on local policy and practice. In many local authorities the traditional models of day provision for people who have learning difficulties persist, therefore denying people the opportunity to experience real work.

In addition, other facets of the move into adulthood, identified by young people who have learning difficulties as desirable, also seem, for these respondents anyway, to be illusive. Independent living was noted earlier as being central to the lives of people who have learning difficulties as they move to adulthood. Yet only two of the participants, with the exception of

those moving into the residential school sector, were actively involved in moving on from their family homes. Part of the problem here is, again, the context within which transition in the lives of young people who have learning difficulties exists.

However, the other part of the problem is that transition is focused on the limited perception that the move into adulthood is a curriculum based activity with emphasis on learning, skills and personal development.”

Many of those involved with services for young adults with disabilities would accept significant gaps in the range and coherence of post school opportunities:

- The availability of further education opportunities would seem to vary greatly from area to area, and the range of courses available, those able to access them, the inclusive or discrete nature of classes also varies.
- Access to vocational training opportunities is often difficult, or the range of choices very limited.
- Supported employment services may or may not exist in an area and may be of varying size and capacity.
- The general range of specialist learning disability services may or may not have sufficient capacity or range and flexibility to meet the needs and aspirations of school leavers.
- Commonly identified gaps in services and support correspond to some of the central needs of young people with learning disabilities - in areas such as opportunities to develop friendships and relationships, in obtaining accommodation in non-emergency situations etc.
- Opportunities for young people to access non-specialist services and opportunities are often very limited.

In some areas, joint groups have also pointed to the fragmentation and incoherence of some post school opportunities. As these are established by a range of different agencies, with different objectives and funding arrangements this is perhaps not surprising.

We would suggest that the development of joint agency groups to produce transition policy and process can be used as a step towards action to address the other key issue of post school opportunities. It will have to be for local decision how best to proceed. Should both issues be tackled at once? In some situations it may be difficult to proceed with developing process without action on opportunities - this may lead to lack of motivation. What is the point improving the process if the choices are so few?

In other situations it may be better to tackle the issues in stages, generating mutual understanding between the participants, using shared information to understand what gaps exist and means to fill these.

Groups established to focus on transition issues can also, of course, present information and proposals to other more general management or planning groups. It can be an advantage for such reports to come jointly from a multi-agency group.

Example of review of post school options

In one district, a joint agency group are undertaking an analysis of the situation in respect of vocational education, training and support for young adults with learning disabilities.

The group have available to them research undertaken by an external consultant and funded by the local TEC which reviewed the range of vocational supports for people with learning disabilities in the district.

Members of the group have undertaken interviews with the providers and funders of the services and opportunities in order to gather views and information as to their sufficiency and coherence, and ways of filling identified gaps.

These findings are to be analysed and summarised and used as the basis of a local conference in order to identify ways forward, create coalitions for development, and action plans to achieve progress

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Post Tomlinson initiatives

The report of the Tomlinson Committee (1996) has clearly stimulated collective review of further education provision in some districts.

Example – Reviewing further education options

In West Cheshire, a local Further Education Development Group has been formed. The membership of this group includes representatives from:

LEA

Social Services

West Cheshire College of Further Education

Chester and Ellesmere Port Training and Enterprise Council

Parents/Carers

The group is intended to provide a forum which will:

- inform strategic decisions by the LEA and local college of further education provision for students who have learning difficulties and disabilities
- provide an interdisciplinary response to national and local consultation documents on FE developments, new legislation etc.
- enable the collection of data on the further education needs of people who have learning difficulties and/or disabilities
- investigate possible joint funding arrangements for further education provision
- influence and collaborate with Service Managers in the LEA and Social Services and with similar working groups in other parts of Cheshire
- provide a two way information and communication mechanism for partner organisations.

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Mechanisms for supporting and developing policy and practice

We know from experience that transition policies and systems are fragile. A bulletin on transition from the Further Education Unit in 1994 listed some examples of practice which the author of the current guide, 3 years later, found to have ceased operation or changed very significantly. It is vital, in the interests of young people and their carers, that systems are sufficiently robust to survive the departure of agency personnel.

It is also important that partners in joint transition policies see the process as dynamic, not remaining as either a paper policy or a static process. It is impossible to predict all eventualities, or how policy will work out in practice at the outset. Given the multi-agency nature of policy it is also inevitable that policy and practice will need to respond to changes in circumstances and contexts within the participating agencies.

Steering groups

In a number of districts transition steering or implementation groups are in operation. Such groups have often emerged from working groups set up to establish transition policy. The groups are being used to both monitor and further develop policy and practice.

Membership of steering groups is likely to vary depending on local service contexts.

Consideration should be given to the balance of membership and practical size of the group. Possible membership might include people who are able to influence policy and practice within their agencies alongside representatives of those affected by the policy, and workers able to report upon the actual operation of transition practice.

In some areas steering groups meet regularly at key points in the year, such as in each school term or linked to key stages in the transition process. Given the impracticability of getting all those with an interest in transition included within a steering group consideration should be

given to ways of including others in reviews and evaluations of practice (see below).

It is important to find ways of including the views of young people and families within these reviews. There is a danger that, without this perspective, professionals and agencies may over focus on issues of process as opposed to outcomes.

Building confidence and relationships between agency partners

One of the experiences of those developing multi-agency policy and practice is that knowledge and understanding of each other's systems and ways of working is crucial. This helps the development of the productive relationships which drive quality joint work.

Good working relationships between the key participants will make the difference between being able to say you have a policy and that policy achieving real things for real people. It can also help to avoid conflicts and difficult times leading to the breakdown of systems.

Participants in joint transition policy and practice need to consider the practical steps they can take to build and sustain these relationships. Some possibilities used in various districts include:

- information exchanges
- joint training
- joint task groups
- shadowing
- joint work around individuals.

Example of joint review

In one district, structured opportunities for participants to feedback on experience and to generate ideas for development are currently running at least yearly. A recent session was attended by people from schools, children's and adult social services, LEA, educational psychology, Careers, health professionals, carers. Such sessions have two main aims:

- to allow opportunity to reflect collectively upon process practice and outcomes in order to build upon learning and to plan improvements
- to build understanding, confidence, motivation and commitment amongst the partners in the transition process.

The second objective is seen to be as at least as important as the first. In these sessions, care is taken to start with the celebration of achievement, with everyone having the opportunity to tell of an outcome or experience that they have felt to be successful, or motivating.

This process is seen as a powerful method of increasing individual and collective motivation towards further progress. These celebrations are often used to give praise and recognition to colleagues. The sessions make deliberate use of non-traditional and creative methods - breaking away from over formal sessions where people have historically faced each other across tables and sometimes defended their corner. In essence, the questions posed in these sessions are:

- what was great?
- what are we doing well?
- what could we do better?
- what could we do differently?
- what are we going to do next? - Action Plan.

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Operational troubleshooting

As has been noted above, implementation of agreed policies and procedures will inevitably throw up unexpected issues which need to be dealt with and learned from. Involved agencies need to find ways of quickly resolving such issues.

Example of troubleshooting

In one district a troubleshooting group of key managers from the involved agencies can be called together by any of the group at short notice to resolve operational problems. In this way damaging conflict can be avoided and experience used productively. Learning from the issues can be fed back to steering groups in order to inform future policy and practice.

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Getting started on improving transitions policy and practice

For managers and workers within the various agencies, the prospect of co-ordination of the wide range of groups and professionals, with their varying functions, methods, cultures, priorities, (and personalities), presents a very daunting task. The complexity involved in achieving and sustaining co-operation is probably one of the main reasons for lack of effective process in many places.

There is perhaps even a danger that detailed guidance and checklists such as those presented in this guide may intimidate those wishing to work on improving process and practice in transition!

Service contexts and local circumstances vary greatly. Whereas in some districts it may be relatively easy to develop and operate a full blown joint agency policy, in others success may be in achieving more limited improvements.

Examples of various approaches to getting started have been offered earlier in this guidance. Whatever approach is decided upon, a few general suggestions are:

- **Do something!** Reviews of collaboration on transition suggest still disappointing current practice. Even if you can only achieve part of the jigsaw in the early phases that can make a real difference for some people and can help develop relationships to be built upon.

- **Start from finding out what transition is like now from those directly affected** - young people and their families.
- **Start from where you are rather than where you wish you were.** Early over ambition that does not lead to tangible results is tempting but can be very demoralising.
- **Involve people that can deliver.** People involved in transition policy, planning and development need to be in a position to follow through on agreed agency responsibilities and activities.

As a final comment we would refer back to the introduction. It was stated there that policy and processes in themselves cannot guarantee better transition experiences for young people with learning disabilities and their families. The collective effort and good will of policy makers, managers and staff from all the key agencies is required. This must be enabled if we are to properly meet our joint responsibilities.

At a recent conference exploring good practice in transition, several presenters talked of individual professionals, managers and staff who were 'going beyond their job descriptions' in order to ensure that young people and their families get good support. The fragmented nature of our service systems means that there is no alternative to the key agencies doing the organisational equivalent of going beyond our job descriptions.

Appendix 1 - Agency Checklist

As has been suggested above, joint agency procedures and protocols need the support of internal arrangements within the involved agencies.

The following section aims to provide a provisional checklist of issues and questions for some of the key agencies involved in transitions work. It is hoped that this will offer some clarification regarding agency responsibilities and, at least as important, help to facilitate decisions where there is unclear or fragmented responsibility. As this section is intended to be used as a checklist, there is inevitably some repetition of material in other sections of the guide. Readers are advised to consult the interdepartmental government guidance *Making Connections* (1997), for more detail on statutory responsibilities and departmental guidance.

General points

All of the agency and professional partners in joint transition work should give consideration to the practical, organisational and resource issues which need to be addressed if they are to meet their commitments, including:

- role allocation
- resources needed
- training for those involved in transition activities.
- a range of methods and tools - Some tools which have been found to be useful include:
 - transition files (which facilitate planning, allow focus during supervision, can be shared with participants etc)
 - transition calendars (which allow participants to see what should be happening when)
 - practice and process guidelines for staff
 - internal and joint reviews of progress at stages of the 'transition year'
 - transition planning/resource panels to monitor progress, receive reports and plans etc.
- support and monitoring systems for involved staff

- proper fit between the approaches, methods and time scales of your agency and the others involved.

Beyond these considerations for all involved agencies are more specific ones for particular agencies and groups.

Local Education Authority

The Further Education Unit (1994), provided a checklist for local education authorities.

"How are the responsibilities for transition planning fulfilled in terms of:

- Convening the review meeting, even when the young person is in school?
- Ensuring that other agencies, such as social services and the careers service, are aware of the annual review and the procedures to be followed?
- Preparing and circulating the review report and transition plan?
- Passing the review report and transition plan to FEFC particularly where a specialist college placement is considered?
- How are plans for transition monitored?
- What is the role of the named person notified to the FEFC?
- Do LEA's receive an opinion in response to information supplied to social services under section 5 of the Disabled Person's Act 1986? Is this notified to schools?
- When social services transfer young people from child to adult services, how are those involved in transition informed of changed circumstances?
- How will LEA personnel maintain knowledge of the range and quality of provision in local and specialist colleges?
- What mechanisms exist for staff in cross-phase and cross curricular fields, such as Technical and Vocational Educational Initiative and European Social Fund projects to be kept up to date about transition issues for learners with disabilities or learning difficulties?
- What is the strategy for transition in response to the Children Act 1989, the Disabled Person's Act 1986 and the Education Acts

of 1992-3? Is this strategy regularly monitored and evaluated? Is this strategy coherent?

- Do the Annual Reviews held after the young person's 14th birthday meet the recommendations in the Code of Practice?
- Are all partners in the review process aware of the recommended discussion areas for the 14+ Transition Review meetings?"

Schools

Schools clearly have a central role in transition both in respect of their own activities and also in terms of how effectively they link with the other agencies. The opportunities and activities of the final school years are crucial to allow students to explore options and evaluate choices. The curriculum of the final years must be carefully planned in order to promote this decision taking.

It is also vital that the school and those offering post school opportunities collaborate and share information so that students are able to explore real possibilities and opportunities. Attention must also be given to ways of ensuring that student experiences and views are logged to support planning. Some key questions for schools are:

- Has the school done all that it can to make sure that curriculum in the final school years effectively prepares leavers for the adult contexts which they will enter. In his book *Transition to Adulthood*, 1994, which focuses upon the role of education in transition, Matthew Griffiths notes:

"Effective teaching for transition should encourage student choice and individual preferences. The curriculum should include a commitment to personal support during transition, experience of integration in the local environment, real work in integrated settings and the effective use of community resources. When a young person reaches the age of 16 and moves outside the framework of the National Curriculum, the skills and competencies necessary for living and working as independently as possible in the community will expand and take over a much larger part of the curriculum for transition".

- What is being done to ensure that the student is central to the planning of their own future? It is very important that

possibilities and options are clearly presented to the student to ensure that he/she is able to take a central and active part in the decision making. Self advocacy and career planning approaches are important here.

- In preparing curriculum and planning individual student programs has the school engaged with adult service providers to ensure necessary coherence and take up opportunities? For example do work placements or college links in later years link with any local supported employment service or FE opportunities? Are people prepared for service changes, new financial arrangements etc.
- Are there clear role responsibilities for transition related activities within the school, including curriculum, information for students and families, liaison with key agencies and professionals etc., (especially roles for further education teachers - time for transition activity liaison etc).

Children's social services

SSD children's sections need to consider:

- How they will contribute to the 14 plus transition plan and to subsequent reviews (including for students placed out of district and students within mainstream schools).
- Any need for assessment for social care services at this point or prior to age 18.
- Systems for responding to LEA requests for an opinion as to whether a student is considered to be disabled under the Disabled Person's Act 1986.
- The contributions of children's services to the goals developed in transition plans and in subsequent reviews.
- How they will link to adult SSD, Health and other agency systems to ensure continuity of planning for disabled young people as they move closer to school leaving. There need to be arrangements which ensure referral at appropriate points in time, transfer of information (both relating to individuals and more general planning information) and for

helping adult services to build on the work of children's services. Such arrangements need to be sufficiently flexible to respond to students who leave school at different points and take up different options at school leaving.

Adult social services

Social services sections responsible for adults with learning disabilities (purchasers and providers) need to consider:

- Do the relevant adult services sections have a coherent policy and process in place for transition assessment planning and resource allocation? Is this process agreed with key partners (schools, education authority, careers, those responsible for services for children - social services and health). This needs to include agreements about when assessment work will begin and how it will be conducted.
- Are the necessary internal procedures and resources needed to support a transition policy and process in place.
- Role allocation - who will undertake assessments, how will services or resources be allocated following on from assessments.
- Are there mechanisms in place to facilitate the co-ordination of roles during the transition period?
- Are there appropriate assessment methods and planning systems for individuals and for transition groups.
- Are sufficient assessment resources available? Crucial here are time resources for care managers and others involved in assessment - there is no point requiring an intensive assessment without protecting workers time for this task. There are likely to be resource implications for provider services also as students and families explore and are introduced to services. Various approaches have been attempted:
 - nominating specific workers as transition assessors/co-ordinators
 - weighting caseloads to protect time for intensive transition work

- providing additional staffing hours to facilitate transition activity at key points of the year.

- Is there a clear process for pulling together the key participants (including young person and family) at the start of the agreed assessment and planning period to plan individual assessments?
- Are a range of useful tools available to managers and practitioners?
- Are there appropriate arrangements for provision of information to students and families - range of methods, tools, stages for information provision. Are the specific needs of people from ethnic minority communities, and people who do not use words for communication properly addressed?

Health purchasers

Making Connections points to a number of pieces of legislation relevant to health authorities:

The National Health Services Act 1977.

The Health and Social Security Adjudication's Act 1983.

The National Health Services and Community Care Act 1990.

The Health Authorities Act 1995.

The Joint Consultative Committees Order 1996.

The recent DoH guidance on health services for people with a learning disability *Signposts for Success*, (1998), also makes reference to the need for input into transition planning to ensure that appropriate adult services are planned (p53).

Making Connections notes that as good practice, health authorities are expected to nominate a designated officer for young people who have special educational needs. The duties include:

- provision of advice to NHS staff and to other agencies on the preparation of statements of special educational need;

- outlining the contribution that the NHS may be able to make towards non-educational and employment provision;
- co-ordination of requests for information on the health needs of young people with special educational needs (p19).

Health purchasers should facilitate the production of joint transition policy and process, ensure that health providers are engaged with this policy, and provide funding as necessary to both enable the process of transition and to support individual service packages as appropriate.

Health service providers

Health service providers have important roles in ensuring continuity and adequacy of a range of services. Some questions providers need to address are:

- Are school health services making an appropriate contribution to the transition process? This includes involvement in transition planning and health objectives emerging from this. Also linking with adult service commissioners and providers to ensure necessary continuities. The links to adult services (health, social services and others) may include transfer of information during assessment; assisting adult providers to develop an understanding of key health needs; advice and training.
- Are there clear roles for specialist and generic health providers? For example which roles might be played by specialist learning disability nurses, which by district nurses or health visitors? Is access to the range of services outlined within *Signposts for Success* being facilitated?
- Are assessments in respect of health care needs undertaken in the later school years? Do these assessments take into account the developing needs of the young person as they become an adult? Are the assessment activities and contributions of the various health care professionals co-ordinated and coherent? Does health assessment activity link effectively with social care assessment and planning? Is assessment information routinely included in transition planning and made easily available to those involved in this planning?
- Are creative and innovative methods being used to enable the young person and their family to play a central role in their own health care?
- Are mechanisms in place to ensure:
 - necessary continuities of health care provision as a young person leaves school in order to avoid loss of health benefits built up through school years. This includes continuity of provision and practice. In addition, any necessary equipment that may be needed should be flagged up in sufficient time, especially if responsibility for it's purchase changes
 - any necessary transfers of professional or practitioner are achieved in a timely and smooth manner
 - that the health care provided as a person leaves school is co-ordinated and not fragmented in terms of objectives and tasks.

Many involved in transition work have noted that the health role in respect of people with particularly complex health needs is especially important. For such people early and co-ordinated planning and service design by health professionals in collaboration with partner agencies is needed to ensure that competent and appropriate adult services replace childrens provision.

Careers service

Making Connections notes that the key legislation here is:

Sections 8 to 10 of the Employment and Training Act 1973, (as substituted by Sections 45 and 46 of the Trades Union Reform and Employment Rights Act 1993). Key policy is provided in the Secretary of State's *Requirements and Guidance to Careers Service Providers*.

Since 1 April 1997 all careers service providers have operated independently under contract with the Department for Education and Employment. The contract specifies the level of work which must take place within each financial year and has quality systems built in.

Each young person has an entitlement to careers guidance which is offered as a specified number of small group sessions and interviews at prescribed stages from year 9 onwards. The entitlement applies to all young people, including those with disabilities. Written Action Plans which summarise the individual's plans and training/education routes are an important part of the guidance process.

People with disabilities remain part of the 'core' client group (i.e. are not required to pay for guidance services) until they are 'settled in their career intention'.

The Careers Service must receive invitations to all 14+ Transition Review meetings and the Code of Practice describes their role in the transition planning process.

Some key questions for the Careers Service are:

- Is the Careers Service response to the invitations to 14+ Transition Review Meetings clear and understood by all the relevant parties? e.g., will specialist or generic careers officers be involved?
- If careers officers do not attend reviews what is their written contribution to the transition planning process?
- Is the role of the careers officer in the transition process clearly delineated and central to vocational planning? This may include:
 - contribution to careers curriculum in final school years
 - involvement in transition planning for individuals.
- How will the careers officer help the school to amend the careers education program where requested for a particular student?
- At what stage in the process will Careers Advisers bring in providers of further education and/or training?
- What will be the Careers Service approach to working with parents or carers?
- Is there a careers curriculum in place in the final school years that is:
 - appropriate to the needs of students with disabilities
 - integrated with adult vocational, educational and other relevant services and opportunities?
 - creative and encouraging high expectations.
- Has the local Careers Service provider contributed to the production and operation of transition policy and process?

Non-specialist agencies

It should be noted that, although this guidance had focused to a significant degree upon the roles for specialist agencies, their role in facilitating access to non-specialist services and opportunities is crucial. If people with learning disabilities are to achieve inclusion into ordinary life opportunities specialist agencies and professionals must be outward looking and avoid transition meaning simple transfer between segregated services.

Appendix 2 - References

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Appendix 3 - Useful Contacts

North West Training and Development Team Transitions Network

Over the past year or so the NWTDT has been exploring issues around transition between childhood and adulthood for people with learning disabilities. This has involved a range of activity including discussions with people involved in transition, collection of useful materials, consultancy work etc.

An informal network of people has been put together as the NWTDT has made contacts and connections. We have tried to circulate useful information and material to this group. We now want to offer more structured support and to offer membership to a wider range of people with an interest. In line with a number of networks being supported by the NWTDT we are developing the opportunity for people to share useful information and developments in a range of ways:

- a central information resource
- regular newsletters
- events and workshops
- a data base of regional work and developments in the area of transition is being developed and will be used to support the network and link with national efforts.

Many of the examples and approaches to transition covered in *After School What Next?*, come from Network members. There are now a growing number of joint agency transition frameworks. For more information contact: Martin Routledge, NWTDT, c/o Oldham Learning Disability Service, Broadway House, Broadway, Chadderton, Oldham, tel: 0161 911 3848.

Checklist

Chris Gathercole from the NWTDT has adapted a detailed pack/checklist from the USA which might be useful for people in this country. Available on computer disk from Sue Canavan, tel: 01254 821334.

General Contacts

The contacts for some services mentioned in the above guidelines are:

Elizabeth Clayton, Head of Learning Disabilities Health Services, **Bolton Community Healthcare NHS Trust**, Avondale Health Centre, Avondale Street, Bolton BL1 4JP, tel: 01204 492330.

Jackie Philips, **Stockport Healthcare Trust**, Oak House, 2 Gatley Road, Cheadle, Cheshire, CH8 19Y, tel: 0161 491 4376

Martin Routledge, **Oldham Learning Disability Service** (see above).

Making Connections

Interdepartmental Government guidance has recently been produced - *Making Connections a guide for agencies helping young people with disabilities make the transition from school to adulthood*, (1997), is intended to assist the various agencies in clarifying their roles and responsibilities. Contact: Further Education Division of the DfEE, tel: 0171 925 5245.

The Council for Disabled Children

The CDC are about to publish *Transition: A Guide to Selected Information Sources Available to Young Disabled People and their Families*. This has been compiled by Wendy Beecher, Information Officer with the CDC. This publication will be very useful for families, young people and professionals. Chapters cover: selected organisations; general reading; benefits and money; vocational, further and higher education; training and employment; independent living; housing and accommodation; clothing and equipment; personal and social relationships; leisure and community activities; health and medical matters; statutory and voluntary services.

The CDC have also compiled a Transition Database including details of projects and relevant reading. For more information contact Wendy Beecher, Council for Disabled Children, 8 Wakely Street, London EC1V 7QE, tel: 0171 843 6000.

The National Development Team

The NDT are undertaking Department of Health funded work on health issues in transition as part of their *Health Wise* program. The program, *Positive Health in Transition* was started with funding from the Department of Health. The project was set up in response to the many anxieties encountered by the NDT about a falling off of health services and childhood supports for young people with learning disabilities leaving school and moving into adulthood. For more information please contact Margaret Pearson, Project Co-ordinator via the NDT at St. Peter's Court, 8 Trumpet St, Manchester M1 5LW, tel: 0161 228 7055.

Total Communication

Oldham Learning Disability Service has, for the last three years, run an annual Total Communication Conference. The conference is open to service users, their friends, relatives

and care workers. Workshops on the use of signs, symbols, drama, computers, video and photographs using the Total Communication approach are offered. Contact Alison Matthews, Anne Dean, Communication Therapists, tel: 0161 911 3848.

Values into Action

VIA, also funded by the DoH, commissioned Tony Ryan to explore the experiences of young people in transition, especially looking at how to effectively involve young people in the planning for their future. For more information see the forthcoming publication *Making Our Own Way: Transition from school to adulthood in the lives of people who have learning difficulties*. Values into Action, London. Contact Tony Ryan, tel: 0114 255 4835.