

Collective Responsibilities, Fragmented Systems:

Transition to adulthood for young people with learning disabilities

Abstract

This paper explores obstacles to the provision of effective support for young people with learning disabilities and their families as they move towards leaving school and the take up of adult opportunities and services. Despite frequently disappointing current experience, there are some encouraging developments that local agencies could build on to offer supportive, creative assistance during this crucial period for young people

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Introduction

In 1997, interdepartmental guidance was produced for those agencies responsible for assisting young disabled people and their families through the transition from school to adulthood. In the introduction it was noted that the publication resulted from 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”. (DOH/DfEE/DoE, 1997)

Research and practice guidance have been published by a range of agencies and authors (Further Education Unit, 1994; Flynn & Hirst, 1992; Pearson et al, 1999; Routledge, 1998; Russell, 1993; Social Services Inspectorate 1995a and b; Ryan 1997). Authors have highlighted fragmentation of policy, of agency and professional roles, and underdevelopment of appropriate and effective practice (Routledge, 1998; Morris, 1999a).

The current author was, for five and a half years from 1994, the chairperson of a multi-agency transition steering group in Oldham. From 1996 he has also led on transition issues within the North West Training and Development Team (NWTDT). In the area of transition, NWTDT activities have included consultancy, the production of guidance and network building. Much of the content of this article is based upon NWTDT work.

What is transition?

In 1986 an OECD/CERI paper identified critical stages of transition and some goals for young people.

Stages:

- 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

Goals:

- 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 (OECD/CERI, 1986)

Those who have gathered the views and experiences of young people with disabilities find, unsurprisingly, that they certainly do have personal goals and aspirations in these areas and that their wishes match those of other young people. We are also cautioned not to establish a rigid list of transitional goals.

“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 over their own lives. Young disabled people do not always state the exact same list but why should they be expected to?” (Tidsall, 1996)

It is equally clear that young people with disabilities need assistance to pursue their goals and aspirations. Parents and families also need support during the transition of their sons and daughters into adulthood. Young people and their families are faced with significant changes and decisions during this time. Many of these relate to services received. There are changes:

- To the curriculum in later school years
- Of workers involved from Education, Health, Social Services and other agencies
- To financial arrangements
- In the places where some services are provided and the personnel providing them
- Of the departments or sections of departments responsible for the main services received
- To the general nature of services, from a mainly educational focus to broader aims within adult services
- In legal status and the implications of these, 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 and to envision the potential adjustment difficulties. Families are also fearful about possible loss of service or unavailability of suitable provision.

System fragmentation

The difficulties faced by young people and their families are compounded by the policy and organisational fragmentation, which makes it difficult for service agencies and professionals to provide the coherent and co-ordinated assistance most likely to promote a positive and successful transition experience.

Unfortunately, despite the implementation of the Special Educational Needs Code of Practice (Department for Education and Employment, 1994), with its important transition related elements, many people are still not benefiting from effectively co-ordinated transition support. A recent Department of Health review of Quality Protects Management Action Plans noted that

“There was widespread concern about transition planning arrangements” (Department of Health, 2000)

Local implementation of the Code appears to be variable. Even when LEAs operate it well, there is no guarantee of effective involvement from other agencies – Careers, children’s and adult social services, children’s and adult health professionals etc. These agencies are not under sufficiently effective requirement to participate fully.

We still appear to have a situation where, in the main, the separate agencies, sub parts of agencies and professional groups are focused upon their own imperatives and where coherence is too often the exception rather than the rule. It appears that local factors such as resources, local policy, organisation and agency cultures, and individual professional interest/availability are strong determinants of defacto transition support arrangements.

Contributing to operational difficulties, local strategic contexts are often not strongly supportive of coherence.

Resources

Resource and workload pressures are often quoted as a major cause of inadequate transition support. One recent study of professional’s views (Cohen et al., 1998b) notes that workload pressures were seen to have

“...affected participation in transition planning across the agencies – from lack of time and administrative support for school nurses in drawing up healthcare transition plans, to social workers and therapists difficulties in finding time for joint visits with colleagues during the handover process, to lack of time for Health, Social Services and further education staff to attend transition reviews as they would like to. Given these pressures it was difficult for some staff to look further than procedural obligations under the Code of Practice”

Specific problem areas

Problems are commonly found in some key areas:

- *Linkage between the LEA organised transition process and the involvement of other key agencies and professionals.*

Parents often note that professionals who they would see as important attend transition reviews patchily. This is reflected in the frequent lack of effective systems between, for example, the LEA and social services for children with disabilities as to which reviews will be attended, how actions will be followed up etc. This is despite the requirements of the Code and of the Disabled Persons (Services Consultation and Representation) Act 1986

- *Transfer of information on individuals and for broader planning purposes between children's and adult services.*

There is often a lack of effective means by which the agencies responsible for children's and adults' services ensure that adult services are properly aware of the needs of young people coming through. The Department of Health Quality Protection review noted particular concerns about,

"Inadequate management information systems between education, health and social services departments"

For individuals, this can have the consequence that adult agencies fail to provide sufficient, timely support or to facilitate appropriate choice and creativity in service design. At the level of broader service planning the consequence may be that patterns of changing need are not properly anticipated.

- *Arrangements for ensuring continuity between children's and adult sections of education, social service departments and health services.*

This includes assessment arrangements, transfer of responsibility and supporting adjustment to new services and circumstances. Parents sometimes feel that it is as though their sons and daughters are "starting again" as they prepare to leave school and move into adult services and opportunities. People often report that they seem to have to provide the same information to different professionals. They are also puzzled by differing eligibility criteria and by transitions which take place at different times, depending on the agency or service.

People often find themselves faced with transfers between services without adequate preparation. An example would be young people moving from children's to adult short-term support services. There are often major differences in size of facility and service ethos, which people are not properly supported to get used to.

Significant problems are also often noted with health service transitions (Pearson et al, 1999). One recent exploration of the views of young people and their carers noted:

"There were a number of problems with hospital transitions, usually in relation to outpatient services, where consultants made individual decisions about transferring to the corresponding adult clinic. Hospital transitions particularly affected young people with PMLDs who often attended several different clinics. Some carers of these young people were having severe problems with health service transitions generally, although they welcomed a (newly introduced) healthcare transition plan and/or follow up from a school nurse" (Cohen et al 1998a)

Disempowerment

These local realities mean that families and young people can be faced with a confusing and stressful period. It is often the case that young people and families feel disempowered by their lack of information about services and opportunities, their rights and how to access them. This makes it very difficult for people to explore opportunities and choices and to exercise real influence over these.

There is some evidence that certain groups of people are least likely to receive effective support in transition. These can include young people from ethnic minority communities, people with “complex needs” and conversely people with mild or moderate levels of disability (Cohen et al, 1998a,b; Morris, 1999b; Pearson et al, 1999).

The North West Training and Development Team have been finding a high level of concern amongst service providers and commissioners with regard to an anticipated increase in numbers of people with “complex needs” coming through from childhood to adulthood. Managers report their concerns that their existing service configurations and interagency working arrangements are likely to make it difficult for them to successfully provide for some young people.

The consequences may be unsatisfactory and insufficiently supported placements within existing services, export on a temporary or permanent basis to external “specialist” providers or even strong reliance on informal care arrangements with the consequent effects upon families. Agencies and researchers report, for example:

- Lack of competence within existing service settings to meet certain needs, especially when people have complex health care needs (Pearson et al, 1999)
- Lack of effective role agreements within specialist services – crucially around health and social care roles
- Inadequate agreements, systems and protocols between specialist and non-specialists – for example between specialist nursing and non-specialist primary care providers

In respect of young people from ethnic minority communities agencies and professionals often report problems both with transition process and service accessibility.

Service outcomes

Linked to the fragmentation of transition support and process, research and experience often shows disappointing *outcomes* for people as they leave school. A recent study of transition outcomes for a group of young people (Ryan, 1998) noted,

“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 that has been brought about by 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.”

These findings are not surprising given the fragmentation of responsibility and provision post school and the historical lack of policy focus or service agency prioritisation of some of these aspirations:

- The availability of further education opportunities seems to vary greatly from area to area, as does the range of courses available, those able to access them and the inclusive or discrete nature of classes
- 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 widely 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 most often stated aspirations of young people with learning disabilities – in areas such as opportunities to develop friendships and relationships, obtaining accommodation in non-emergency situations etc.
- Opportunities for young people to access non-specialist services and opportunities are often very limited
- Parents and carers often find that service gaps make it difficult for them to continue in paid employment or to access appropriate family support, such as good quality leisure opportunities or short-term support

The development of college courses accessed by people with learning disabilities in many areas is often a very welcome addition to the usually narrow range of choices for school leavers with learning disabilities. However, college courses often seem to be set up in ad hoc ways, not linked to any coherent career planning and support. For many there is the danger that a period at college simply delays entry to more traditional forms of service, or to unemployment.

The consequence of a combination of inadequate transition support and lack of post school options can be a simple transfer of people between special school and traditional adult service provision.

Promising possibilities

An informal national network of those interested in improving transition was helped by work undertaken at the Council for Disabled Children (CDC) and more recently the National Development Team (NDT). The CDC developed a database of transition practice from around the country. The NWTDT has made contact with a number of those striving to improve transition and a range of approaches was evident. What seems clear is that attempts to improve transition tend to be limited, with pieces of the “jigsaw” in place in some areas but rarely anything like a full picture. It is noticeable that many attempts at improvement result from the initiatives of individuals, small groups and local alliances.

To date there is little research evidence in this field on “what works”. A very welcome and significant piece of research has recently been commissioned by the DfEE to track a cohort of young people with disabilities and SEN during and beyond transition to give us some longitudinal information about what works.

It is therefore not yet possible to point to approaches that can be clearly and confidently demonstrated to be successful. In this context the best we can do is consider approaches that seem promising in that they seek to address some of the identified deficiencies of existing

practice. A suggested checklist for agencies seeking to support positive transition experience is listed in Table 1.

The development of multi-agency policy and process

In a number of areas agencies have come together to develop joint transition policies and processes. These are very varied in their scope, detail and ownership. Some, for example, set out policy relating to all young people with disabilities, others to specific groups such as young people with severe learning disabilities. Some are established at strategic levels of the agencies, others at middle or service levels. The participating agencies also vary.

The initiative for the development of transition policy and process may come from a range of sources. The author has noted initiatives from professionals directly involved in transition, from middle managers and from carers. The success of these groups is varied. It seems that they often require champions in a position to turn the urge for improvement into practical action and to influence agency decision-making systems.

Table 1 – Suggested checklist for transition process and practice

- Do 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?
- Are the process and stages of transition explained to people at the right time and in the right way for that person/family?
- Do people have consistent, friendly and available staff to answer questions and support decisions and choices?
- Is transition activity co-ordinated between all key agencies and professionals, avoiding confusion, duplication and overlap and service gaps for young people and their families?
- Do the contributions of the different agencies and professionals offer coherent and complementary support for young people coming into adult services?
- Does transition related work start 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?
- Do 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?
- Are the health care needs of young people properly assessed and continuities of health care assured?
- Can all people with learning disabilities access good transition support including people with complex support needs, people who do not use words to communicate, people from minority communities, people placed in mainstream or out of district schools?
- Are options to be taken up on school leaving designed around the informed choices and needs of the person, including support for access to non-specialist and non-service opportunities?
- Is there a range of options and choices available to the young person on leaving school?
- Do post school educational or vocational options allow young people to build careers?

Establishing joint policy and process

Given that no one agency has responsibility for developing comprehensive transition policy and practice there can be difficulties in moving from identification of the need for action through to the development of policy and practice. Those involved are invariably busy professionals and managers. Progress seems most likely when some resources can be identified to facilitate mapping of the current situation and to generate proposals for development

In some areas local conferences exploring transition have led to working parties, secondments or use of Joint Financed posts for development of policy and process. There are many examples, however, where initial enthusiasm has not led to systemic action or where policy and practice has been developed but dissipated through over reliance on individuals or small groups.

As noted above, the scope and detail of policy and process varies. Some of the key components for potential inclusion are suggested in Table 2. In some areas there seem to be dangers that the construction of policy process and practice is not sufficiently influenced by the actual experience of young people and families. In these situations the result can be an over focus on administrative issues.

Table 2 – Possible content of joint agency transition policy

- Joint agreement regarding the central aims and functions of transition activity
- Clarity as to who is to benefit from the policy and process
- Stages, phases and activities of transition
- Specification of roles for agencies, parts of agencies, and professionals
- Procedures and protocols in key areas, including:
 - ❑ transfer of information for planning;
 - ❑ clarity of roles and activities associated with the 14 plus review and implementation of plans;
 - ❑ agreed approaches to the empowerment of young people and their families in the processes of transition;
 - ❑ arrangements in respect of the key provisions of the Disabled Person's (Services Consultation and Representation Act) 1986;
 - ❑ post 14 arrangements and roles between children's and adult sections of social service departments and health services;
 - ❑ arrangements for assessments under relevant legislation and for co-ordination of assessment and service planning between the key agencies and professional groups in the final school years;
 - ❑ agreements in respect of key operational issues;
 - ❑ arrangements for transfers between specific services;
 - ❑ roles and responsibilities in respect of post school transitions, including management co-ordination across agencies

Improving transition practice

A range of approaches to increase the coherence of agency and professional work in transition are being attempted:

Organisational mechanisms

- Transition steering groups

These groups seek to bring together key stakeholders in transition, sometimes including family members and people with disabilities. Their roles vary. Some aim to develop, support and implement joint transition policy and process. Others have a more limited remit, such as meeting at key points of the year to make arrangements for individual transitions

- Joint or integrated transition teams

There are many variations on the theme of transition teams. The degrees of jointness vary. There are single or joint agency teams which span children's and adult services and joint teams within either children's or adults. Whatever the form adopted a key principle is the understanding and acceptance of the need for focussed investment of time and resources during transition

- Transition co-ordinators

These may be cross agency or co-ordinators within each key agency who link to provide overall coherence. Equally the functions of co-ordinators vary. They may operate at a senior level in agencies, ensuring increased coherence of effort and better linking to other agencies transition work. Some work on a more operational level, for example being the nominated officer to attend 14+ reviews and/or meetings which pull together planning around individuals.

- System linkages

For example information system links. In some districts technical and protocol solutions to these problems have been developed.

In addition to these "hard" components, some have recognised the importance of measures that seek to improve knowledge across agencies and professionals and to build and maintain the relationships that can be key to effective and productive joint working.

Practice tools

A range of tools has been developed to improve transition practice in general and joint working in particular. These include:

- Joint or integrated assessment. A prominent example of this is that developed by the Oxfordshire Joint Commissioning Reference Group for Children with Special Needs (Roiser, 1998).
- A range of other tools, such as:

- ❑ transition files (pulling together professional, young person and family contributions)
- ❑ joint transition calendars
- ❑ practice and process guidelines
- ❑ joint progress reviews
- ❑ transition planning/resource panels;
- ❑ personal health records.

Increasing the influence of young people and families

In some areas, recognition of the crucial importance of empowering young people and families in transition has led to the development of practical methods by which this can be achieved

- Means by which useful information can be accessed and used by families and young people to assist informed choices – examples include videos, information booklets, “transition fairs”, courses for families and young people about adult services and opportunities, link courses, taster opportunities
- Approaches which empower young people and their families in the transition process, including the use of advocacy in schools, independent advice and support, person centred planning, adjustments to traditional “report and meeting” type planning and reviews, creative assistance to those who do not communicate with words, focussed assistance for people from ethnic minority communities

Broadening choices and opportunities

Some have explored means by which a greater measure of choice can be introduced into transition outcomes

- The availability of workers with appropriate skills offering involvement over a substantial period to plan with young people and their families. This investment can promote the opportunity to explore a wider range of opportunities and possibilities, including the development of new services and partnerships
- Mechanisms for turning more person centred assessments/plans into new forms of service or non-service opportunities. Examples include transition care management budgets, new contracts with providers and commissioning systems that respond to needs/aspirations identified and aggregated in transition planning.

Changing policy

At the time of writing, there are many policy developments with potential implications for transition. At this point it is not possible to do more than “crystal ball gaze” about the possible impact of most of these. Some of the key developments are:

- **The Learning and Skills Bill** – The role of the Learning and Skills Councils. To what extent will their membership and priorities reflect the needs of young people with

learning and complex difficulties? Proposals to extend transition planning beyond school leaving – to be welcomed but who will manage such planning post school?

- **The role of the Youth Support Service and Learning Mentors** – for all young people of thirteen plus. Will these new advisors have the necessary skills to support young people with disabilities in transition?
- **The introduction of direct payments for young people and carers** – will young people with disabilities have personal advisors as under the **Children (Leaving Care) Bill**?
- **Implications of the Disability in Education Bill** – the impact of bringing education within disability discrimination legislation, including school, further, higher and continuing education
- **Quality protects** – The CDC analysis of QP Management Action Plans shows that transition is becoming a higher priority in most areas but there are questions about how much focus there is on the specific needs of people with a learning disability

Conclusions

There do appear to be some hopeful signs that the need for focussed, multi agency, transition support is becoming increasingly recognised. Whilst activity aimed at improving transition still tends to be located mostly at operational or middle management levels, more senior managers are requesting assistance for their agencies.

At the time of writing a National Learning Disabilities Strategy is in preparation. The need to improve transition experiences and outcomes is a recurring theme in consultations for the Strategy. We might hope, therefore, for some clear messages for the responsible agencies.

It seems unlikely, however, that we will see major and sustainable improvements until some of the structural sources of fragmentation of agency effort are removed or undermined. At the time of writing there do seem to be attempts at a national policy level to promote the reduction of some sources of fragmentation. The development of Joint Investment Plans, shifts towards joint or integrated commissioning, opportunities likely to emerge from the potential pooling of budgets - are all ways of breaking down the barriers. At the same time as these potentially helpful policy initiatives, however, local agencies will also have to incorporate new players such as the Primary Care Groups/Trusts.

In reviewing the Code of Practice the DfEE (1998) has indicated its desire to strengthen the transition elements. The author's view is that co-ordinated guidance from the major Government departments would probably be required to give teeth to such a strengthening. In addition, resource incentives to support investment in both single agency and joint transition effort would be very helpful.

In addition to policy likely to impact upon organisation and systems there is emerging policy direction towards social inclusion, promoting independence, inclusive education and lifelong learning which could be seen to reflect the aspirations of young people with learning disabilities. In order for these initiatives to impact on their lives, however, local agencies will need to ensure that people with learning disabilities are properly included in local implementation.

As a final thought, the author would offer the view that if young people and their families are to receive the kind of support in transition that they deserve, local agencies and professionals

will have to face whatever system context they find and take collective responsibility for constructing workable and effective local solutions.

At a recent conference, exploring good practice in transition, several presenters talked about individual professionals, managers and staff “*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 currently no alternative to the key agencies doing the organisational equivalent of going beyond their job descriptions.

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