Where are they now? Transition Pathways - A small scale study into the post school experiences of a group of young people with learning disabilities in the 21st Century.

Aims:

To explore and map the experiences of a small group of young people with severe and complex learning difficulties as they make the transition to post school life in the years since leaving their special school.

Research Questions:

- What do the young people and their families feel about their experiences since leaving school?
- How did school and service providers prepare them for their post school experiences?

Context:

There has been a great deal of time and effort invested by special schools and a multitude of organisations and stakeholders involved towards the transition to post school life of young people with learning difficulties. Multiple processes and procedures support this process (Dee, 2006). Has all this considerable effort been misguided or misinformed by schools and their partners, in an effort to guide the young people along pathways that ultimately may not be in their best interests?

This research study was commissioned by Dave Victor, Headteacher of Greenside School in Hertfordshire an all age day special school for children and young people with severe and complex learning difficulties (sld). Colin Gladstone a teacher at Greenside with experience of practitioner based research and a special interest and knowledge of the transition process conducted the study. It seeks to question the effectiveness of what the school and associated organisations deliver towards the transition to post school life for these young people. Importantly, unlike most research in this area, it takes a group of young people who left school six years previously to examine how their lives have unfolded.

Historically, most young people with severe and complex learning difficulties (sld) went to their local Day Centre. Post Warnock (1978) this began to change as FE colleges began to provide discrete courses for students deemed as having special educational needs. There was a dissemination of specialist curricula and guidance throughout the 1980's by the Department for Education and Science's (DES) Further Education Unit (FEU). The Further and Higher Education Act (DfE, 1992) arrived bringing new funding mechanisms. The Tomlinson Report (1996) reconceptualised provision for students with learning difficulties. This initiated an arbitrary movement from sld schools to further education (FE) provision that meant most attending their

local FE college with the outcome that, arguably, 'they got lost in a carousel of provision over many years that had limited useful benefit to their future lives' (Wright, 2006). Anecdotal evidence appears to point an abiding reason for this group going on to FE provision being largely due to the fact that there was nothing else and parents believed they were putting off the need to face the future for a few more years. Within this group there is a significant number with additional medical or challenging behaviours whose choices and opportunities were even more restricted as provision meant either residential college placement away from their community or limited and inadequate day care.

My professional belief and the basis for this research derive from the premise that the role of education in society should be to prepare and equip any young person to fulfil a valued, and purposeful place, with some measure of independence, in their community. These are key words and indicators of a successful transition process. The Department of Health paper, 'Valuing People: A New Strategy for Learning Disability for the 21st Century' (2001) provides a set of strategic objectives for Health, Social Services, Education, Employment and Housing which aim to provide opportunities for young people to live 'full and independent lives as part of their local communities' (DOH 2001). It seeks to ensure that young people with learning disabilities are empowered where appropriate to work, live in their own homes and have a choice over who supports them. How Valuing People is translated into local action is crucial to success.

There has always been good intention by many parties involved but is there a fundamental flaw in the way education, health and social services and indeed, other organisations action their role? The impact of person centred planning and the rhetoric surrounding it has yet to make a significant difference to the life choices of young people with severe and complex learning difficulties. Has a constant stream of central legislation, restrictive funding mechanisms and over complicated systems restricted person centred planning? There has been within Hertfordshire a genuine desire by child and adult services to adopt a multi agency framework supporting the notion of person centred planning in the transition process, but do the way they are structured present barriers to this being achieved?

In order to explore possible solutions to these questions I present a view that any coherent transition strategy must begin from the expectation that 'work' is central to the planning and implementation of any education, training and service provision for young people with learning difficulties. Without 'work' as a key life goal for the majority of young people with sld there will never be purpose to their transition process. The multi agency transition protocol and plan needs to reflect this. Mainstream education is organised and delivered with the central focus being future employment as the eventual goal. Special schools and associated services need to change their culture to embrace this all-important key life goal. Only then will the considerable resources invested have purpose.

The notion of 'work' can mean a variety of things including employment, sheltered, supported part or full-time or otherwise, work experience or experience of work. I see 'work' as a multi-faceted opportunity related to time and place. Work might not be experienced for several years after leaving school; it might be part or full-time, work experiences or experiences of work. It might be sheltered or supported or unsupported employment full or parttime a realisation for some, but not necessary for all. There should be an expectation that whenever a form of employment is undertaken it is paid. The time factor is important as it allows the flexibility to ensure that the vocational and work skills needed are developed over, if necessary, many years. This positioning of 'work' as an important component of any transition plan requires schools, colleges, the connexions service and other organisations to respond in a meaningful and practical way. By this I infer a person centred approach that challenges services to consider and plan collaboratively for adulthood post 25. Questions need to be asked about whether six years in FE college provision is a necessary step for some young people with sld? Work and living away from home, but in their local community, needs to be seen as a realistic goal by stakeholders for the majority of young people with sld. There are considerable issues with parents in ensuring they have the knowledge, information and a sense of meaningful involvement in the process so they can be confident in 'letting go' when the time comes.

We must plan and support the young people and their families to attain this goal for life post 25. This is crucial in young people with learning disabilities realising a valued, purposeful and measure of independence in their community. Working and being paid a wage empowers, but crucially it also promotes respect, control and importantly greater purpose in their lives.

This paper outlines the findings of a small-scale study investigating the views of a group of school leavers and their families from Greenside School for students with severe and complex learning difficulties. The young people are all approximately 25 years old so at the point of leaving their entitlement and access to full-time education. Their dominant educational need is related to cognitive impairment manifested by difficulties in learning. This has been commonly described as severe or complex learning difficulties (sld) for the students at a school like Greenside. Two young people have profound and complex needs and five have severe learning difficulties. provides an appropriate time to reflect on whether the transition to post school life has been deemed successful. The research questions, at the beginning of this paper will be tackled by the three successful transition indicators; valued, purposeful and measure of independence in their community. What would a valued place look like? What purpose would the young person need for a successful transition? And finally, what do we mean by measure of independence for the young people?

Policy Context

The Disability Discrimination Act (1995) enabled a policy drive towards a more inclusive educational provision started in the early eighties for 5 to 16 year

olds to move into further education with policy guidance and legislation designed to enhance educational opportunities for all young people. Learning Skills Council created in 2000 raised awareness of the challenge to develop educational opportunities for young people aged 19 to 25 however vulnerable or excluded, in local FE provision. The Tomlinson Report on Inclusive Learning (1996) explored the inclusion of students with learning difficulties into further education without legislative backing. It wasn't until the Special Educational Needs and Disability Act (2001) arrived that arguably meaningful change came about. Also in 2001 the Department of Health paper, 'Valuing People: A New Strategy for Learning Disability in the 21st Century arrived. This provided a set of strategic objectives for Health, Education, Social Services, Employment and Housing to provide opportunities for children and adults to live, 'full and independent lives as part of their local communities' (DoH, 2001). The Special Educational Needs Code of Practice (DfES, 2001) promoted the inclusion of young people in the transition and annual review process. More recently the National Service Framework for Children, Young People and Maternity Services (DoH, 2004) established a transition task group to promote key recommendations specifically a personcentred planning approach and a greater control over their choices for education, training and employment.

In November 2005 the Learning and Skills Council (LSC) published the findings and recommendations of the strategic review of the LSC's planning and funding of provision for learners with learning difficulties and/or disabilities across the FE system, Through Inclusion to Excellence. The follow-up report Learning for Living and Work: Improving Education and Training Opportunities for People with Learning Difficulties and/or Disabilities (Oct 2006) outlines the LSC's strategy for implementing the vision of *Through Inclusion to Excellence*. It contains many powerful statements of intent, '...collaborative deployment of public funding', '...the importance of progression to employment where it is appropriate', 'enable economic participation', '...live autonomously and contribute to the communities within which they live'. The LSC will support in the next three years a move away from work-preparation programmes to a supported employment model where learning in the workplace is central. Further the LSC states '...this should provide the skills and knowledge leading to part or full-time employment'. I contend that the LSC's position provides a clear mandate for special schools to affect a sea change in the way they perceive the future life prospects for their students.

As outlined there has been no shortage of guidance, recommendation and legislation in recent years and a move towards the importance of work, but has it provided empty rhetoric with little meaningful change in the future life prospects of young people with sld and their families. Wright (2006) in her small-scale study on provision in FE colleges found, 'no established infrastructure to support effective partnerships to ensure transition to work or independent living'. She found a 'lack of effective partnerships with social services, Connexions, employment providers, employers, health authority and housing'. By exploring directly the views of the people in receipt of this endeavour I hope to inform future school policy and practice and raise

questions about the suitability of service structures and practice in the transition process.

Methods

In order to tease out the experiences, personal stories and aspirations of the young people and their families a case study approach was used incorporating semi structured questionnaires and interviews. A review of current and past literature was carried out to support the research process. The multiple method approach to this study was designed to collect qualitative data, which, by its very nature, is difficult to collate and categorise. In presenting the findings here I am employing the following hypothesis: the more often an issue appears, via different collection modes, the more likely it is to be important. A second hypothesis is also employed: communication is central to effective data collection using multiple modes and the interpretation of language used will provide important assumptions.

Ethically, I was acutely aware of my particular relationship with the respondents as not only had I worked with the students in some cases for many years, but I also knew the parents well. I felt that my position on balance provided me with an opportunity to meaningfully gain their views and that this outweighed the issues surrounding bias. Contact was made initially by telephone and then a letter was sent, outlining the aims and nature of the study and asking for the parent's permission to participate.

The sample comprised 7 young people and their families. The difficulties of meaningfully gaining the views of children and young people with disabilities have been well documented in recent years (Lewis, 2001; Lewis & Lindsay. 2000; Begley, 2000: Shevlin, 2001). The ethical protocol for this piece of research demanded that issues concerning informed consent, confidentiality and anonymity were addressed. Consent was obtained from both parents and their youngsters to the research with particular time spent on exploring what research was and might mean for the two young people interviewed. I felt conscious of endeavouring to place their concept of 'research' into a meaningful context but again concluded that it was crucial to give them the opportunity to air their views. Protocols were used with each instrument in order to ensure reliability of data. To enhance the use of the questionnaires the young people were consulted over its formulation. This sharing in the design proved useful on a number of levels, empowering the students, language used, piloting and the question reply grid. A review of current and recent literature on the subject of transition from school to post school placement was carried out. Two experienced professionals were consulted over their views of the transition process. This allowed for the use of 'critical friends' in the data received and the subsequent findings. Information was gathered in naturalist settings by interviewing the young people and their parents in familiar settings.

Six questionnaires were completed, two semi-structured interviews with young people and two semi-structured interviews with parents. As far as possible

the participant's anonymity and confidentiality was assured. The young people interviewed had fewer questions with key words and a combination of symbols and pictures to support understanding. There is no doubt in my mind that knowing the respondents very well and their ability to respond to the questions enabled me to meaningfully gain their views. Information was gathered from experienced professionals closely associated with the transition process and this supported the analysis of data.

Findings

In presenting the findings it is important to remember the small sample of this study. However, the views and actual experiences of parents and their youngsters who have gone through many years of post school provision, as service users are valuable. The findings raise a number of issues pertinent to the aims of this study and the belief that all young people have a right to a valued and purposeful place in the community with some measure of independence in their lives. Six years on since leaving school 5 young people still access a mixture of part-time college courses and day centre with 2 attending their local day centre 4 to 5 days a week. None have, or have in the near future, any expectation of paid employment.

Post School Pathways

Questionnaire Findings

In reporting the parents views from the questionnaires evidence points to a lack of purpose, value and independence in the majority of young peoples lives. Decisions about where the young people went after school would appear to be dictated by what provision is available as opposed to individual aspirations. This dilemma between aspiration and provision is still apparent. Parents now, almost 6 years on weren't sure if accessing several years of different college courses had provided any direction towards a secure future for their youngsters.

On leaving Greenside 4 young people went to their local FE College after participating in a link programme from school for 2/3 years one day a week prior to leaving school. The course is a two-year full-time course 21 hours per week, 34 weeks per year. On completion of this they went on to access other college courses. All 4 young people are still accessing part-time college provision.

Two young people went to different FE Colleges in another part of the county. One went 4 days and one day at their local day centre, while the other went 5 days.

One young person went to live in a residential establishment out of County because their family and professionals deemed it the most appropriate pathway for them. This placement did not work out due to their challenging

behaviour and they are now living at home with a comprehensive day care package, including day centre 5 days.

Five out of the seven young people are living at home with their parents. One person lives in a social services home in the community and has done since before leaving school due to medical and family bereavement issues. One young person lives in a Housing Association facility attached to the local FE College and targeted specifically at students who attend that college. At present five are in receipt of a local part-time day centre and FE college package of provision. One attends five day a week and one receives part-time day centre provision. Importantly, all the young people attend and attended discrete courses for youngsters with learning difficulties.

Parent's views

Most parents expressed satisfaction with what school had provided for their youngster based mostly on a happy, supportive and safe environment within which to learn. They commented more than once on the dedication of the staff. They mostly expressed positive views about the school's role concerning post school placement and did not seem to attach blame for the perceived lack of choice. One youngster's parents thought that school had not prepared them for post school placement. These were parents who despite considerable support from a variety of services felt no nearer a secure future for their youngster than when they left school 6 years previous.

Interestingly, parents commented on the fact that school was the main source for obtaining information about the transition process. They also saw staff as a support and confidant at a difficult time in their youngster's life. Headteacher and teachers were seen as the key people involved in the transition process and not Service Providers like the Connexions Personal Advisor or Social Worker.

All parents except one stated that involvement by Social Services, whether Child or Adult Care, was sporadic and inconsistent during the transition process. This ranged from not having a link social worker, having very little contact with them or having plenty of contact but little satisfaction with the service provided. Attendances by the link worker at school annual review of the statement meetings were said to be haphazard at best and not at all in some cases. Most parents felt that there was a problem in the handing over from CSF (Hertfordshire's joint Children, Schools and Family Service) to Adult Services. It usually meant long delays in resolving existing issues such as respite care provision. Respite care was mentioned by the majority of parents as being problematic with concerns over the amount and quality of what was offered. The amount of respite varied widely between parents of young people who were very similar in need.

In exploring what the young people did with their leisure time, those who lived at home tended to do less outside of family activities and had a smaller circle of friends. The two young people who were living away from home had more active social lives and a wider circle of friends, particularly people outside of the learning disability community. Leisure Direct, a North Herts charity, provides sporting and leisure activities for over 18s who have learning disabilities and/or mental health problems. Some young people accessed this group on an adhoc basis but transport proved an issue with most of them. There were a minority of young people who attended local youth clubs but they were all discrete to people with learning disabilities.

The Connexions Service was an organisation that most parents felt had provided little ongoing support in the transition process. They were not sure what part they played in the transition from school to post school placement and had received only minimal involvement in the years since leaving school.

Most parents stated that they had been given very little if any choice over post school placements and felt that the local college course offered for the majority was not what they deemed to be full-time and that it had not led anywhere useful towards a secure future, apart from another college course. Some parents felt that a lot of what their youngsters had done at college was 'enjoyable', but deemed it 'unchallenging' and 'doesn't really lead to anything does it?'

When asked about aspirations for their youngsters they used phrases like, 'secure future with good care and quality of life", 'I would like to see my youngster in a flat with some assistance', 'happy, healthy and content'. These are all aspirations that any parent might have. All parents/carers expressed concern and anxiety about the uncertain future for their youngster in respect of day care provision now they had come to the end of entitlement to full-time education and also where they would live. For most youngsters part-time courses at college represented an increase in anxiety about what would happen for the rest of the week. For those parents with their youngster still at home there were serious concerns about what the future held. Although some parents had considerable packages of support from services they largely remained ignorant of how the services operated and what could be available.

None of the young people were in any form of paid or unpaid employment. A minority had undergone different work experiences while at college and one had undertaken some work training. The majority of parents felt that some form of work was important as a future goal because it gave their youngster's something to aim at. Interestingly, comments were made about how school had provided good work experiences and that it was not generally continued at college.

The findings from the questionnaires appear to describe a transition process that points to the later school years as well intentioned but recommending college as the only viable route post school. FE college provision was then accessed on a contested view of what full-time meant for many years until the entitlement stopped at 25 years of age. This would support the view that the successful transition indicators of 'purpose' and 'measure of independence' were not being planned for. Parents are still very apprehensive for their youngsters about the same things they were at 16 and 19 years old. For the

majority of parents there was no change in those concerns for a happy, secure life in their community.

Interview findings

The questionnaire findings were used to inform the interviews with two parents and two young people. The questions used were intended to examine more deeply the three indicators of a successful transition that being 'valued', 'purposeful' and 'a measure of independence'.

In using responses and themes from the questionnaires both parents and young people saw school as the key player in determining their youngster's future. Both parents felt that school had improved their youngster's level of independence but felt that the school transition curriculum could better reflect the skills needed to be 'more independent' and 'do more for themselves'. One parent spoke of too much time being spent on academic work and not enough on vocational. They felt school had provided many opportunities for meeting with other professionals involved in the transition process but this tailed off dramatically after they left school. A single resource pack with easy to follow information about all transition services was raised by one parent as a useful way of explaining the complex structures at play. It is interesting to note that the County CSF services transition protocol guide to parents establishes them as 'the crucial partner in transition planning and must be involved by professionals throughout the process'. Parents felt they had very little control over the process, partly due to a lack of accessible information, but also to a lack of faith in the services to listen to them.

Both parents and youngsters were generally happy with college but for very different reasons. The youngsters enjoyed college because they could be with 'friends', 'use computers' 'do sports' and enjoy the social situations it presented. The parents saw college primarily as somewhere for their youngster's to go and not necessarily a place to improve their education, training and skills toward a future life. Neither parent could articulate whether there had been any particular course progression while their youngster was at college. They thought that people moved to a different course if there was a place available.

The parents were still mostly concerned with what their youngster would do in the future. One parent's aspiration for their youngster as being a 'secure future with good care and quality of life' was still acutely worried about where they would live and what they would do. Both youngsters still lived at home and there was no change in the situation envisaged. This was despite a wish for their youngster to move away from home because it was what 'all young people eventually do'. Lack of day care provision was an issue in the past and remained a concern for the future. The levels of respite care obtained were very different between parents without any obvious rationale or reason for it.

The youngsters both said they missed school and some of their friends. They still saw friends from school, mainly at college, on a regular basis. They said

they had made new friends but could not think of their names. Neither went out into the community without another adult. One said they had undertaken travel training while at college and expressed a desire to do more.

When asked about whether they thought their youngster was part of the local community the parents felt this was not so because of the lack of opportunities available. There youngsters almost entirely only mixed with family, family friends or people from the learning disability community.

When asked about future aspirations, both youngsters expressed the desire to 'get a job' and 'get some money'. They were both able to acknowledge that work was important and linked living away from home and working as worthwhile things to do in life. The parents both thought that work was achievable and could be an important element in their youngster's life. They did not feel it was high on anybody's' agenda when their youngster left school and remarked that it still wasn't. Most emphasis over the last few years had been on reacting to situations rather than any coherent long term planning by services. They felt that this was probably due 'nobody in particular being in charge'.

Discussion

One of the stark realities of this small study has been the overwhelming sense that parents and their youngster's still have little meaningful control over the transition process. Dee (2006) comments on the, 'often very public and bureaucratic nature of the decision-making processes', in that it is largely conducted in public involving a large number of different agencies. This public and bureaucratic process of transition, 'dominates the essentially very ordinary personal confusion and uncertainty'. This has certainly been the experience in this study with both parents and their youngster's largely leading lives that are dictated to a greater or lesser degree by organisational structures.

This study set out to judge how successful the transition to post school life had been by adopting three measures. Having value in their lives and being valued, having a purpose in life and some measure of independence. While nearly all respondents saw school as a happy, secure time with good learning opportunities has this been in their best interests? The then inevitable college provision was arguably characterised by years of 'enjoyable' but comfortable, circuitous discrete courses that have resulted after six years in a combination of day centre and part-time college courses. Arguably, they are no further forward in securing a valued, purposeful and measure of independence in their lives.

Parents might need to be supported as much in finding ways of 'letting go' as they generally have no choice but to continue to be closely involved in supporting their youngster. Success might be judged by these young people following a path that will realise a circle of family and friends, a place to live in

their community, a job that they enjoy, good health care and to be happy and content.

McConkey (1998) reflects on

'how much of schooling was a planned preparation for self-reliant living or were they merely passing through?' p.55

It was noticeable that while there was a small amount of research that explored what had happened to young people up to three years after leaving school there was only an unpublished research study commissioned by Ellen Tinkham School in Exeter, that looked up to the point of finishing entitlement to full-time education at 25 years. Arguably, one needs to be fully involved in a process in order to understand and take an active part in it. It was striking how little the parents and carers knew about how the transition process worked. They knew little about the services and agencies involved in the process and had only minimal contact from those who represented them. This was most noticeable with the group of young people with sld but not more profound or complex needs. The young people with more complex needs tended to have appreciably more contact with services. In looking at what the young people are doing now, six years after leaving school, only one has moved away from their parent's home as a step towards a measure of independent living. One other young person lives in a house in the community but as a result of family bereavement when still at school and not as any planned, purposeful move towards independence. They are developing independent living skills but no planned route to any form of work. The other young people are all receiving varying packages of part-time discrete college and day centre packages or full-time day care with again no plan towards any form of work.

In returning to the research questions and a successful transition being measured by the three indicators.

- 1) What would a valued place look like? A valued place in their community should be two-way with being valued and giving value important. Work would help to enable this as would friendships and mixing freely with different people and groups. By this I mean some part in the day-to-day life of the 'mainstream' community and not as a member of a separate group largely operating within the learning disability community. The findings from the study point to the young people largely operating within the learning disability community by living at home attending discrete college and day services and importantly, only taking part in mostly leisure pursuits and clubs for the disabled. Having a route to employment of some kind and being paid would provide a sense of value and would be contributing to the greater community.
- 2) What purpose would the young person need for a successful transition? I contend that having purpose in life relates to having a notion of future life goals, some control over your life and provides emotional well-being. Work can help provide purpose by raising self-esteem and a sense of contributing

to the community. Also that earning a wage can empower you to have more control over your life.

3) What do we mean by measure of independence for the young people? This relates to living away from your parents, working, and the ability to move freely within your community and make decisions about ones life in general. Only two out of seven young people live away from home and not one has a job of any sort.

I suggest that all three indicators are closely interrelated and that work is an important component of them and will provide the key ingredient to drive school and associated services to organise and plan in a way that achieves a successful transition. It is important to recognise that work might not be a realistic aspiration for some young people with more profound and complex needs but that the three indicators of a successful transition are still true for all.

Conclusion and what of the future?

This study has explored the experiences and views of young people and their parents with severe and complex learning difficulties as they made the transition to adult life. They have raised many important issues about the degree of agency or control they have in determining the course of their lives. This study challenges my school and other sld special schools to change their culture and adopt a transition framework that no longer accepts pathways such as the arbitrary movement from school to FE College for the majority. It must ensure that pathways to work are a key element in a multi-agency approach to transition that focuses on not only meaningfully listening to the students aspirations but crucially, raising their aspirations. Special schools are well placed to begin this change, but the Connexions Service as demanded by the SEN Code of Practice, should drive the process.

As documented in the policy context section of this paper what comes through strikingly is the chasm between local and central government's aspirations, as for example in Valuing People (2001), and the actual experiences of these young people and their families. The importance of person centred planning (Holburn et.al.. 2007) is often stressed, where the needs and aspirations of the young people are assessed and provision developed relating to this assessment. However, the experience in this study has been the exact opposite of this. It is the range of provision that is assessed and then the young person placed in what is available. The most worrying aspect is there does not appear to be a body or mechanism to bring about a substantial improvement. Low expectations and limited options inhibit the young peoples potential to fulfil lead fulfilling lives where they are happy, achieve and become confident individuals who are economically active and participate in the wider community.

This study challenges policy makers, service providers and all other people involved in the transition process to bridge the chasm. Future research is

appropriate and perhaps might benefit from an International perspective to explore other countries experiences.

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