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Carer Perspectives on the Transition of Young People With Learning Disabilities[1] to Employment

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Abstract

The paper reports the views of carers on transition to employment, college or other services for young people with learning disabilities (LD). The research draws on interviews with 87 carers in six areas of the U.K. conducted over a period of 12 months. The research found that advice to carers from careers services did not successfully cover employment as an option, whereas advice from employment services did. Carers did aspire to their young people getting a paid job as a next step, but follow-up interviews showed the majority went to college. The results suggest that employment organizations need to be involved earlier in the transition process if young people and carers are to be fully informed of their options.

The transition from school to employment has become a central issue in planning for young people with learning disabilities (LD). In the U.K., the importance of transition planning to social policy formulation and service delivery is exemplified by the fact that the Blair government has improved the legal framework for local authorities, careers services, and schools/colleges to deliver effective transition planning.

In the U.K., young persons with LD most often attend schools offering Special Education from the age of 5 to 18 years, though a minority of individuals with less significant LD attend mainstream schools. The school system now has a clear responsibility to initiate and implement a transition plan for each student aged 14 years or older, which includes a

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[1] *Editor's Note:* People with learning disabilities (LD) is used in the U.K. to describe those referred to elsewhere as people with “intellectual disabilities”, “developmental disabilities”, or “intellectual or developmental disabilities”. The term describes a different group from that referred to as having “learning disabilities” in the U.S.

statement of Special Educational Needs that describes whether the student is receiving School Action or School Action Plus[2] (Beyer, McConkey, Banks, Dunlop, & Morgan, 2005). Further, Colleges of Further Education (CFE) offer vocational input to all students from the age of 16 years onward, including those with LD.

Beyond the school, the carers of young persons with LD (most often a parent or foster parent) play a crucial role in the transition process. They are the main providers of support and often have a clear view of the aspirations and preferences of the young person with LD, and frequently influence the young person's choices in life (Smart, 2004). However, carers have also been identified as sometimes being over-protective, acting as an obstacle to increasing the independence of the young person with LD by limiting exposure to new experiences (Bowey, McGaughlin, & Claire, 2005). The aspirations of carers for the lives of the young person with LD is somewhat dependent on their relationship with professional service providers. Studies have shown that carers tend to express general dissatisfaction with professionals (King, 1997), but that more positive relationships are possible when professionals provide clear and appropriate information and interventions, and acknowledge the parents' needs, expertise and involvement (Case, 2001).

Certainly, the success of transition processes will, in part, depend on how informed carers are about the opportunities available, and their involvement in the process. Although the onus for organizing transition review meetings is squarely placed on schools, they are urged to co-operate with the Connexions services (the English careers advice service), the Careers Services in Scotland and Wales (who advise young people in school and colleges on careers and courses), and care managers (if the young people receive service from local authority social services departments). Policy makers have envisaged the transition period to be marked by a spirit of service collaboration, involvement of carers and the young person to identify valuable post-school goals and to ascertain ideal life paths for young people with LD after school. This co-operative spirit was reflected in various government policy documents and Acts such as the Connexions strategy (Learning and Skills Act, 2000), and Valuing People (Department of Health, 2001) which obligated co-operating agencies to identify a lead orgnization responsible for each student. The Special Educational Needs and Disability Act (2001) provided the general framework for support agencies that work with people with LD, which made it unlawful to discriminate on the grounds of disability in education and provided an important impetus for mainstreaming. Since the Disabled Persons Act (1986), local authorities have a clear responsibility to link practitioners in the educational sector with welfare services effectively, in order to facilitate smooth transitions into day centre provision, employment, or further training/educational opportunities. However, the National Service Framework states clearly that 'there is still a lack of co-ordination between the relevant agencies and little involvement from the young person' in transition (DfES, 2004), and a recent report highlighted the lack of multi-agency work in providing meaningful post-transition opportunities for young people with complex needs (CSCI, 2007). The most recent cross-departmental strategy paper tries to address this issue (HMG, 2007).

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[2] In the U.K. School Action or School Action Plus refer to a set of interventions that are arranged by school teachers if the pupil does not make adequate progress compared to their peers. Individualised learning plans, different learning materials from the standard ones or involvement of educational psychologists can be part of this set of interventions.

In addition to problems in coordinating the involvement of multiple organizations, there are also issues regarding involvement of youth with LD and their family in transition planning. Too often transition processes are implemented without effectively eliciting the views of young people themselves as these tend to be dismissed as unworkable or uninformed (Carnaby, Lewis, Martin, Naylor, & Stewart, 2003; DfES, 2004). Further, cultural differences and dissimilarity in preferred transition outcomes between carers and professionals can also confound transition planning (Dowdy, 1996). Ineffective or late planning for post-school transition can significantly increase stress for carers as well as for the young people with LD who go through a multitude of changes at that time, while effective collaboration can reduce stress for carers (Schneider, Carpenter, Wooff, Brandon, & McNiven, 2002).

Just as problematic is the limited range of post-school options beyond further education and social services day centre provision. The lack of alternative options for young people with LD post-school is blamed on a lack of sufficient resources for support services (Wehman & Revell, 2000), lack of inter-agency funding or even duplication of services (Hart, Zimbrich, & Ghiloni, 2001). The pursuit of employment does not feature prominently in transition planning, although it contributes to the increased confidence and independence of young people with LD (Kilsby & Beyer, 2002). There is ample evidence that employment increases social inclusion in comparison to conventional day centre provision (Kilsby & Beyer, 1996), though predictors of employment retention are still under-researched (Beyer, 2001; Rose & Saunders, 2005).

This study seeks to understand how carers are involved and supported in the transition process, particularly around the issue of employment as the next step for the young person with LD in their care.

Method

Recruitment

The study was carried out in a purposive sample of six different local authority areas in the U.K.; each area offered employment-related transition planning services to young persons with LD in their last year of school. In all, fourteen special schools, one mainstream school and five colleges were included in the study. In particular: Area 1 involved one mainstream Specialist Arts College in the study out of eight Specialist Colleges in the area altogether (13%). Area 2 recruited two CFEs in one county and one CFE each in two other counties; this represents all the CFEs. Area 3 was included by one special school each in two counties, in both cases representing a third of all local special schools. Area 4 comprised 7 Special Schools out of a total of 24 in the area (30%). Area 5 focused on 3 special schools out of a total of 11 and one CFE out of 3 operating in the county. Area 6 involved two special schools in one county from a total of eight, one special school in a second county with no other special schools, and one special school for autism, again the only one of its kind.

The current study is part of a larger study on transitions of young persons with LD post school, and focuses on carers of young persons with LD in his/her last year of school. In the larger study, young people with LD and their carers were eligible and invited to take part if: (1) the young person had a diagnosed LD; (2) the young person with LD was in their last year of school or college; and (3) the young person with LD and/or his/her carer had received input from the target employment service in the area. For the purposes of this study, LD was defined as the presence of a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), concomitant with a reduced ability to cope independently (impaired social functioning) which started before adulthood with a lasting effect on development (Department of Health, 2001). Presence of a LD was confirmed in the interview with carers, who reported their child's score on the Adaptive Behaviour Scale (ABS) (Nihira, Leland, & Lambert, 1993). This scale has demonstrated psychometric properties among young persons with intellectual disabilities (Nihira et al., 1993; Schalock, 2004).

If the young people with LD were eligible, informed consent was obtained from them and their carers prior to arrangement of home visits. A total of 89 young people were identified and 87 young people, where 87 young people and their carers (also *n*=87) provided written consent to take part. Young people could veto the participation of carers and carers themselves could consent to their young son or daughter taking part in the study while withholding consent for their own participation. Table 1 presents information on the characteristics of young people with LD.

About 61% of the sample was male, and the average age was 17.8 years (*SD*=1.7). The mean percentile rank of the young people's ABS as recorded through carers' interviews was 77.7, indicating that the group had "average" functioning (across self-care, sensor and motor abilities, managing money, communication, use of number and time, independence in the home, vocational skills, active lifestyle, acting responsibly and interaction with other) compared to a normative sample of people with LD living primarily at home or in social care facilities. In addition to meeting the definition of LD, 9% were reported as also having Autism, 1% had Asperger's Syndrome, and 5% as having emotional or behavioural difficulties. Sixty three percent had a Statement of Special Educational Need, and 7% had School Action or School Action Plus status.

Participants

The actual participants in the current paper are the carers of young persons with LD recruited in the larger study. Table 2 presents information on the 87 carers who took part in the study.

Table 1. Characteristics of young persons with LD (n=87).

	Study sample
% Male	60.9%
Mean age (*SD*)	17.8 years (1.7)
Mean percentile rank of the ABS (*SD*)	77.7 (16.8)
Additional diagnoses/problems	
Autistic spectrum disorder	9%
Asperger's syndrome	1%
Emotional or behavioural difficulties	5%
Presence of a Statement of Special Educational Need	63%
Receiving School Action or School Action Plus	7%

Table 2. Carer Characteristics (n=87).

	Carers
Relationship to young person with LD	
Parent	96%
Foster parent	1%
Sibling	1%
Professional	1%
Marital status	
Married	91%
Unmarried/Single parent	9%
Employed head of household	67%

Carers were made up primarily of parents (96%), though one respondent was the care manager of the young person, one was the sister, and in one case the foster parents were interviewed. The majority of carers were married (91%). In 67% of the cases the head of the family household was employed.

Procedure

Carers were interviewed using semi-structured questionnaires asking about their involvement in transition planning, knowledge of post-school options available to the person in their care, as well as other issues (i.e., benefits, transportation). Specifically, carers were asked about: their involvement in transition review meetings; whether employment was discussed during review meetings; advice received from school, careers service and employment service and how this helped inform them about employment; their hopes for the person in their care when they leave school; their post-school transition expectations. A five-point Likert scale was also used to evaluate the carer's satisfaction with each of the above-listed areas, from 1=Very unsatisfied to 5=Very satisfied.

The initial interviews were conducted in the carer's home and lasted about two hours. The interviews occurred mid-term in the young person's last year in school/college so that carers' views reflected the transition planning that had occurred in that year.

The carers of this cohort were re-interviewed six months after the young person with LD had left school. At this time, the carers' views on the experience and outcome of transition were elicited. Questions included: details on what the young person with LD was currently doing; details of any job, further education/course, day service, or other placement; carer views on the appropriateness of the placement; and what most influenced the decision to take up any given placement.

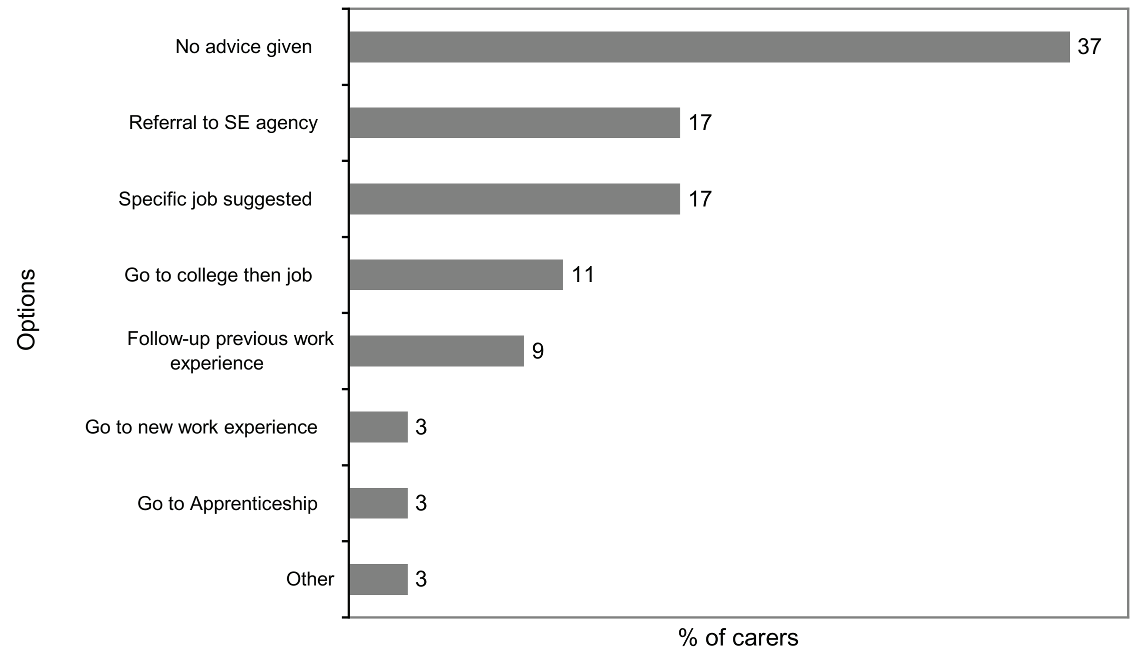

Figure 1. Options for Taking Employment Forward Discussed at Transition Reviews.

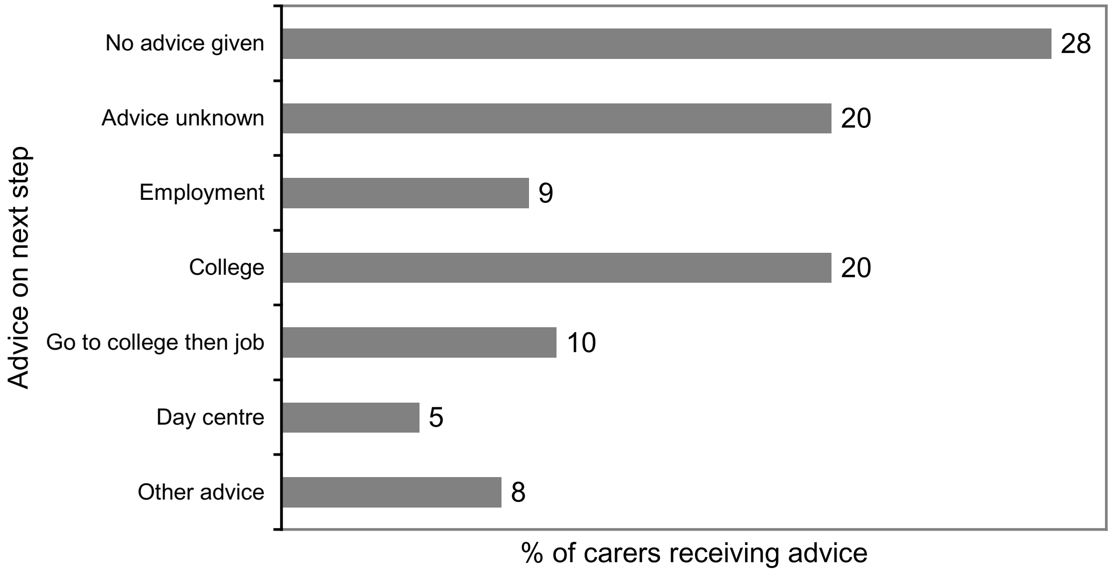

Figure 2. Advice Given by Careers Services to Carers.

At both times, carer responses were categorised, coded and analysed using a theming approach (Ritchie & Spencer, 1994). The interviews were coded into an initial framework that reflected the topic areas in the questionnaire, as well as emerging themes. Data for each respondent was then indexed against each theme. These were then charted to enable the assembly of quotes for each of the themes, for all respondents.

Results

Topics Covered in Transition Review Meetings

While the majority of carers had attended the transition review meeting, 25% of carers reported that they had not been involved. Among those who had been involved in the review meeting, 61% reported that employment post-graduation from school had not been discussed; instead, transition to a CFE (24%) was most often suggested. For the remaining 39% of carers who had discussed employment during the review meeting, a number of options had been discussed to take employment forward (Figure 1) [see page 99].

While many carers (37%) did not receive specific advice on employment (i.e., only discussed the option of employment in general terms), concrete options related to specific jobs or referral to a supported employment (SE) agency was reported by 17% of carers. Approximately 11% of carers received advice regarding college, 9% received suggestions regarding re-exploration of previous work experiences, and 3% were encouraged to explore new work opportunities, to seek out apprenticeships, or got other advice.

Advice was also offered by careers services in the six local authorities (see Figure 2). Many carers had not received any transition advice from this source (28%), and many that had received this service were not able to remember their advice (20%). For those carers who had received advice from careers services, advice on further educational opportunities (i.e., a place at a CFE, or on a specific course at

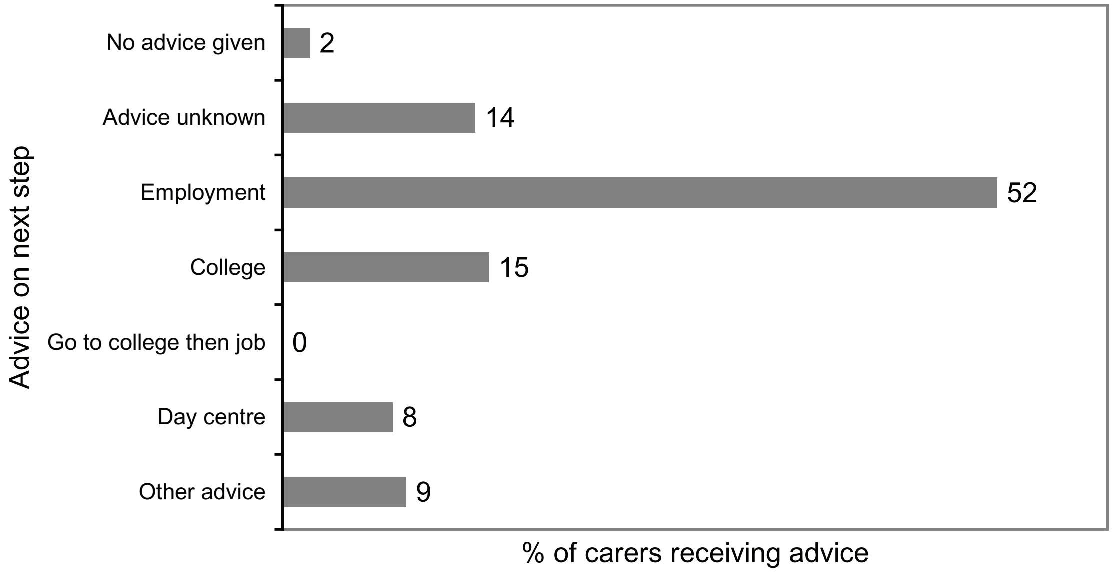

Figure 3. Advice Given by Employment Services to Carers.

a college), was again most common (20%). Of those advised on further educational opportunities (17=20%), 6 people (8%) felt that it was satisfactory. In these cases, 35% felt the advice was appropriate because these carers only wanted advice on college options. Employment opportunities had been discussed in approximately 9% of cases, though it was discussed in terms of being a later step, after college.

Carer Satisfaction With Employment-Related Transition Service Planning

We also asked carers if they were satisfied with the advice they had received on employment. Those who received advice on employment were generally positive (65%) about the advice given as the following quotes illustrate:

> *"Gave my son an idea of what he may want to do as paid employment as an option. Factory work, repair work."*

> *"Connexions did mention a part time job but he wasn't accepted for this. He was given the opportunity to apply for work by Connexions."*

However, 15% of carers were dissatisfied with advice given by careers services about employment as an option. As one person stated:

> *"No, I had to make the approach. Only option given was college."*

The type of transition advice given by the employment organizations in our six local authorities differed greatly from one another (see Figure 3). Despite being an employment organization, only 52% of carers reported that advice on employment had been provided. College was discussed as a next step in about 15% of cases, and 14% could not remember the advice given. Compared to what had been offered by career services, the advice given by employment agencies was more often concrete, for example suggesting a work experience placement (e.g. work in a garage, nursing home, housing association, fast food restaurant, garden centre). Most carers (79%) who had received advice from employment organizations reported that they were satisfied with the experience. For example:

> *Led to a paid Saturday job. Worked during the summer holidays (without pay) as a volunteer. Made him feel that getting a paid job now a possibility.*
>
> *He really enjoys it. Gets on with everyone.*
> *[Job placement officer] says management was very pleased with him.*

However, the advice provided only appeared to strengthen the decisions to pursue employment, or a job, for a minority of carers (16%):

> *"Quite enjoyed it but hasn't affected what she thinks she wants to do."*
>
> *"Think he found them interesting and he enjoyed them, but don't think he thought of them as employment options. Feel X would need a lot of support to go into employment Didn't really inform me about employment options."*

Post-school Transitions: Carer Preferences (Time 1) and Actual Experiences (Time 2)

Table 3 shows what carers wanted as the next steps for the person with LD they were caring for. The majority of carers (56%) hoped that the young person would enter into paid employment after leaving school, 27% believed that further education would be the option that would be taken up on leaving, 17% cited other aspirations, and the remainder wanted the person they were caring for to go to a day centre or do unpaid work (1% each).

Table 3. Aspirations of carers for next placement of young person after school/college

Placement type wanted	*% of cases*
Paid job	56%
College	27%
Other (e.g. be happy, be occupied)	17%
Unpaid job	1%
Day centre	1%

Table 4. Actual placement 6 months after leaving school/college

Placement type achieved	*% of cases*
Paid job (Full or part-time)	21%
College	63%
At home	6%
Unpaid job	9%
Day centre	1%

A follow up study of young people with LD six months after they left school revealed that only 21% entered the workforce, and an additional 9% had an unpaid job or work experience (Table 4). The majority (63%) went on to a college, and only 1% went on to a day centre. Among carers who expressed a wish to have the person they care for transition into employment, only 21% were working. However, for those carers who preferred a transition to college, 66% of young persons with LD were in college 6 months later.

Last, we asked carers what had influenced the actual transition pathway post-graduation from school. The young person's own motivation for a particular route was most often reported as being key (17%). Having made a prior visit to a college was another significant factor (7%), as were the desire to follow friends (7%) and lack of choices (7%). Advice from employment agencies (5%) and social worker (4%) were also found to play a part, whereas advice from careers service did not.

Conclusions

For many young persons with LD, paid employment is not a pathway that is explored as a possibility post graduation from school, or even suggested as an option. College and further education remains the predominant pathway, where skills and qualifications are the primary focus, regardless of whether these will assist the individual to obtain meaningful employment at a later stage.

As a result, employment does not feature high on the agenda in the transition review processes, and there is a distinct lack of information on available employment options provided to carers through transition planning services, careers services in particular. Only employment agencies acted as effective promoters of the employment route, offering concrete advice regarding next steps. Our data suggests that, where employment organizations are not involved, advice on paid employment is much less frequently given, and that as a result, fewer carers are likely to pursue paid employment as a next step for the person that they are caring for. Consequently, employment organizations need to be involved earlier in the transition planning process if young people with LD and their carers are to be fully informed of their options and work toward fulfilling aspirations for paid employment.

Carers had clear aspirations for the futures of the young people they care for, and were often frustrated when employment was seemingly rejected as a legitimate next step. Our results also showed that the wishes of the young persons with LD greatly influenced the decisions made by carers. For this reason, it is necessary that information on all transition options needs to be offered early on in the transition review timetable. For example, this information could be discussed as early as the first transition review meeting to ensure that all possible options are considered and explored by the young person with LD and their carer.

Even more problematic than the lack of information regarding possible transition options is the lack of any type of transition support at the time of graduation, the refusal to fully explore the choices and preferences of young persons with LD, and the fact that carers struggle to be involved in the transition process in a meaningful way. It is often as a result of these barriers that day centres or sheltered employment are chosen, despite the fact that participation in a day centre placement/program is rated low among carers' preferred next steps. Our results suggest that it is more often the outcome options favoured by careers services that become reality, rather than what the person with LD and their carer want. Given that the ultimate goal of career services and transition planning services is to assist young persons with LD reach their goals, there is clearly a need for a shift in how that happens in reality.

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