Multi-agency transition services: greater collaboration needed to meet the priorities of young disabled people with complex needs as they move into adulthood

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Abstract

Purpose – Drawing on a wider study about the effectiveness and costs of different models of multi-agency transition services, this paper aims to present new evidence on the ways in which such services meet the priorities and concerns of young people identified in previous research.

Design/methodology/approach – The evidence is based on qualitative interviews with 130 managers and staff in five transition services across England, and a quantitative survey of parents and young people receiving these services (pre-transition), or having received the services in the last-two years (post-transition). In total, 110 pre-transition and 33 post-transition parents, and 73 pre-transition and 24 post-transition young people, completed questionnaires. Statistical analysis included calculating frequencies and mean values for the responses that measured met and unmet need, and qualitative results were analysed thematically. The consequence of, and reasons for, the low response rate to the family survey are also discussed.

Findings – The research found examples of good practice and innovative services to meet young people's needs. However, provision of such services was patchy, and unmet need for transition support remained high in all the priority areas studied both during and after transition: ranging from 52 to 84 per cent in parent reports and 59 to 82 per cent in young people's reports.

Originality/value – With the onset of public service cutbacks, the paper concludes that improved multi-agency commissioning of services, based on the priorities and concerns of disabled young people, and greater engagement of transition services with a broader range of agencies, will help to address these deficiencies.

Keywords Transition services, Young people, Disabilities, Multi-agency, Unmet needs, Young adults, Disabled people, England, Support

Paper type Research paper

Introduction

There is considerable research which indicates that many disabled young people do not gain the support they need to make the transition from children's to adult services satisfactorily (Kirk, 2008; Commission for Social Care Inspection (CSCI), 2007; Cope, 2003; Hendey and Pascall, 2002; Morris, 2002). Government policy has sought to improve transitions to adult services, as highlighted in *A Transition Guide for All Services* (Department for Children, Schools and Families/Department of Health/Council for Disabled Children, 2007); *Transition: Moving on Well* (Department of Health/Department for Children, Schools and Families, 2008); and *Valuing People Now* (HM Government, 2009b). Key elements of transition policy are the promotion of better coordination of services and full involvement of young people and their families in the transition process, particularly through person-centred planning. This aims to involve young people more effectively in planning for the future, by focusing on their

aspirations and development needs, and encouraging family involvement and collaboration and problem solving between agencies (Michaels and Ferrera, 2006).

Research points to a number of problems in achieving positive transitions, including lack of multi-agency working; lack of an holistic approach; lack of information for young people and parents; lack of young people's involvement in transition planning; insufficient attention to the concerns/priorities of young people; and lack of appropriate services/provision onto which young people can transfer (Kirk, 2008; CSCI, 2007; Dewson et al., 2004; Cope, 2003; Dean, 2003; Forbes et al., 2002; Heslop et al., 2002; Morris, 2002).

A CSCI (2007, p. vi) study found that implementation of person-centred planning (PCP) was patchy, with only half of the professionals and managers interviewed saying that PCP was "well-used" at transition, and social workers feeling that they lacked training in PCP and that there were not sufficient funds to commission independent organizations to carry out PCP. CSCI concluded that "inadequate commissioning, poor co-ordination of services and a failure to properly plan with young people and their families are resulting in anxiety, delays, multiple assessments and confusion".

Previous research, before the development of multi-agency transition services, has identified young people's and parents' priority issues during the transition process. Heslop et al. (2002) found that leisure and social opportunities, benefits, future housing opportunities, independent living skills, adult sexuality and relationships, further education and careers opportunities were areas of concern for young people and their families but did not always feature highly in transition planning. Tarleton and Ward (2005) investigated the information needs of young people with learning disabilities at transition. Besides general information about the transition process, 14 categories of information needs were identified: work, college, where to live, money, friends, sex and relationships, safety, being in charge of your life, living independently, healthy living, having fun, music, sport and helping others.

Multi-agency transition services are relatively new and have the potential to provide better and more coordinated support for disabled young people. Drawing on a larger study which aimed to investigate the impact on young people and parents of different models of multi-agency transition services (Sloper et al., 2010), this paper reports data on young people's unmet needs for support in these priority areas and on some ways in which services attempted to provide such support.

Methods

The study included a postal survey of multi-agency transitions services in England and case studies of five services selected to provide representation of different models of multi-agency transition services. Key differences between the service models were between coordinating services, which supported generic workers working with disabled young people, and transition teams who had a designated role working solely on transition for disabled young people and provided direct support to the young people and their families (Sloper et al., 2010). The case studies were also selected to reflect a range of localities, from mainly rural to inner city and different socio-economic profiles, including ones with substantial ethnic minority populations.

The views of young people and parents were obtained through a postal survey carried out in early 2009. Transition service staff were interviewed through face-to-face and telephone interviews conducted between April 2008 and April 2009. Approval for the research was obtained from an NHS Research Ethics Committee, and research governance approval was obtained from local R&D Committees in case study sites.

Survey of parents and young people

Questionnaires were developed for parents of young people who were in the process of transition planning (pre-transition), and for parents of those who had transferred to adult services within the last-two years and had received the transition service (post-transition).

Simplified versions of the questionnaires were designed for young people (one using symbol-based language and two written).

The extent to which services were providing enough help for young people was assessed in the parent questionnaires and the young people's written questionnaires, using a 22-item checklist based on one previously used in research on families caring for a disabled child/young person (Greco et al., 2005; Beresford, 1995), and adapted to suit this age group drawing on existing literature and consultation with disabled young people and parents. Items included help related to leisure and social life; benefits/finances; housing; further education/training; career/employment opportunities; independent living skills; adult relationships and sexuality and identifying/planning future goals/aspirations. These were rated on a three-point scale, of "Getting enough help", "Need help" or "Help not needed". Additionally, the extent to which young people's information needs were met was explored. The symbol questionnaires were briefer and did not include the needs checklist.

In total, 717 questionnaires were sent out to families via the transition services, 567 pre-transition and 150 post-transition. A total of 143 (20 per cent) completed parent questionnaires were returned (110 pre-transition and 33 post-transition). About 97 young people completed questionnaires (73 pre-transition, of which 19 completed the symbol questionnaire; and 24 post transition, of which eight completed the symbol questionnaire). It is not possible to calculate a response rate for these as services were not able to give us information on the number of young people who would be expected to be able to complete a questionnaire.

Amongst pre-transition parents, respondents were predominantly mothers (85.5 per cent, $n = 94$), 14 respondents (12.7 per cent) were fathers; one was a grandmother and one a carer. The ages of the disabled young people in these pre-transition families ranged from 14 to 22, with a mean age of 16.98 years (SD = 1.85, median = 17.00), with 70 were male and 40 female. One young person was adopted. Among them 76 young people were white (69.1 per cent), six were Indian (5.4 per cent), five were Black-African (4.5 per cent), three were Black-Caribbean (2.7 per cent), one was Pakistani, one was Chinese, six (5.4 per cent) were mixed race and seven (6.4 per cent) were from other backgrounds (including Iranian, Sri Lankan, Kurdish, Colombian, Black British). Three did not provide data.

Amongst the 33 post-transition parents, respondents were predominantly mothers (81.8 per cent, $n = 27$), five respondents were fathers and one was a foster father. The ages of the disabled young people in these families ranged from 18 to 22 years, with a mean age of 19.47 (SD = 1.34, median = 19, $n = 32$); 21 were male and 12 female. Two young people were adopted and one was fostered. In total, 22 young people were white (66.6 per cent), four were Black-Caribbean (12.1 per cent), three were Black-African (9.1 per cent), one was Indian, one was Pakistani and two were mixed race.

The young people had a range of diagnoses (Table I), with most having more than one condition. All except one young person had learning difficulties and most (74 per cent) had high levels of learning difficulties. This reflected the eligibility criteria for the transition services.

Table I Most common conditions of young people reported by parents

| | Number of young people | |
Diagnosis	Pre-transition	Post-transition
Autistic spectrum	43	10
Cerebral palsy	17	
Epilepsy	16	6
Down's syndrome	12	4
Other chromosomal abnormalities	10	10

Young people sample

About 73 young people completed at least part of the pre-transition questionnaire, with 19 of these completing only the symbol questionnaire, which did not include questions on met and unmet needs. The ages of respondents ranged from 14 to 22 years, with a mean age of 17 years (SD = 1.82, median = 17). About 24 young people responded to the post-transition questionnaire, with eight of these completing only the symbol questionnaire. The ages of respondents ranged from 18 to 22 years, with a mean age 19.41 years (SD = 1.33, median = 19).

Interviews with staff

In each case study area, a key figure in the transition service (typically the transition manager) provided a list of staff closely involved in the planning or delivery of their service. The research team then contacted each of those individuals to explain the study further and ask if they were willing to take part in the research. In all, 130 interviews were carried out with transition workers/team members and their line managers; members of steering groups for the service which included the transition service managers); and relevant staff in health, education, social care and Connexions and in schools/colleges attended by young people receiving the service.

The interviews investigated a range of issues, including the views of staff on ways in which their services were addressing the priorities of young people during transition, as identified in the existing research literature. Interviews, with participants' permission, were digitally recorded.

Data analysis

Statistical analysis of the survey data using SPSS included calculating frequencies and mean values for the child met and unmet need variables from parent questionnaires and young people's written questionnaires.

Staff interviews were transcribed. Two researchers read transcripts to identify a priori and emergent themes. A coding framework was agreed and transcripts were coded using MAXQDA. Analysis was initially done by site and then drawn together to produce a cross-site analysis.

Limitations of the study

A significant limitation of the study was the low response rates for the family survey. Various reasons may account for this, including some families having had little contact with the service; transition being a particularly stressful time in families' lives; and young people being unable to complete questionnaires.

Results

The results described here focus on whether young people received enough help during transition in nine main areas of their lives; these areas were selected, because they have been identified in previous research as key priorities of young people as they move into adulthood. The quantitative data from the family survey are considered alongside the qualitative data from staff interviews. Table II presents data on information needs. Table III presents data on the eight other topics. While staff acknowledged considerable gaps in support, they also identified ways in which their services attempted to support young people in these areas.

Information/advice about the transition process

Around three-quarters of parents of pre-transition young people felt their son/daughter had unmet needs in relation to information about future options, and two-thirds felt their need for someone to talk to about transition and/or to explain the transition process to them was not being met (Table II). For parents of post-transition young people, the greatest unmet need was for information about future options; almost half felt their son/daughter's need for someone to talk to about transition and/or to explain the transition process to them had not been met.

Table II Young people's unmet information needs as reported by parents

	Percentage of pre-transition needing but not receiving help (n)	Percentage of post-transition needing but not receiving help (n)
Information for your son/daughter about future options	77.9 (74)	58.1 (18)
Someone for your son/daughter to talk/communicate with about transition	68.1 (62)	48.1 (13)
Someone to explain the transition process to you son/daughter	68.2 (62)	46.4 (13)

Note: Throughout unmet need was calculated as the percentage of parents reporting young people having a need that was not being met

Table III Young people's unmet needs for services and support

	Parents reporting on their children's needs		Young people reporting on their own needs	
	Percentage of pre-transition needing but not receiving help (n)	Percentage of post-transition needing but not receiving help (n)	Percentage of pre-transition needing but not receiving help (n)	Number post-transition needing but not receiving help (n)[a]
Leisure and social life	78.3 (72)	69.2 (18)	82.2 (37)	(9)
Benefits/finances	77.8 (63)	52.0 (15)	78.9 (30)	(8)
Housing needs/future housing	76.3 (45)	61.1 (11)	80.6 (25)	(7)
Further education/training	69.2 (63)	64.3 (18)	70.8 (34)	(10)
Career/employment opportunities	83.6 (56)	68.4 (13)	81.6 (31)	(10)
Independent living skills	74.7 (62)	75.0 (15)	69.2 (27)	(10)
Adult relationships and sexuality	61.8 (42)	64.3 (9)	58.6 (17)	(7)
Identifying/planning future goals/aspirations	72.6 (61)	73.7 (14)	78.7 (37)	(8)

Note: [a]Percentages not calculated due to low numbers

Staff in all services reported providing verbal information about the transition process to young people and their families, and seeking out additional information for them when necessary. However, only two services had written information packs for both parents and young people that were comprehensive and up-to-date. Other forms of information for young people and families included DVDs and, in one service, a transition web site for young people. Additionally, staff in two services referred to information events held in special schools about the transition process.

Leisure and social life

Responses from parents and young people showed high levels of unmet need (ranging from 69 to 82 per cent) for help relating to leisure and social life.

Staff reported providing families with information about local leisure and social opportunities. Whilst reportedly scarce, specialist leisure provision was typically provided through voluntary sector organisations or through special schools. Staff noted that mainstream sport and leisure provision was not always accessible to young disabled people. Lack of money (both to pay for and get to activities), transport, lack of support and attitudes of staff and the general public were cited as barriers to participation.

Staff reported several initiatives in their local areas aimed at encouraging disabled young people to take part in mainstream sport and leisure activities, including appointing a worker to develop inclusive provision; providing free taster sessions for disabled young people to try out a sporting or leisure activity; and running a "summer university" with free transport, where disabled young people were supported to take part in a range of academic and recreational courses by workers from their own schools. Staff also reported instances where

young disabled people used direct payments or individual budgets (IBs) to pay for a personal assistant to help them participate in leisure activities.

Benefits/finances

Pre-transition, over three-quarters of young people and parents reported needing more help with finances and benefits. This need was less pronounced for young people and parents post transition, probably because benefit changes had already occurred.

Transition workers in all services reported they were able to provide basic information about benefits and sometimes got involved in assisting with applications such as claims for Disability Living Allowance. However, generally transition workers advised families to seek specialist support from organisations such as the Citizens Advice Bureau, disability or carers' organisations, welfare rights services or local job centres. Staff reported that welfare benefits for young people in transition were complex, particularly when young people were living in supported or residential accommodation and they were anxious not to misinform families.

Future housing options

Pre-transition, 81 per cent of young people and 76 per cent of parents reported help with housing as an unmet need. This decreased to 61 per cent for parents of post-transition young people.

Staff across all services highlighted the chronic shortage of housing in their local areas, particularly a lack of supported and/or accessible housing. The most commonly reported housing option was supported housing, where young people live independently in flats or shared housing with support from visiting support workers. Developments reported by staff to smooth the transition to supported housing included plans in one area to set up a two-stage housing scheme where young people with learning difficulties and complex needs are initially housed in a residential home until they have developed the skills and abilities to live more independently in nearby supported living accommodation. In another area, the transition service had joined with Mencap to run supported living workshops, and had provided young people with a "taster" of supported living by placing them in supported housing for a short-residential break.

In all services, transition workers reported signposting young people for housing advice and support to the local authority's housing advice service or to local voluntary agencies. In one of the transition services based in adult social care, transition workers reported doing a lot of work around housing, including liaising with the council's preferred housing providers and supporting young people to make housing applications and sign tenancies. In contrast, a children's social worker from another area said that she did not provide young people in transition with housing support as most children lived at home and this was something that adult social workers addressed.

Further education

Around 70 per cent of pre-transition young people and their parents wanted more help in relation to further education provision. This decreased slightly to 64 per cent for parents of post-transition young people. For young people who had transferred to adult services, further education provision was reported as a current unmet need by the highest number of young people (along with career/employment opportunities and independent living skills).

In all areas, staff reported that options for post-16 education for those not remaining in special school were sixth form at another school or college, a mainstream further education college (often enrolled on segregated courses), or for those whose needs could not be met elsewhere, a specialist college (often a residential placement due to the distance from home). Connexions personal advisers often took the lead in supporting young people in relation to their further education. In three services, the transition teams included connexions workers.

College staff reported a range of "pre-entry" further education courses for post-16 students with learning difficulties, which were designed to encourage independence and confidence, teach new skills and prepare students for higher level courses or work. Whilst there were

reported to be examples of "excellence" in provision, across all areas staff acknowledged problems with further education provision. These centred on a lack of suitable courses for young people with profound learning or severe physical disabilities or autistic spectrum conditions; a lack of staff experienced in supporting students with disabilities; and, in three areas, problems with transport to and from college for young people whose educational statement had ceased and/or who were over aged 19.

In four of the five areas, staff highlighted the importance of "link courses" whereby pupils in special schools would attend college for one day a week to prepare them for the new learning environment. However, many young people required specialist support to attend college courses which was not always available. Staff noted the potential for young people with high-support needs to use direct payments and IBs to pay for classroom assistance.

Lack of suitable local provision meant that some young people had to secure residential college placements outside their home authority. These were expensive and staff in two areas noted a drive to increase facilities for disabled young people locally specifically to reduce out-of-area placements. For example, one area had established a Development and Training Unit to train college staff in complex disabilities, and a brokerage programme to put together bespoke packages of learning for young people.

Employment

High levels of unmet need (68 to 84 per cent) were reported in the area of career/employment opportunities by both pre- and post-transition young people and parents. A lack of opportunities for disabled young people to get a paid job was reported by staff across all areas, especially for young people with profound and complex needs.

Transition workers in all areas reported signposting young people to connexions for advice and support, or to Disability Employment Advisers within local job centres who could refer young people to government schemes such as Access to Work, New Deal for Disabled People and Work Preparation Services.

Local initiatives were also reported which staff hoped would improve job prospects for disabled young people. These included a "Taste for Work" project in one area that had funded work tasters with a local employer progressing to unpaid work experience placements for 11 young people with learning disabilities. In the same area, "Routeway to Employment for People with Learning Difficulties and/or Disabilities", was a two-year LSC-funded project to place 21 young people in jobs with a local employer. In another area, the Learning and Skills Council had appointed an employment transition worker and there were plans to develop social enterprise schemes to provide employment opportunities for disabled young people.

Independent living skills

High unmet need related to independent living skills was reported by parents of pre- and post-transition young people (75 per cent) and by pre-and post-transition young people themselves (69 per cent and 10 out 16).

Across all services, staff reported that independent living skills, such as managing money, travel and safety issues, were delivered through the curriculum in special schools and colleges of further education. Where particular concerns were identified, transition workers or others supporting young people in transition, would generally refer to other practitioners or organisations within the statutory and voluntary sectors for help with teaching life skills. In one service this included a Buddy travel training service which provided trained "buddies" to accompany disabled young people on bus journeys until they were confident enough to do this alone.

Adult relationships and sexuality

Unmet need for support with adult sexuality and relationships was around 60 per cent for both pre-transition young people and their parents. Over half of post-transition young people and 64 per cent of parents reported this as a current unmet need.

Several staff noted the importance of providing guidance to young people about sex and relationships. In most services, this was seen largely as the responsibility of schools and a subject that should be covered within PSHE lessons. In services that included transition nurses, transition workers would refer young people to them for advice and support about sexual matters. In other services, staff reported signposting young people to a variety of sources within health services, Connexions, schools and local voluntary organizations.

Identifying/planning future goals or aspirations

Asked about the help young people were receiving to identify and plan their future goals and aspirations, parents reported similar levels of unmet need for both pre-transition (73 per cent) and post-transition (74 per cent) young people, and 79 per cent of pre-transition young people reported unmet needs. Transition workers across all services reported that planning future goals was paramount to their work and central to the process of assessment, planning and reviews. In particular, they highlighted the tools and approaches of PCP as a way of helping young people think about what is important in their lives and what they would like to do in the future. However, only in one service did transition workers report that they undertook PCP with all the young people they supported. In each of the other services, PCP was not universal.

Discussion

Despite the multi-agency composition of the transition services, there were still very substantial levels of unmet need amongst young people both pre- and post-transition. The results may be partly affected by the fact that three of the five services had only been recently set up or re-launched, so families may not have experienced the full impact of these new services at the time of the research. Similarly, across all services, newly developed innovative practices may not have had sufficient time to take effect. In addition, a key finding of the study is that the transition services focused mainly on young people with severe learning disability and thus were not addressing the needs of other young people with complex needs, for instance young people with complex health needs or those with autistic spectrum conditions who did not have a learning disability.

Comparison between pre- and post-transition results is limited by the small sample post-transition. However, parents' responses indicate that unmet need was high for young people post-transition, but not as high as for young people pre-transition with regard to information needs, leisure and social life, benefits/finances, housing, further education, career/employment opportunities and adult relationships and sexuality. This suggests that young people's needs in these areas had, to some extent at least, been met during the transition process. However, levels of unmet need did not decrease for young people post-transition with regard to independent living skills and help with future goals and aspirations. This lack of any progression suggests these areas were ones where transition support was weak. Key to both these areas is PCP, where young people's aspirations and future goals are identified and the skills and support they will need to enable them to achieve these goals are also addressed. Despite the government's promotion of PCP and evidence endorsing its success (Robertson *et al.*, 2005), interviews with staff confirmed PCP was not routinely practiced with all young people using their service. Transition workers need time and training to communicate and build a relationship with young people to be able to carry out PCP effectively.

The findings also point to a lack of services and options for young people, particularly around employment, housing and social and leisure activities and in some areas there were difficulties in access to FE college courses. This is consistent with the findings of Morris (2002), Dee and Bryers (2003) and Beresford and Clarke (2009). Some staff shared a frustration at the lack of accessible services and opportunities. As one senior social care manager said:

> [. . .] you can get the assessment process right, you can get a dedicated team set up and you can
> try and improve [. . .] information and communication between different agencies, but the bottom

line is actually our young people need access to services when they leave school in terms of employment, housing, [...] education [...] leisure [...].

Improved multi-agency commissioning of services, based on the priorities and concerns of disabled young people and their families, and greater engagement of transition services with a broader range of agencies, is needed to address these deficiencies. Additionally, services should monitor and respond to unmet needs.

Nevertheless, there was evidence of some good practice, particularly in the provision of transition workers to work directly with young people and their families to support them by providing information and advice about the transition process and adult services, liaising with all the relevant agencies involved and facilitating young people's access to services. In this way, transition workers were able to build up a body of knowledge and expertise around transition to act as a reference point for both families and other services/agencies involved in their care.

Staff responses suggested pockets of innovative practice. Although these were not widespread, they demonstrate how transition services could help to address some of the unmet need young people experience as they transfer from children's to adult services. On the other hand, staff interviews also revealed problems with understaffing across all services, which meant that not all young people had the support of a transition worker or were able to secure the holistic support they needed. It is important that these services are adequately staffed and systems are in place in all agencies to replace staff who leave.

Based on these findings, it is clear that transition support for young people and their families is patchy and needs further development. Since the study was carried out in early 2009, there have been several developments in transition services that have the potential to make a difference to the unmet needs found in this research. *Aiming High for Disabled Children* (HM Treasury and Department for Education and Skills, 2007) established the Transition Support Programme (TSP) (running over three years until March 2011 with £19 m of funding) to provide support, including funding and regional advisers, information, regional hubs and networking, to help local areas to improve transition practice. Although TSP has now ended, the Transition Information Network continues to provide a useful signpost to resources and information (www.transitionsupportprogramme.org.uk).

Personalisation policy has the potential to transform young people's transition experience by enabling them to purchase personal assistance and other services to live as independently as possible. Through *Aiming High for Disabled Children*, four pilot areas were set up to look at how IBs can be used by young people in transition. However, for this to happen, IBs need to be adequately funded and implemented with proper support (Glendinning *et al.*, 2008). Early indications from a recent evaluation are that this is happening in one local authority region in Yorkshire (Cowen *et al.*, 2011).

Similarly, progress in addressing young people's unmet needs should result from *Valuing People Now* (HM Government, 2009b) which aimed to improve the care and life chances of people with learning disabilities, and from *Valuing Employment Now* (HM Government, 2009a) which aimed to close the gap between the employment rate of learning disabled people and that of the disabled population as a whole. However, it will be important that such policy developments are not limited to support for young people with severe learning disabilities and address the needs of a broader range of disabled young people.

If these developments become embedded in practice, better outcomes could be achieved for young people in transition. However, the difficulties that some areas experienced in access for young people with severe or profound disabilities to FE college courses were of concern. It is not yet clear what impact the recent changes in the administration of funding for FE, from the closure of the Learning and Skills Council to the creation of the Young People's Learning Agency and the Skills Funding Agency (*The Apprenticeships, Skills, Children and Learning Act 2009 (Consequential Amendments) (England and Wales) Order 2010*), will have on education provision for disabled young people.

Of serious concern is the impact on transition services of the recession, the cuts in public services and the end of the TSP. Aspects of transition support are often fragile and dependent upon short-term funding. At a time of economic uncertainty, this short-term funding is at greater risk. If funding for appropriate services to support transition was to be withdrawn or diminish, this could lead to even higher levels of unmet need and poorer outcomes for young people transferring to adult services.

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