School’s Out: pathways for young people with intellectual disabilities from out-of-area residential schools or colleges

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Abstract

Background Previous research, and official guidance, has suggested that planning for the transition between children’s and adults’ services is failing young people with intellectual disabilities and their families in the UK. Youngsters placed away from home in residential schools or colleges are likely to be at even greater risk of poor transition planning and outcomes, yet there is little understanding of what factors parents consider contribute to a smoother transition and what a satisfactory outcome would be. Method The parents of 15 young people from five areas of the UK were interviewed about what they thought contributed to a satisfactory pathway for their son or daughter from an out-of-area residential school or college on to the next phase of their life. Results Parents identified four main process issues: being well-connected with other parents or with key professionals; being proactive; having sufficient information; and good forward planning. Most considered a good outcome to be if the young person was happy, fulfilled and stimulated. Conclusions Parents were clear about what they thought helped, and there was little disagreement between their views. While some of these factors have been previously identified regarding the transition of disabled youngsters, they raise some unique issues for families with a youngster educated in an out-of-area residential school or college.

Keywords intellectual disability, out-of-area placement, residential college, residential school, transition

Introduction

Previous research has suggested that transition planning is failing young people with intellectual disabilities (ID) and their families in the UK (Heslop et al. 2002). A number of recent reports have highlighted the difficulties experienced by young people and their families at transition (Morris 1999; Beresford 2004; Smart 2004; McGill et al. 2005; Hudson 2006). A few have focused on factors that seem to be important in determining a satisfactory outcome of the transition process (see DfES 2005; Hudson 2006). The Department for Education and Skills study in 2005, for example, identified four key factors: young people’s capacities and characteristics; the purposefulness of family support; the nature and effectiveness of local support systems; and the range of local opportunities available.

Research has also highlighted concerns for young disabled people who live away from home in ‘out-of-
residential placements at transition (Pinney 2005). First, they are likely to be at greater risk of poor transition planning and outcomes because of the distance between the ‘home’ local authority that arranges the placement and that which ‘hosts’ the young person. This can contribute to difficulties in supporting good, ongoing relationships between the youngsters and their family, and add to confusion by the agencies involved about their roles and responsibilities (Abbott et al. 2000, 2001; Grove & Giraud Saunders 2002). Second, it is the additional disadvantage that the youngsters are moving on from a segregated form of educational provision that has isolated them from their home community, and that many of the reasons why they were there in the first place are unlikely to have been addressed. Many residential placements are made because of a lack of suitable alternative local provision, or because of difficulties in the provision of social care (DfES 2003).

Sending a young person to a residential school or college may be a short-term response to this, but is often no more than that. Parents of young people already in residential placements report added anxieties about the next transition because of a lack of forward planning for their son or daughter, fears about the future provision of a suitable placement, and the impact of funding limitations (McGill et al. 2005).

Despite the concerns mooted about out-of-area residential placements for young people with ID, and parental anxieties about the next transition onwards, there is little research evidence about what happens at transition for this group of people. The data reported in this paper form part of a larger UK research project, one part of which explored what families think contributes to a satisfactory pathway and outcome at transition for their son or daughter with ID in an out-of-area residential school or college.

**Methodology**

Five local authorities took part in the research. Together, they represented a range of characteristics, including a mix of predominantly urban or rural communities, local authorities that were ‘importers’ or ‘exporters’ of young people with ID for residential education, and an authority with a significant minority ethnic population.

At each of the five sites, the Connexions Service (an advice and support service for young people in the UK) or Social Services invited young people with ID in their final or penultimate year at an out-of-area residential school or college to take part in the research. The research team then sent interested youngsters a DVD and written materials about the project that had been produced in conjunction with young people with ID.

Fifteen young people took part in the research. The response rate across the five authorities was 39% (range 11–57%). All of the young people consented to the research team talking to their parents about their experiences; the response rate from parents to taking part was 100%. Each of the young people and their parents also nominated people they thought helped them in preparing or supporting them through transition. Thirty-two ‘supporters’ were nominated (mean per youngster = 2; range 0–4). All worked with the young people in a professional capacity and are therefore referred to as ‘professionals’. Almost all (91%) of the nominated professionals agreed to take part in the research.

During the first half of 2005, interviews were conducted with:

• 13 young people with ID (one young person was too unwell to be interviewed, and one was considered to be too upset);

• 16 parents; and

• 27 professionals (two of whom were interviewed in relation to different young people).

The interviews with the young people were conducted at their residential school or college. Most took place over two consecutive days. Discussions with young people able to communicate verbally were tape-recorded with consent. Other young people used pictures to indicate their likes and dislikes, hopes and concerns, and notes were kept of these. A third group of young people indicated through their gestures and activities what they liked or disliked and what gave them pleasure. Some of the young people had physical impairments in addition to ID; some

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1 ‘Out-of-area’ placements are those where people are placed outside their own local authority boundary.

2 The term ‘parents’ used throughout includes one grandparent.
had behaviour thought to ‘challenge’ services. None was excluded from the research, or not interviewed, because of their level of ability or means of communication. All the young people were given a £10 gift voucher in recognition of their help.

Interviews with parents and professionals were held at a convenient time and place for them. The interviews were semistructured, following a topic guide and covering particular aspects of the transition process. Each took approximately 1.5 h (range 0.5–3 h). The interviews were tape-recorded with consent, and interviewees given the opportunity to read the transcripts of the tapes and correct any factual inaccuracies. The parents were offered a £10 gift voucher in recognition of their help.

All tape recordings were transcribed and, together with any notes, entered into MAXqda, a qualitative data software package (Verbamix Software, Berlin, Germany; http://www.winmax.dex). Two researchers independently read all the texts and coded selected text segments into main and subthemes. A random sample of texts was cross-checked for accuracy and consistency.

Issues explored within the research interviews included the circumstances that led to out-of-area placements, problems with past, current and future transition plans, and examples of good practice. This paper reports on one strand of the findings: what the parents of young people with ID think contributes to a satisfactory pathway and outcome from an out-of-area residential school or college on to the next phase of their son or daughter’s life. Professionals’ views are included where they provide background information or particularly illustrate a point that a parent is making.

**Factors contributing to a satisfactory pathway at transition**

Four main themes emerged from the interviews with the parents about the process of transition. These were:

• being well-connected with other parents or with key professionals;

• being proactive;

• the provision of information; and

• good forward planning and allowing adequate time to prepare.

**Being well-connected with other parents or with key professionals**

Two-thirds of the parents thought that what contributes to a satisfactory pathway for their son or daughter at transition is being well-connected with other parents or with key professionals. These were very often the people who provided information, offered suggestions or generally pointed them in the right direction.

Parents spoke about the practical and emotional support they gained, such as the exchange of information, sharing transport, or knowing that other parents had experienced similar issues and they were not alone in the process. One parent, for example, said:

I was very lucky in as much as I have a friend whose daughter was a year older than Mary[^3], went to the same school . . . and she sort of had accumulated masses of information and done loads of the legwork to find out places for her daughter and passed it all onto me, otherwise I probably wouldn’t have known much about the sort of options post-school.

A number of parents commented that it would be helpful for dedicated events or contact lists through which they could meet other parents whose youngsters attended the same out-of-area school as their son or daughter.

In relation to connections with professionals, some parents mentioned a key individual who eased the process for them. One mother, for example, spoke highly of her daughter’s Connexions Advisor:

. . . if I needed to get anything I can phone him and just say ‘Oh John, by the way, can you give me a bit of advice on this, that or the other?’ . . . I know that if I did need to know anything I could just give him a ring and he would help me if he could. And if not, he’d put me onto the right people to get the information I needed.

Other parents felt that having a range of connections was important:

What we gathered very early on was it wasn’t just a question of having your name on a waiting list, you’ve also got to be known . . . We’ve made it our business to know who we should know.

[^3]: Pseudonyms have been used throughout to protect confidentiality.
In general, parents appreciated continuity of support over a long period of time from their connections with professionals. If there was to be a change, they said that prior warning, an overlapping period and a smooth transfer between professionals was helpful.

A number of parents commented on the importance of having a named social worker. Social workers were considered to be key professionals for support, advice and information, and gatekeepers to funding future housing and support needs. This was reiterated by an educational professional, who considered a named social work connection to be crucial at transition:

Basically it boils down to whether the student has got a social worker at the time; some of our students often don’t have contact with social workers. If they haven’t then we need to get them one in adult services, that’s the first step.

One area had recently made changes to the way in which the allocation of social workers was made. Young people at transition waiting for a social worker were now prioritized and their details held on a separate list. In this way, the needs of young people at transition could be addressed on their own merits, and not ‘in competition’ with other people. As the social worker explained:

If you incorporated that [the transition list] into the larger waiting list, would you ever get allocated? Because there’s always somebody who hasn’t got a roof over their head tomorrow, there is always going to be somebody who is very ill and they don’t know who’s going to look after them tonight, you know, and an allocation is never going to get there.

Being proactive

The second theme regarding what parents thought contributes to a satisfactory pathway for their son or daughter with ID from an out-of-area residential school or college was how proactive a part they themselves played. Parents said that they needed to chivvy up professionals or get wheels in motion to secure a future placement. They also had a role in advocating for and supporting their son or daughter’s wishes. As one mother related:

She [her daughter], she pretty much she just folded her arms and said ‘I’m not going there and that’s that’ and I pretty much said the same sort of thing . . . I think you just have to be that single-minded and refuse to take no for an answer.

Not only did parents feel that how proactive they were was important, so too did a number of professionals. One social worker in particular recognized the contribution of a youngster’s parents:

She’s fortunate that she’s got two parents who can advocate really well for her and who will fight right to the end to get what they think is best for their daughter.

While many parents considered how proactive they were to be a factor that contributed to the success of their son or daughter’s transition, or at least mitigated against the whole transition process falling apart, it was not something that they always felt they should have to do, or had the energy to do. For some of the parents, the role of advocate, activist and combatant was immensely difficult and stressful, and clearly took its toll. Parents spoke about feeling drained, of feeling guilty, upset or scared, of being ‘in a state’, and of blocking out their thoughts and feelings because they felt that they could not cope with them. As one parent summed up:

It just does all get a bit much really.

A number of parents thought that there should be a ‘transition champion’ in each area to take over some of this role, with most parents seemingly unaware of local transition champions attached to Partnership Boards, as introduced by the English learning disability White Paper, Valuing People (DoH 2001). Some authorities were additionally developing champion-type roles. In one area, a Development Worker had been employed to consider the housing needs of people with ID, particularly those at transition. In another, a ‘Transition panel’ had been established with a strategic planning role and to oversee the arrangements for individual young people. At a residential college, a Transition Worker was specifically employed to coordinate the transition arrangements for students. Whatever model was adopted, one professional was clear:

It does work but I think the main thing is . . . the key worker who’s working for that person and the time that they put in – that is what makes all the difference.
The provision of information

The third theme regarding what parents thought contributed to a satisfactory pathway was the provision of information. Parents recognized the importance of having sufficient information for them and their youngster to make an informed decision about their options for the future.

The most meaningful way for information to be provided for young people was for a first-hand look at what different options might be like. With the young people living away from home, parents were often reliant on the school or college to facilitate this, by visiting a variety of placements so that the young person could get a feeling for what options might be available. One Further Education Unit was particularly proactive in this, as one professional explained:

Part of our careers programme was to visit six or seven different specialist colleges, maybe the local college, and various other options . . . We set up our own form [for the young people to complete after their visits] . . . What was good about it, what was bad about it, so the kids could come back and say ‘yes I really liked that one because they have a swimming pool but I didn’t like that one because I couldn’t go out’ so they were able to grade them. And the idea was that they would be able to choose two or three that they liked and then go with their parents.

While many of the parents relied on the schools or colleges to make preliminary visits, all of them were crucial in supporting their son or daughter in coming to a decision and helping them to plan for the next move. One mother appreciated an information pack about the place that her son was moving to which helped prepare him:

They sent a very good pack through . . . and in their pack was lots of pictures of students doing things and a picture of the actual main house . . . so when Adam came to me we would spend quite a lot of time, something very simple really isn’t it, just looking at these pictures and saying ‘Oh look, I wonder if that’ll be your room’ . . . and then we’d turn over the page and ‘Oh look, this person’s painting and you’ll be able to paint’.

When asked what might be the best way to disseminate information, parents mentioned:

• ‘A newsletter . . . They’ve got a list (or should do) of young disabled people on their books and they should send out a newsletter, monthly would be fine, twice a year would be fine. Just so that people are updated’.
• Information about possibilities was categorized according to specific criteria. One parent explained that she was sent ‘lists and lists and lists of possible places . . . they all sort of say for people with learning difficulties but . . . it might be useful to have that information available sort of in sections’.

Professionals also acknowledged the important contribution of the provision of information and suggested a number ways it could be disseminated, including:

• a database of local provision;
• a video showing young people with ID living in different types of housing provision;
• videoing possible options if the young person cannot visit in person;
• inviting school/college leavers to return and talk to current students about where they are now living and the activities they are doing; and
• an Information Officer post responsible for compiling and disseminating information.

Good forward planning and allowing adequate time to prepare

The fourth theme that emerged from the interviews with the parents was the importance of good forward planning and allowing adequate time to prepare for whatever moves were to come. Good forward planning would involve:

• that necessary aids or equipment were in place and the staff knew how to operate them;
• that arrangements had been made to meet the holistic needs of the youngsters, including their social, leisure and communication needs; and
• ensuring that the youngsters would be able to maximize their potential.

On the whole, good forward planning was viewed by parents as being the shared responsibility of a number of people: themselves, the residential school or college, the next placement, and the person coordinating the transition arrangements.

A number of examples were given of where good forward planning was helping the transition process of young people. One mother, for example, explained:
Evie learns the PECS communication where you’ve got a picture and a word. . . . The next placement have the picture symbols on their fridge and on their walls so that Evie knows what’s going to happen next, which is essential for her.

For one young man, forward planning involved having short breaks at a potential future placement while he was still at college. In this way he could get to know the place and the other people living there, and move in on a full-time basis when he finished college. For other youngsters, a residential college set up work experience placements with national companies so that when the students left college and moved back to their home area, they would find it easier to transfer within that company, as they would already know what was expected of them in that environment.

Inevitably, good forward planning would involve allowing adequate time to prepare for whatever moves were to come. The amount of time that parents thought optimal for searching for a suitable place and preparing their son or daughter for the move varied from 1 to 5 years. One father commented:

I think if you’re looking for a long-term placement in the area and you want some choice I think you’ve got to start looking five years before you want it.

What was clear from the parents’ discussions was that when finding a place for the young people to move onto was left until their final year, the time available for parents to feel fully involved was too limited. Parents often only saw their youngster during school or college holidays or weekends, and they did not have sufficient time together to then visit and discuss possible future options.

**The parents’ views on the outcome of transition**

When considering how they would know that the transition of their son or daughter on from their residential school or college was ‘successful’ or not, most parents commented on the transition between services, rather than thinking of transition to adulthood in a more general sense. In the transition between services, parents measured a good outcome to be one in which their son or daughter was happy and content, was able to pursue existing interests, had a social life, and had the opportunity to engage with a range of activities. Some also considered a successful transition to be one where the young person was able to communicate their wishes and needs freely, and had the confidence and self-esteem to do what they wanted to do, rather than what might be offered or expected of them. For two parents, the opportunity for progression was important. They considered a good transition to be one in which the young people would be supported to make further transitions in their lives: in one case, to some form of employment and in the other, to more independent living arrangements.

**Discussion**

The findings of this study should be viewed in the light of its possible limitations. First, local authorities had a number of difficulties identifying out-of-area students with learning difficulties to invite them to take part in the study despite national data being available (SEN Regional Partnerships, 2005). There is some doubt therefore as to whether all eligible young people were contacted. Second, the study was based on 15 young people with ID and a total of 58 interviews. Third, the different subgroups involved may not have weighted the importance of the different themes in the same way.

Even so, the views of parents about what they think contributes to a satisfactory pathway for their son or daughter with ID from an out-of-area residential school or college are noteworthy because of their clarity and universality.

The importance of supportive connections with key professionals might have been influenced by the circumstances in which parents found themselves. Other research (e.g. Abbott et al. 2000, 2001) suggests that by the time an out-of-area placement has been secured for a young person, often after much struggle and disagreement, working relationships between professionals and families are neither harmonious nor cooperative, and evidence of this was apparent in an number of the families in this study. Clearly, these difficulties would have to be addressed to ensure a smooth transition of the youngster back to their home area.
The Special Education Needs Code of Practice (DfES 2001) states that from Year 9 of school onwards, annual reviews should involve agencies that may play a major role in the young person’s life during the postschool years. At the Year 9 annual review, a Transition Plan must be drawn up, to be reviewed at each subsequent annual review. Attendance by ‘home’ professionals at annual reviews for young people in out-of-area placements, however, was often sporadic, with some having to juggle the demands of attending an annual review at considerable distance that would take a full day’s work, against sending their apologies and devoting the time to more of their caseload at a local level. Given the difficulties of young people in out-of-area placements at transition, a re-prioritization of the workload, or the use of video conferencing at reviews, could be a way forward for this.

Allowing adequate time to prepare for whatever moves were to come additionally assumes that time has been spent on identifying with the young people what they want for their future and the supports they would require. Government policy explicitly states that person-centred planning⁴ should be the focus of transition planning (DoH 2001; Prime Minister’s Strategy Unit 2005), although there was little evidence of this in the study. Rather than the continual pushing back of the theoretical age at which transition planning should begin, what could be effective would be a more concentrated period of work based on the principles of person-centred planning beginning in the penultimate year of a school or college placement and supported by the allocation of dedicated resources with which to do so. Pilot projects introducing a person-centred approach in the statutory transition planning process for people with ID in London have suggested that early planning, coupled with intensive support to put the plan into action, could result in young people asking for very different services in the future (see examples at: http://www.valuingpeople.gov.uk/transition/stories).

Taking up employment, moving to independent living arrangements, economic self-sufficiency, social participation and adult role-taking are factors generally thought to mark the successful transition of young people to adulthood. Only two of the 15 parents interviewed for the study, however, considered any of these factors to be useful outcomes of a ‘good’ transition. This may reflect their overriding concern with traditional service provision for their son or daughter; their own reluctance to think about their son or daughter as becoming a more autonomous adult; or their anxiety that until ‘services’ were in place, other issues could not be fully addressed. Their views were emphatically supported by a college tutor who related the story of a young man whose transition would have been considered a ‘failure’ by Office for Standards in Education (Ofsted, England) and the Learning and Skills Council because he had opted out of further education. However, the tutor considered the transition to be successful because, despite there being a lot of pressure on the youngster to carry on with his education, he was using the skills he had learned, had the confidence to decide for himself what he wanted to do, and was able to direct the people supporting him to make that happen. Clearly, measuring outcomes is important, and in England, a number of regional government initiatives are collaborating on developing a multi-agency outcomes framework for monitoring residential placements. This may go some way to contributing to our knowledge about the longer-term outcomes for disabled young people in residential provision compared with others.

Conclusions

While there are a number of continuing concerns about the placement and onward transition of young people with ID from out-of-area residential schools and colleges, the Help to Move On study has clarified what parents think contributes to a satisfactory pathway and outcome. On the whole, they were clear about what they think helps: being well-connected with other parents and with key professionals, being proactive themselves, being kept informed through the provision of sufficient and adequate information, and knowing that sufficient time was allowed for planning and preparing for the next move. Most considered a good outcome to be if the young person was happy, stimulated and fulfilled. While many of these factors have been identified in previous research about the transition of disabled young people, they have a particular salience, and raise unique issues for families with a youngster in an out-of-area residential

⁴For information about person-centred planning, see: Planning with People: Towards Person-Centred Approaches – Guidance for Implementation Groups, published as part of the Valuing People strategy (DoH 2001).
school or college who is preparing for their next move.

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