

Transition issues in education affecting young people with life limiting conditions. Year 9 to leaving school.

The purpose of this work was to:

1. Identify, from the perspective of Education, the issues and opportunities for young people with life limiting conditions, and for their families/carers, in managing their own best transition to becoming young adults
2. Create a map of the existing education journey routes for young people with life limiting conditions making the transition to adulthood, analysing and illustrating any perverse effects and their causes.

Scope

This work was intended to provide a brief exploration of the education perspective in relation to the central question that we focused on in Phase 1. As a small but important part of the much larger phase 2 of the Marie Curie Project, the consultants were able to allocate 6 days to this element. Within this time frame we undertook some initial scoping desk research and 13 interviews. (See appendix 1 for breakdown of roles of interviewees). This has helped us create a snapshot of the complex educational situation for this group of young people from the age of 13 to 16 in and around London. We made an attempt via their specialist nurses to identify and speak with four young people with life limiting conditions but, as we found in Phase 1, we were unable to complete the contact within the time frame. If the opportunity presents, we will carry out these interviews later in the project in order to gain the young people's perspective on their educational journey

Context and Background

The process for each young person with a life limiting condition, whether they are in mainstream education, special or hospital school or having home tuition should include transition planning. The way this should be conducted is clearly set out in the Special Educational Needs (SEN) Code of Practice 2001¹ (appendix 2) and it seems that some form of this planning takes place but with wide variations across counties, cities and in London, across boroughs.

¹ Special Needs Code of Practice Nov 2001 DfES/581/2001. Related doc Education Act 19996

Each young person with special educational needs whether statemented or not, [they may be designated school action or action plus] has an annual review. In year 9 this has a particular focus: 'The aim of the annual review in year 9 and subsequent years is to:

- (a) review the young person's statement if existing
- (b) draw up and subsequently review the 'Transition Plan.'

The school arranges the meeting, inviting the young person, their parents/carers, and all the agencies involved with the young person. This could include, social services, health services, educational psychologist, the local authority special education needs officer (SENO), and importantly a Connexions personal adviser. Since the Connexions service was closed down in March 2011, this coordinating, careers advice and wider support role still continues but is funded by private companies or local authorities in, it seems, a much reduced form. The review is repeated each year and the plan updated until the young person leaves school.

This process can be seen in appendix 3 where we have attempted to provide a visual representation of the possible education routes taken by young people with life limiting conditions. This map includes potential support systems and is as described to us by interviewees therefore we are aware that such a map could vary from area to area. Other parts of the education process and routes taken as represented in appendix 3 will be referred to later in the report.

Areas of good practice identified

Interviews with key stakeholders revealed a number of examples of good practice. Evidence of detailed, individualised and young-person centred plans for education were described, such as a young person with frequent hospital admissions who returned to the hospital school room for his education as the hospital was across the road from his home and the journey to school was long and exhausting at that stage of his illness. Another young person attended mainstream school but had an arrangement whereby she could attend the specialist provision school geographically close to her main school when she required 'catch-up lessons' following long periods of illness and absence from school.

Effective collaborative working of this kind was evident in a number of examples given by interviewees such as an educational psychologist who was supporting the school to support the young person who was about to be given a diagnosis of a life limiting condition.

A school for children with profound and multiple learning disabilities and complex health needs had an exceptionally rigorous and regular transition planning which included the use of a 'multi-media DVD' acting as a passport that the young person

could take with them as they moved on to other institutions. This is a DVD made with the young person which films aspects of the young person's education and living which may be difficult to capture in a written report and which could include details such as, 'this is me having physio., this is how I communicate, this is how I move.' For young people in this school, innovative communication tools such as this formed part of the 'person-centred planning' referred to by a number of people as being an approach rooted in the social model of care and one which is used to plan *with* a person not *for* them.²

Multi-agency reviews aimed at producing an individualised plan for the young person were described as happening annually when the young person was statemented and would include a wide variety of people involved with the young person. Connexions were positively mentioned as being pivotal to multi- agency reviews and were perceived as being 'very good at the holistic approach'. A Connexions advisor interviewed saw her role as, 'listening to the young person and introducing to them and their parents the options that are and will be available.' She tries to facilitate the young person's transfer to adult services and to help parents seek the help that is available in adult services but stated that some parents can be very wary because of past bad experiences.

Gaps and issues in services

One of the major gaps described by most people interviewed was that of inconsistency of services between conditions and across boroughs in London. One interviewee believed there was a 'condition inequity' with some medical conditions attracting better resources and in some cases better care than others. This was also referred to in an All-Party Parliamentary Report on sickle cell disease and thalassaemia³ which reported that, 'schools being told a student has sickle cell disease or thalassaemia appears to make no appreciable difference to reported poor treatment'. Condition inequity was further described by Dyson⁴ who found that of schools that had policies on specific conditions, 28 had a policy on epilepsy as against 2 with a policy on sickle cell Disease.

This could suggest that those conditions that affect the majority white population (and not those that affect the black and minority ethnic population) attract better resources and in some cases better care than others.

Further inconsistency was described in a geographical sense, summed up by one senior teacher who said, 'I can arrange home tuition for a young person quite easily

² O'Brien, C and O'Brien, J. 2000. The origins of person-centred planning. Responsive systems Associates Inc.

³ APP Sickle cell and thalassaemia Report: The Social Aspects of SCD and Thalassaemia in Young people. 2009.

⁴ Dyson, S et al. Local Authorities and the education of young people with Sickle cell disease in England. 2008. International Studies in Sociology of Education, 18(1), pp 47-60

if they live in my borough but it practically killed me to arrange it for a young person living in a neighbouring borough.'

Another issue arising from inconsistencies between boroughs was that the knowledge of what a local education authority approach is and how that translates into what is available for the young person is kept within the education system making it difficult, if not impossible, for a parent or carer to know exactly what is available.

In London, differences in what happened to young people with regular school absences were apparent, with some boroughs placing all such children under the Pupil Referral Unit umbrella. This meant that in one borough a young person with a life limiting condition might be sent to a Pupil Referral Unit, which also catered for young people who were there due to serious behavioural difficulties. A neighbouring borough had a medical section and a behavioural section though one teacher felt that young people with life limiting conditions were 'the forgotten ones' with no uniform policy addressing their educational entitlement unlike students with behavioural problems who she felt 'tended to get their 25 hours a week'.

In some areas, stakeholders felt that it could be difficult to identify who was taking the responsibility and ownership for co-ordinating the plan for an individual young person. Whilst the Special Educational Needs (SEN) framework described in the introduction to this report details the Year 9 planning meeting, [see appendix 2]. In reality this was not experienced as happening in as complete a way as it used to or should do. One Special Educational Needs Coordinator (SENCO) said that as cuts are being made to local authorities and to central services; it is rare to see someone from the local authority or an educational psychologist at the meeting. This interviewee felt that therapists who may be involved with the young person such as physiotherapists or speech and language therapists are so thinly spread that they would prioritise seeing young people above going to meetings. Furthermore, he felt that 'health professionals have their own meetings and don't usually link up with the review meeting.' He said 'things have never been grimmer.'

Some people interviewed feared that the demise of the Connexions Service would lead to a yawning gap in the crucial co-ordinating and holistic role, which this particular service seemed to excel at.

A Connexions advisor who was interviewed said that after the closure of Connexions in March 2011 the work has been taken over by private companies or the local authority. In her borough, a private company has a contract to deliver careers advice and there have been cuts to this service. The former 28 connexions staff have been reduced to 9 (in East Sussex the reduction has reportedly been from 7 to 3). This interviewee described radical changes to the service. In the past she would have seen *all* young people in a school in year 9 whereas now only those with statements will be seen.

Whilst this advisor deals with young people with SEN educated in borough and those being educated out of borough, she stated that the local authority is finding it almost impossible to fund specialist education out of borough anymore. In her borough, schools arrange the review meetings and she has an obligation to attend. The review/transition planning process ends with a final meeting before the young person leaves education when a moving forward plan is made and is needed to access funds to support the next step. She stated that, 'It is very hard to get services agreed for young people from Adult Services as the criteria are unclear.

For young people in mainstream school, a particular challenge highlighted by a specialist nurse was that in primary school, both their peers and the school tended to know about their condition. However, at transfer to secondary school, a number of young people were very keen that their peers should not know as they did not want to be treated differently. The wish for privacy could of course compromise the support afforded to a young person by their peers especially when they are frequently absent. One interviewee suggested that whilst missed learning was an issue, of equal importance was the missed social connections, a gap which in some schools had been addressed by the use of a 'buddy' who visited the young person when they were absent from school, acting as a social link both in periods of absence and on return to school following the absence.

A transition co-ordinator in a London borough, funded by the former Primary Care Trust works with an outreach team of three, to promote health and well being for young people with special education needs and disabilities. He monitors what happens to all such young people in the borough and says that there are two young people with life limiting conditions currently in this age group. He does not go to all transition planning meetings but would try to do so where the situation is complex and there are difficulties in accessing funding as the young person moves on e.g. in a dispute about who should fund the cost of a young person in a residential school or college. He is also working with the further education strategy lead in the borough to improve the local college's accessibility and relevance for young people with a variety of needs so they can stay in borough.

Conclusion

1. There is a formal process that has been designed to deal effectively with transition of young people with special education needs and that should, in principle, apply to young people with life-limiting conditions, and should involve all agencies including health.

2. However, this formal process does not appear to be applied in a recognisably similar way across the areas from which we drew our interviewees. In fact, what seems clear is that the process for dealing with these young people is inconsistent and fragmented. Variation occurs from authority to authority and from borough to borough and is likely to get worse in the current context as described to us.

3. It is clear that making sense of these arrangements by young people or by parents, who are often already under considerable stress, is difficult.
4. There is widespread support for the Green Paper⁵ and a view that this had the opportunity to bring about positive change assuming that the rhetoric is matched in reality.
5. As we found in Phase 1 of this project, there is no consistent role player for the key worker function.
6. There is evidence to suggest that the reduction/removal of the Connexions service removes the one agency through which, coordination (the key worker role) might have been effected.
7. Where crucial stages – like the Year 9 review - are reached, it is unusual to find that all agencies are represented. Health professionals in particular are sometimes missing and social services are said often to be absent unless they have the lead or unless child protection issues are involved. It is hard therefore to see this stage as a genuine inter-agency event.
8. There appears to be a ‘condition inequity’ with some medical conditions (perhaps those that for historical reasons have been more widely recognised) attracting better resources. The brevity of this element of the project did not allow for further exploration on whether this is the case and if so, what factors may contribute to it.
9. Individualised budgets may provide certain groups of young people with some leverage over a generally fragmented support framework. This might link with the idea that all young people should have an ‘entitlement offer’ so that all agencies are clear about what the offer is and what their individual service should be doing.
10. Yet good practice exists.
 - We heard of evidence of detailed, individualised and young-person centred plans for education that resulted from collaborative cross-agency action
 - The ‘DVD passport’ is an example both of a person-centred approach and the use of an effective and relatively simple communication tool
 - Where they were implemented, the individualised and flexible plans for some young people were exemplary and dynamic, enabling the young person to continue their education in a way and place that was best suited to their needs at a particular time

⁵ DoE. March 2011. Support and Aspiration: A new approach to special educational needs and disability. A Consultation.

So, the picture emerging is one in which there are examples of excellence juxtaposed with experiences of inconsistent and difficult to access information and services. Our experience was that it was difficult to piece together a coherent view of what happens for this group of young people from year 9 to when they leave school. This reflects the fragmented nature of the process that they encounter. It is difficult to avoid the view that effectiveness where it occurs is 'down to individuals driving the communication rather than effective systems'.

Recommendations

- For the Marie Curie Transitions Programme:
 - To disseminate this report to the Pilot Sites
 - To ensure Education is a theme in the Pilot Sites and the learning network with effort made to engage education professionals, schools and colleges in the sites
 - To disseminate this report to emerging structures such as the Health and Wellbeing Boards once those boards are established
- For the Education service:
 - To take steps to set out the education process and options within it in a transparent way to young people and parents perhaps in the form of an 'entitlement offer'
 - Further work should be done, if not already in train, to share examples of good practice through existing education networks.
 - Policy needs to be formulated at government level to address the need for an integrating perspective such as that provided, in the past, by the Connexions service.

Appendix 1

People who contributed their views and expertise to this work stream

Staff interviewed held the following positions:

- Service Manager for Haemoglobinopathy Nursing Service London
- Educational Psychologist Kent
- Development Manager, East Sussex County Council
- Head Teacher of East London Primary School
- Head of Children and Young People's Nursing London
- Head Teacher, Hospital School London
- Deputy Head, Post 16 Provision, Specialist Provision School for children with profound and multiple learning disabilities and complex health needs London
- Team Leader Borough Learning Support Services London
- Specialist Nurses for Cystic Fibrosis: Children, Young People and Adults London
- Special Educational Needs Coordinator(SENCO) London
- Special Education Needs Coordinator East London
- Ex - Connexions Personal Adviser, London Borough
- Transition Co-ordinator for young people with special needs PCT London borough

Appendix 2

Extracts from the SEN Code of Practice 2001 Sections 9.50- 9.62

‘The aim of the annual review in year 9 and subsequent years is to: (a) review the young person’s statement (b) draw up and subsequently review the Transition Plan.’

The annual review of the statement held in year 9 should involve the agencies that may play a major role in the young person’s life during the post-school years and must involve the Connexions Service.

The annual review procedure in year 9 differs from previous reviews in the following ways:

- the head teacher must invite the Connexions Service to provide written advice and invite them to the review meeting, to enable all options for continuing education, careers and occupational training to be given serious consideration
- a representative of the Connexions Service is obliged, by the conditions of grant, to attend the review
- the head teacher should ensure that other providers, such as health authorities and trusts, are aware of the particular procedures to be followed in year 9
- the head teacher must invite the social services department to attend the review so that any parallel assessments under the Disabled Persons (Services, Consultation and Representations) Act 1986; the NHS and Community Care Act 1990; and the Chronically Sick and Disabled Persons Act 1970 can contribute to and draw information from the review process
- the head teacher must ensure that a Transition Plan is drawn up. This should be done in consultation with the Connexions Service

The Transition Plan

The annual review in year 9 and any subsequent annual reviews until the young person leaves school must include the drawing up and subsequent review of a Transition Plan. The Transition Plan should draw together information from a range of individuals within and beyond school in order to plan coherently for the young person’s transition to adult life.

Transition Plans when first drawn up in year 9 are not simply about post-school arrangements; they should also plan for on-going school provision, under the statement of SEN as overseen by the Local Education Authority.

All those involved in the process should adhere to the principles that underpin the nature of transition and transition planning and the requirements of the young people and their families. Transition planning should be:

- *participative*
- *holistic*
- *supportive*
- *evolving*
- *inclusive*
- *collaborative*.

The Connexions Service is responsible for overseeing the delivery of the Transition

Plan and the Connexions Personal Adviser (PA) should co-ordinate its delivery.

Student involvement in decision-making during transition

The views of young people themselves should be sought and recorded wherever possible in any assessment, reassessment or review from year 9 onwards. PAs, student counsellors, advocates or advisers, teachers and other school staff, social workers or peer support may be needed to support the young person in the transition process.

Involvement of social services departments

LEAs must seek information from social services departments under section 5 of the Disabled Persons (Services, Consultation and Representation) Act 1986, as to whether a young person with a statement under Part IV of the Education Act 1996 is disabled (and so may require services from the local authority when leaving school). Multi-agency input at year 9 is important for all young people with SEN. Under the Children Act 1989 social services departments may arrange multi-disciplinary assessments and must establish Children's Service Plans which may include the provision of further education for children in need (likely to include those with significant special needs). Social services departments should ensure that a social worker attends the year 9 annual review meeting and contributes to the formation of the Transition Plan where a young person is subject to a care order, accommodated by the local authority or is a 'child in need'.

Involvement of health services

Health professionals involved in the management and care of the young person should provide advice towards transition plans in writing and, wherever possible, should attend the annual review meeting in year 9. They should advise on the services that are likely to be required and should discuss arrangements for transfer to adult health care services with the young person, their parents and their GP. They should facilitate any referrals and transfers of records, which may be necessary, subject to the informed consent of the young person and parents, and should liaise with the Connexions Service as appropriate.⁶

Annual reviews from year 10

The school remains responsible for convening annual review meetings until such time as the pupil leaves school. Some pupils with statements of special educational needs will remain in school after the age of 16. LEAs remain responsible for such pupils until they are 19. There will be occasions where the natural completion of an academic year or completion of a particular course would take a pupil with a statement beyond their 19th birthday. The Learning and Skills Council, when it

⁶ Special Educational Needs Code of Practice Nov 2001 DfES/581/2001. Related Docs –Education Act 1996

becomes responsible for the funding of sixth form provision, will, as a condition of funding, require LEAs in those situations to maintain statements until the end of the academic year in which their 19th birthday falls. Whatever the intended future destination of the young person, the annual review has an additional significance as the young person approaches the age of 16. The Connexions Service should be invited to and should attend the review meeting in year 11 in order to ensure that the Transition Plan is updated appropriately. In the young person's final year of school, the Connexions Service has a separate responsibility, under section 140 of the Learning and Skills Act 2000, for ensuring that an assessment of their needs on leaving school is undertaken and the provision identified. Every effort should be made to link this final annual review of the statement and to consider the Transition Plan together with this assessment so that a holistic approach is maintained. Where post 16 provision has already been identified it is good practice for the head teacher to invite a representative from the provision to the review meeting.

Appendix 3.Young People (YP) with Life Limiting Conditions (LLC): Possible Education Routes and Potential Support Systems

