

The Law & Transition

Overview and current duties



Joint Improvement
Partnership

This paper is a briefing on the legal framework surrounding transition. It is one of a series of resources produced for the London JIP Transition Project . Written by Kate Whittaker, Housing & Support Alliance- December 2012

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1. Introduction

This document contains an overview on the legal framework surrounding young people with learning disabilities. It has been written to accompany a training programme for local authority employees on the law and is intended as an overview.

2. Transition overview and current duties¹

Current legal position:

- **Continuing duties on social care and health bodies** to assess and provide services as disabled young people move into adulthood
- Education services generally take the lead in transition planning
- Education duty to produce a **transition plan** following the Annual Review of a child's statement of SEN at 14
- **Learning difficulty assessment** in the child's last year at school if they are continuing to college or university
- **Health action plan** to be developed for every disabled young person with health needs as part of the transition process
- 'Looked after' children entitled to a **pathway plan** and related support under the leaving care legislation, to support transition out of care

3. What/When is transition? What is shifting to what?

Rather than framing transition in terms of the changes in services that young people may be entitled to, it may be helpful to think about transition in terms of the fundamental principles that need to be bridged as smoothly and effectively as possible:

(1) Legal capacity/decision-making responsibility

Capacity:

- MCA 2005: Children and young people aged 16 and over are assumed to have capacity to make decisions for themselves, unless shown otherwise

¹ Some of the material in this paper draws on the Chapter on 'Transition to adulthood' in *Disabled Children: A legal handbook*, by Steve Broach, Luke Clements and Janet Read (Legal Action Group, 2010).

- Assess in accordance with MCA and Code of Practice
- Capacity is issue-specific
- Under 16, assumed to lack capacity unless Gillick-competent
- If lack capacity, decisions can be made in person's best interests

(2) Paramount or guiding principle(s)

Children:

- Children Act: welfare of child is paramount

Children and young people who are disabled or who have complex health needs:

- NSF for Children, Young People & Maternity Services (2004): Standard 8: *'Children and young people who are disabled or who have complex health needs receive co-ordinated, high quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, which enable them and their families to lead ordinary lives.'*
 - Must be taken into account by NHS bodies and local authorities when making decisions and/or developing policies
 - Cited by Ombudsmen as benchmarks re whether public body actions have fallen below an acceptable standard

Adults:

- If lack capacity: 'best interests' (MCA), but NB:
 - capacity is issue-specific - so not very helpful as an overarching principle
 - use of a best interests process isn't necessarily conclusive or binding in terms of what statutory bodies actually need to provide - certainly doesn't change duty into one to provide **optimal** provision just because someone lacks capacity
- As far as social care is concerned: White Paper: the 'overarching statutory principle' - new **general** duty to promote the individual's well-being when exercising any function under the new legislation
- Draft bill clause 1: 'Well-being' includes not only physical and mental health, but also social and economic well-being, family and personal relationships, and 'control by the adult over day-to-day life (including over the care and support provided to the adult and the way in which it is provided)'.

- Clear that not intended to create an individually enforceable duty
- But (p.114) 'failure to follow the principle' will be challengeable by way of judicial review

(3) Approach to family, carers and other relevant people - including:

- i. consultation/involvement in decision-making
- ii. expectations regarding their roles, contribution to supporting the person, and entitlement to support for the caring role
- iii. issues about right to a private and family life - Article 8 ECHR

NB importance of consultation with relevant people (including the young person themselves). In many ways this is the thread of continuity between children's services and adult services - certainly in terms of ensuring respect for Article 8 rights - or rather the nub of discontinuity that is at the root of many of the worst failures to manage a transition process effectively.

Children Act consultation requirement: CA 1989 ss1(3) and 17(4A)

(4) Shift from dependence to independence

- Disabled adults have the right to not have to be dependent on their parents or other family members for care support, if they don't want to; and family carers have the right to choose not to provide direct care support to an adult child, or to reduce the support they provide
- But both young disabled people and their family carers have the right to respect for their Article 8 rights, and to be consulted about their preferences, and they may wish to continue living in the family home
- Complex decisions, at a time of strain and loss of services: dangers of:
 - overestimating the ability of young people to move to independence without high levels of support, especially as well supported education placements may come to an end
 - making instant assumptions that family's view is of less weight because their child is now an adult
- Continuity in terms of person-centred approaches and listening to the wishes of the young person and their family is key.

4. Getting the legal basics right:

Public bodies (LAs, NHS bodies) must:-

- **act reasonably** (i.e. in terms of process), including:
 - act fairly
 - give logical reasons for decisions
 - not cause unnecessary delay
 - honour promises
 - exercise discretion properly - not use blanket policies where discretion is a must
 - follow policies

- **act lawfully:**
 - comply with statutory duties
 - not act *ultra vires* - exceed lawful authority: eg the *Neary* case:²
 - 'The ordinary powers of a local authority are limited to investigating, providing support services, and where appropriate referring the matter to the court. If a local authority seeks to regulate, control, compel, restrain, confine or coerce it must, except in an emergency, point to specific statutory authority for what it is doing or else obtain the appropriate sanction of the court.'
 - (Don't get carried away with assumptions of having general authority eg because of overall safeguarding context - must have specific authority and know where the boundaries lie)
 - comply with **Human Rights Act 1998** (section 6 - duty on public bodies to act in accordance with rights under the Convention)
 - comply with **Equality Act 2010** - public sector equality duty

5. Education

Unless there is substantial health or social care involvement with a child approaching transition, then education should be the lead agency for the transition process.

At present the two main education duties relating to transition for disabled young people are:

- **transition planning duties from age 14 for children with a statement of SEN** (SEN Code of Practice) - this is aimed at ensuring proper

² *LB Hillingdon v Steven Neary and others* [2011] EWHC 1377 (COP)

- planning, in good time, for positive futures for young people with SEN after school
- duties to carry out a **learning difficulty assessment** in the young person's last year at school (s.139A/s.140 Learning and Skills Act 2000) and deliver an **action plan** (s.139B LSA 2000) - to meet the educational, training needs and related care needs identified, after they finish compulsory education and up to age 25

Since the transfer of responsibility for post-16 assessment and provision to local authorities under the ASCLA 2009, they are now responsible for planning, commissioning and funding education and training for all young people with a learning difficulty aged 19-25, regardless of where it is decided that their assessed needs should be met (such as local FE sector college or specialist FE college).

The transfer of responsibility to local authorities is intended to establish a single point of accountability. However further change is likely under the proposals for the single 0-25 assessment process and HECF.

SEN transition planning

Children with statements of SEN receive an annual review. In Year 9 (age 14) this should be extended to plan for the child's transition from school. It should be attended by the Connexions service (now funded and delivered by LEAs).

Education has the lead responsibility but planning must be a multi-agency process. The LEA must seek information from adult social services as to whether the young person is likely to require adult social services assistance (s5 Disabled Persons (Services, Consultation and Representation) Act 1986). If so, a representative of adult social services should attend, and it is likely that a core assessment will need to be undertaken before the review meeting takes place, to inform the transition planning. Similarly if it appears that the child will potentially be eligible for adult NHS continuing healthcare funding, an NHS representative should attend.

Non-attendance by social services or the NHS, and/or failure to undertake appropriate assessments to inform planning, commonly lead to these reviews being completely ineffective. A common assumption is that if the child is not already receiving support from local authority or NHS children's services, then there is no need to be involved. Another common error is to wrongly conclude the child will not meet adult eligibility criteria and there is therefore no point in being involved, due to a failure to take account of how the child's support will change

on transition - for example they will lose the considerable support they are getting from their school placement. Different departments within local authorities also sometimes fail badly to cooperate with each other.

These are serious failings with long-term consequences: see, for example, Ombudsman complaint report 05/B/00611: failure of social services to carry out a core assessment or attend the annual review at age 14, indeed the review did not happen until age 15 and even then the education department failed to participate - there was a finding of maladministration and recommendation of over £5000 in compensation.

The Year 9 transition review should lead to production of a **transition plan** which should be reviewed at each subsequent annual review. This should be developed in a person-centred way ensuring that young people and their families are involved in the process (DH, *Person-centred planning: advice for using person-centred thinking, planning and reviews in schools and transition*, 2010). The SEN Code of Practice (9:52) states that transition plans should be:

- participative
- holistic
- supporting
- evolving
- inclusive, and
- collaborative.

The young person may need the support of an advocate to make sure their views and aspirations are heard and shape the transition plan. However, another mistake that commonly arises is that professionals may not give sufficient weight to views and points put forward by parents and carers, insisting that if the young person has not raised an argument themselves, with or without support from an advocate, then the raising of it by a parent or carer has little or no validity. This is a particular problem where young people have limited insight into the extent of their dependence on support - both because of their condition itself (as a result of which they may lack capacity to weigh up the necessary information about their future options and the support they will realistically need), and because their ability to manage without intensive support has never been tested. Parents and carers, on the other hand, will often be acutely aware of how very extensive their child's support needs are because they are currently meeting a high proportion of them, and equally aware of how much additional support will be needed in adulthood to keep the young person safe if they are to become more independent and less reliant on parental support.

When first drawn up in Year 9 the transition plan should cover both on-going school provision and plans for post-school arrangements.

The Connexions personal adviser should co-ordinate the delivery of the transition plan (SEN CoP 9:53)).

Where a young person has a statement of SEN it continues while they remain in school or until such time as the LEA determines to 'cease to maintain' it (a decision which gives rise to a right of appeal to the First Tier Tribunal (SEN and Disability)). However if they move into further education the statement cannot move with them and it will be the learning difficulty assessment and plan which will be the critical document setting out the support they can expect to receive.

In recent years an increasing proportion of young people with SEN have had their support provided not through a statement but through support devolved to schools: Schools Action or Schools Action Plus. The formal SEN transition planning options only apply to those young people with statements of SEN: for those without statements there is a much more limited requirement on schools to ensure that they receive 'appropriate advice and guidance' on their post-school options (CoP 9:65). They also come under the general responsibility of the Connexions service to provide support to all young people. Therefore the separate (but later) duties to carry out a learning difficulty assessment and deliver an action plan in light of it are particularly important for this group.

Learning difficulty assessments and post-school provision for young people with SEN

The ASCLA 2009 inserted new sections into the Education Act (EA) 1996 placing a duty on local authorities in England to **secure enough suitable education and training (s15ZA) and work experience (s560A) to meet the needs of young people with learning difficulties aged 16-25.**

There is much evidence that many young people with learning difficulties do not continue in education, training or employment because the curriculum or programmes did not interest them or were not at the right level for them,³ that the range of opportunities are extremely limited,⁴ and there is often a feeling that there is nowhere for young people to go once they have finished at school.⁵ Young people with learning difficulties and/or disabilities have been found to be

³ Ofsted, *Reducing the numbers of young people not in education, employment or training: what works and why*, 2010

⁴ K. Martin, R Hart, R White and C Sharp, *Young People with SEN/LDD: Research into planning for adult life and services*, LG Group Research Report, Slough: NFER, 2011

⁵ Ambitious about Autism, *Finished at School*, 2011

twice as likely to be not in education, employment or training (NEET) as those without.⁶ Local authorities therefore face a significant challenge in fulfilling this duty, particularly given the anticipated rise in the number of young people with learning disabilities staying on in education and training following the raising of the participation age from 2013.

Despite the strong policy intention of securing appropriate education for disabled young people within the minimum disruption, and evidence that spending money on improving outcomes in this area can deliver significant net benefits due to increased engagement with employment, and reduced dependency on care, there are many reports of local authorities acting contrary to the intention of ASCLA 2009, and in particular seeking to influence the outcome of learning difficulty assessments in such a way as to avoid potential liability for expensive placements.

s15ZA EA 1996 (inserted by s41 ASCLA 2009) defines learning difficulties as follows:

'A person has a learning difficulty if:

(a) he has a significantly greater difficulty in learning than the majority of persons of his age, or

(b) he has a disability which either prevents or hinders him from making use of facilities of a kind generally provided by institutions providing post-16 education or training.

But a person is not to be taken to have a learning difficulty solely because the language (or form of language) in which he is or will be taught is different from a language (or form of language) which has at any time been spoken in his home.'

The *Learning difficulty Assessment guidance* for local authorities⁷ makes clear that this definition may encompass young people with a wide range of learning difficulties and/or disabilities, including those with 'mental health difficulties, autistic spectrum conditions, dyslexia, attention deficit hyperactivity disorder, behavioural emotional or social disorders, physical, sensory and cognitive impairments and other identified and non-identified difficulties in learning'.

⁶ *Learning difficulty assessment guidance*, 2.10

⁷⁷ DCSF, *Supporting young people with learning difficulties to participate and progress - incorporating guidance on learning difficulty assessments*, 2010 ('*Learning difficulty assessment guidance*')

The *Guidance* indicates that learning difficulty assessments should be the 'culmination of careful planning, starting at least at 14, placing the learner at the centre' and setting them 'on a pathway to a positive outcome, and wherever possible/appropriate leading to employment.' (*Guidance*, 1.10)

Young people with statements of SEN must have a learning difficulty assessment in their last year of school (Learning and Skills Act s139A (England) and s140 (Wales)). Learning difficulty assessments may also be carried out in the final year of school for young people with SEN but without statements. In this situation local authorities must have a transparent process setting out the circumstances in which they will use their power to assess (*Guidance*, 3.4). The guidance suggests that the power to assess should be exercised when:

- a) a young person has needs which are 'very unclear or very complex';
- b) there has been a major change in circumstances that has affected needs;
- c) specific highly specialist support may be required;
- d) a young person will, in the view of the special educational needs co-ordinator or others, struggle to access post-16 learning without support over and above that usually offered within the college;
- e) a young person will find significant difficulty in coping with the transition to a different learning environment; or
- f) a young person has needs equivalent to those requiring statementing but has not been formally assessed. (*Guidance*, 1.7 and 1.9)

Learning difficulty assessments should always be undertaken by the person who is best placed to identify and make judgments about the needs a learner is likely to have *when he or she undertakes further education, training or higher education*. Assessors should be qualified to NVQ Level 4 and should have received specific training in relation to the needs of disabled young people, being more than just basic disability awareness training. All learning difficulty assessments should be person-centred and must take account of the young person's views and wishes. The assessor should work closely with the young person, their parents and/or carers and other professionals to ensure the assessment of needs and the provision required to meet them is evidence based and valid. The assessments should be holistic and multi-agency, linking into other assessment processes as required.

Where a young person is attending a residential school, the 'home' local authority should complete the learning difficulty assessment, seeking support from the 'host' local authority (in whose area the school is located) as required.

Learning difficulty assessments should result in a written report of the person's educational and training needs and the provision required to meet them, known as an **'action plan'** (Learning and Skills Act 2000 s139B(3)). In *Alloway v Bromley*,⁸ a case concerning the previous duty to carry out assessments in England under the Learning and Skills Act 2000 s140, the court held that provision identified as capable of meeting assessed needs had to be 'actually and practically available'. Assessments and resulting action plans should clearly identify the young person's needs and set out 'appropriate provision that can actually and realistically be provided to meet them'.⁹ The placement recommended as capable of delivering the required provision must be named in the assessment.¹⁰

The court has also indicated that learning difficulty assessments also consider an individual's care needs if they are closely linked to his or her educational and training needs.¹¹

Having determined that a young person requires a learning difficulty assessment 'a local authority must continue to support the young person through to positive outcomes up to the age of 25'.¹² It is important to consider this obligation alongside the duties mentioned above for local authorities (in England) to secure sufficient suitable education and training (Education Act 1996 s15ZA) and work experience (Education Act 1996 s560A) for young people in their area with learning difficulty assessments up to the age of 25.

While funding for a period of further education or training can be of great benefit in a young person's transitional arrangements, it can only be on part of a longer-term plan. It is unfortunately all too common that such a placement results in the young person's wider needs and pathway being neglected or given less priority by the local authority, with the result that they reach the end of their course and nothing is in place that enables them to progress to appropriate adult services. Tragically the independence skills that the further education placement may have fostered may be lost because no community care support is in place to enable the young person to exercise them safely in a community setting; they may be

⁸ [2008] EWHC 2499 (Admin)

⁹ *Alloway*; *Guidance*, 3.6

¹⁰ *R (P) v Windsor and Maidenhead RBC* [2010] EWHC 1408 (Admin)

¹¹ *P v Windsor & Maidenhead*, at 60

¹² *Guidance*, 1.8

thrust back into the care of their parents and regress in terms of dependence. A cautionary example of this is given in a decision of the LGO in which it was recommended that a compensation payment be made to the parents of a young person of £1,000 per week for every week they had had to care for their daughter as a result of the local authority's maladministration (a period of two years).¹³

The importance of combining the provision of further education and training opportunities with a focus on the wider

Up until the end of the academic year 2011/12 functions relating to the funding arrangements for learners aged 16-25 with LDD/SEN under the ASCL Act 2009 were exercised by the Young People's Learning Agency (YPLA). The YPLA was responsible for allocating funds to different providers, either directly, through local authorities, or through the Skills Funding Agency, based on a national funding formula, and would consider the performance of providers against national minimum standards and inspection outcomes. Statutory guidance issued by the YPLA (under the ASCL Act 2009) set out the three main routes for funding for learners aged 16-25 with LDD/SEN at the time:

- The post-16 SEN block grant - distributed to local authorities to cover expenditure on pupils aged 16-19 with statements at maintained mainstream and special schools, non-maintained and independent special schools
- Additional learning support (ALS)- allocated to providers for direct support for learning to assist individual learners to reach their goals, and split into two levels:
 - lower level ALS - below £5500 (paid to school sixth forms and mainstream colleges), calculated using a formula for school sixth forms and a mix of formula and historical spend for colleges
 - higher level ALS - between £5500 and £19000, paid to mainstream colleges and based upon a historical average spend per learner
- Provision funded for individual learners with LDD aged 16-25, as part of the specialist placement budget, which includes (a) specialist placements in mainstream general further education colleges, (b) ALS costs over £19,000 in mainstream general FE colleges, and (c) provision at independent specialist providers (ISPs) where the assessed needs of young people cannot be met locally.

¹³ Investigation into complain no. 05/C/11921 against Trafford MBC 2007.

In April 2012 under the Education Act 2011 the functions of the YPLA were taken over by the Education Funding Agency (EFA), which also now has the responsibility for the direct funding of Academies, Free Schools and all 16-19 provision (general FE colleges, sixth form colleges and independent provision). The EFA also continues to distribute resources to local authorities to pass on to schools other than Academies and Free Schools. The funding arrangements for learners with LDD remain largely the same in 2012/13 as for 2011/12.

The Government has announced (2012) that having considered the responses to the SEN Green Paper it will be making reforms to the funding arrangements for children and young people with LDD to 'develop simplified and streamlined funding for these learners for 2013/14 and beyond'. This is to 'secure greater consistency and equivalence to ensure that funding arrangements support the Government's plans to introduce a single approach to assessment and planning for young people with special educational needs from birth to 25'.¹⁴ The EFA has indicated that it will publish Funding Guidance for 2013/14 that will set out the new arrangements for providers in the FE sector (including Independent Specialist Providers) reflecting its new approach to 'high needs funding'.

Disabled student allowances

Disabled student allowances (DSAs) are grants to help meet the extra course costs students in higher education face as a direct result of a disability, ongoing health condition, mental health condition or specific learning difficulty. They can be used to meet a wide range of additional disability-related costs, including:

- specialist equipment needed for studying - eg computer software
- non-medical helpers, such as note-taker or reader
- extra travel costs resulting from a student's disability
- other costs such as tapes or Braille paper.

The amount of support available is based on the extent of the person's needs, not their financial circumstances. The amount can be significant - in 2012 it was up to £20,520 for a non-medical helper for a student on a full-time course. The support is not available if the learner would have the needs regardless of being on the course.

The availability of financial support through DSAs does not absolve higher education providers of their responsibilities under the Equality Act 2010 including making reasonable adjustments and ensuring equality of access.

¹⁴ Education Funding Agency, *Placement Information: Learners with LDD at ISPs 2012/2013*, September 2012

Equality Act 2010 in (and in planning for) further and higher education

The Equality Act (EA) 2010 Part 6 Chapter 2 sets out the equality duties which are specific to providers of further and higher education.

In relation to admissions, a responsible body¹⁵ of a further or higher education institution must not discriminate¹⁶ against a disabled young person:

- in the arrangements it makes for deciding who is offered admission as a student;
- as to the terms on which it offers to admit the person as a student; or
- by not admitting the person as a student.¹⁷

In the context of disability, discrimination may be:

- a) **direct discrimination** - when a decision is taken concerning a disabled person which is based on prejudicial or stereotypical assumptions concerning disability generally, or the specific disability in question
- b) **combined discrimination** - combining disability discrimination with discrimination in relation to another protected characteristic
- c) **discrimination arising from disability** - where a disabled person is treated unfavourably because of something arising 'in consequence of' his or her disability, and the person so treating him or her cannot show that the treatment is 'a proportionate means of achieving a legitimate aim'
- d) **indirect discrimination** - where a person applies a 'provision, criterion or practice' which puts, or would put, disabled people 'at a particular disadvantage' when compared with non-disabled people, and it puts (or would put) the individual disabled young person at that disadvantage, and the person applying the provision, criterion or practice cannot show it to be a proportionate means of achieving a legitimate aim
- e) **a failure to make reasonable adjustments.**

Furthermore, responsible bodies must not discriminate against a disabled person in respect of the provision of education at the institution, by excluding the disabled person or in the way qualifications are offered. Harassment and victimisation by responsible bodies are also prohibited.

Finally, the responsible bodies owe the duty to make reasonable adjustments in favour of current or prospective disabled students. This may include the obligation to make appropriate changes to their provisions, criteria and/or practices; to provide auxiliary aids and services; and to adapt physical features.

¹⁵ Governing body or board of management: EA 2010 s91(12)

¹⁶

¹⁷ EA 2010 s91(1)

The same duties apply to providers of further and higher education in relation to courses of further education for which they are the responsible body and to providers of recreational or training facilities. All these duties are explained in more detail in the Equality and Human Rights Commission's (EHRC's) guidance on education.¹⁸ Taken together the duties require providers of FE and HE to adapt their provision to the greatest possible extent to enable disabled people to access its benefits. Individuals with grievances in relation to breaches of the further and higher education duties under the EA 2010 can bring county court proceedings to seek remedies including damages.

6. Social care

It is in relation to the shift from children to adult social care services that there is perhaps the most overwhelming evidence of disabled young people being failed within the transition process. All too many experience serious disruption, reduction in services, and often long-term damage to outcomes. The local government ombudsman has repeatedly expressed concern about failures in transition planning and the severe shortfalls in provision at this crucial stage. A particular emphasis has been on the importance of the duty to continue to meet assessed needs, rather than to 'use available resources as a starting point and just fit people into them'.¹⁹

There is no reason in law why this should be the case, since most services provided to disabled children are provided under s2 Chronically Sick and Disabled Persons Act (CSDPA) 1970 which applies to both children and adults. Even if there is a change in the statutory basis for the service the young person receives - for example residential accommodation, which will change from one of the provisions under the Children Act (s17, s20(1) or s20(4) to (generally) the National Assistance Act s21 - there is no reason in most cases why this legal change should make *any* practical difference to the service being provided, as long as the service continues to meet the young person's assessed needs. If a new placement is required at transition to adulthood, funding decisions to enable such a placement to be made should be taken as quickly as possible and a failure to do so may constitute maladministration.

Local authorities have a clear obligation under the Children Acts and other statutes to make sure that their children's services and adult services departments are co-operating to anticipate the transition of young disabled people. If effective assessments have been carried out when the young person is

¹⁸ EHRC, *What the Equality Act 2010 means for you in education: a guide for students, pupils and parents*, 2010, chs 4 and 5

¹⁹ Complaint no. 03/C/16371 against Stockton-on-Tees BC

a child, the records and care plans can be adopted to form the basis of adult assessment and planning. If there has been no assessment or only inadequate ones when a young person is a child, adult services will need to carry out a full assessment under the NHS and Community Care Act 1990 s47. In either event, it will almost always be necessary to determine whether the young person is eligible for adult community care services using the approach prescribed by the statutory guidance.²⁰

It is the quality of that assessment and the consequent care planning duties that is most crucial and yet so often lacking, particularly in understanding and achieving the adult lives that disabled young people want, whether that be living at home with parents, or an alternative such as supported living or residential care. Resource-driven approaches which ignore the fundamental principles behind good assessment and care planning can and do often lead to disastrous outcomes and prove to be a false economy - and this seems to be particularly the case in the context of transition in social care. This is starkly illustrated by a 2008 LGO report (Complaint no. 07/A/11108 against Surry County Council) regarding a failure by a local authority to progress with adaptations (and the associated disabled facilities grant) to enable a disabled young person to live in the family home, as she and her parents wanted, leading to her spending at least two and a half years in residential care unnecessarily. The ombudsman also considered that this delay engaged her rights under Article 8 ECHR, and expressed the opinion that:

'The greater a person's disability, the greater is the need to give proper and timely consideration to that person's basic rights and, what concerns me most, the values and principles underlying those rights - such as dignity, equality, fairness and respect.'

There is also a clear expectation that adult social services departments will engage effectively in transition planning for disabled young people. There is a specific requirement within the statutory guidance on the role of director of adult social services to ensure that adequate arrangements are in place to ensure that services are in place to meet young people's needs throughout the transition process. Many local areas have set up transition teams - either actual multi-disciplinary teams based together in either children's or adult's services, or 'virtual' teams who meet regularly and have effective systems for communicating between agencies.

²⁰ DH, *Prioritising need in the context of Putting People First: a whole system approach to eligibility criteria for social care - guidance on eligibility criteria for adult social care in England*, 2010 ('Prioritising Need Guidance') and in Wales, Welsh Assembly Government, *Creating a unified and fair system for assessing and managing care*, NAFWC 09/2002 and 09A/2002, 2002

7. Carers

Whether young people live with their families or progress towards living separately, ensuring that the rights of family carers are respected and their needs met is vital. Resources pressures may lead local authorities to seek to place continued heavy responsibilities on family carers to provide voluntary care for their adult children, and to construe assessments and service decisions accordingly. This is an issue both in relation to local authority duties towards carers themselves (to offer and carry out assessments, and provide support to meet carers' needs where appropriate) and in the way that local authorities take account of the potential availability of voluntary support from family carers in determining what support it is necessary to provide to disabled individuals.

Local authorities may feel driven to ignore quite concerted pleas from family carers and/or disabled young people they support, to be provided with additional support (perhaps only a modest amount) that would enable the young person's needs to be met more effectively rather than risk a crisis or breakdown of the whole set-up. In many cases this is completely contrary to the rights of parents to choose not to provide or continue to provide care for their adult children, and the rights (and often best interests) of the young disabled person to have their own independent support rather than continuing in a state of high dependency on parents. And it may alienate family carers who would otherwise be willing to continue to offer a great deal of support to their sons and daughters as they become young adults.

In other cases persistent failures and refusal of support can lead to parents and family carers becoming permanently embattled with services and in turn a wall of defensiveness and hostility being built up by professionals who see the family as a 'problem'. The long-term damage caused by the creation of such 'toxic' relationships between families and services cannot be underestimated, both in terms of the effect on the disabled person themselves, the loss of opportunities for positive care arrangements involving voluntary care, and the cost of conflict, for example in the form of best interests proceedings in the Court of Protection.

8. Duties to disabled young people 'leaving care'

Where a disabled child is accommodated under the Children Act s20 the child becomes a 'looked after' child and is entitled to the same protection and support as a child who is in the local authority's care under a care order or otherwise. Disabled young people who are looked after have the same entitlements when leaving care as other looked after young people.

The Children (Leaving Care) Act (CLCA) 2000 introduced significant new duties into the CA 1989, requiring local authorities to continue to support these young people into adulthood. These duties are clarified by regulations and guidance issued by the Dept of Health.²¹ The guidance is binding 'policy' guidance issued under Local Authority Social Services Act 1970 s7 and states that the purpose of the leaving care provisions is 'to improve the life chances of young people living in and leaving local authority care'.

The CLCA 2000 imposes different duties on local authorities in respect of:-

- **eligible children** - children aged 16 and 17 who have been looked after for at least 13 weeks since the age of 14 and who remain looked after;
- **relevant children** - children aged 16 and 17 who were looked after for at least 13 weeks since the age of 14, were looked after at some time while 16 or 17 but have stopped being looked after; and
- **former relevant children** - a young person aged 18-21 who was either an eligible or relevant child. NB: if a former relevant child's pathway plan sets out a programme of education or training extending beyond his or her 21st birthday, he or she remains a relevant child until that programme is completed.²²

(In relation to disabled children, short-term periods of respite care are ignored for the purpose of calculating whether 13 weeks have been reached.)

The duties are:

- a) **Eligible children** - in addition to all the provisions of the looked-after system, they are entitled to a needs assessment leading to a pathway plan and to have a personal adviser
- b) **Relevant children** are also entitled to a pathway plan and personal adviser, and in addition must be supported and maintained by the local authority unless they are satisfied that the child's welfare does not require such support and maintenance. In particular, local authorities must provide assistance (including cash if required) to meet a relevant child's needs in relation to education, training or employment as provided for in his or her pathway plan. If a local authority has lost touch with a relevant child they must take reasonable steps to re-establish contact.

²¹ DH, *Children (Leaving Care) Act 2000 Regulations and Guidance* ('Leaving Care Guidance') 2000; National Assembly for Wales, *Children (Leaving Care) (Wales) Regulations 2001* SI No 2189 (W151) and guidance

²² CA 1989 Sch 2 para 19B(2), s23A(2), s23C(1) and s23C(7), plus provisions of the *Children (Leaving Care) (England) Regulations 2001* SI No 2874

- c) **Former relevant children** - local authorities must continue to appoint a personal adviser for the child and keep their pathway plan under review. They must provide former relevant children with assistance with employment and education and training. They must also provide other assistance 'to the extent that their welfare requires it'. They must take reasonable steps to keep in touch with the young person, whether or not they remain in their area, and to re-establish contact if they lose touch.

Personal advisers must be appointed by the local authority to support and befriend the young person. Their functions include providing advice and support, co-ordinating the provision of services and participating in pathway planning and reviews. Young people should be given a choice of personal provider. It is expected that the same personal adviser will remain with the young person once they become a former relevant child.

Pathway plans should be produced 'as soon as possible' after the assessment is completed and cover all the issues identified. The Leaving Care Guidance states that pathway plans should ensure that disabled young people obtain access to mainstream healthcare services as well as to any specialist service related to their impairment. Pathway plans should contain contingency plans to address potential difficulties and should be reviewed every 6 months to check that the goals and milestones are still relevant and being met.

The case of *R (J) v Caerphilly CBC*²³ illustrates major failures in relation to the assessments and pathway planning produced in relation to a relevant child with complex needs and a history of offending behaviour, including:-

- failure to produce a 'detailed operational plan' clarifying who would do what and by when to help J,
- failure to identify specialist support for J
- failure to properly involve J in the planning process, even if he was 'unco-operative'.

The Guidance contains specific mandatory provisions in relation to disabled young people, including giving advice on disability benefits as a priority for young disabled care leavers. It contains principles aimed at ensuring that their additional needs are addressed by the care leaving process.

9. Health

²³ [2005] EWHC 586 (Admin)

As with social care discontinuities between the paediatric services for disabled children and the health services available to adults are rife, despite the fact that the legal duties under the NHS Acts remain fundamentally the same for children and adults.

However, a genuine difficulty is created by the fact that many therapeutic interventions, particularly speech and language therapy, are delivered to disabled children through their statements of SEN and so a seamless transition will often require adult health services to take on an additional responsibility for meeting the young person's therapeutic needs.

Since 2004, the **National Service Framework for children, young people and maternity services** (in England)²⁴ has required that health services develop appropriate adolescent/young persons services to enable smooth transition to comprehensive adult multi-disciplinary care. Standard 8, relating to disabled children and young people and those with complex health needs, sets out the following detailed expectations in relation to transition:

'Local Authorities, Primary Care Trusts and NHS Trusts ensure that:

- Transition planning has as its main focus the fulfilment of the hopes, dreams and potential of the disabled young person, in particular to maximise education, training and employment opportunities, to enjoy social relationships and to live independently. Transition plans take a person-centred planning approach, as described in *Towards Person-Centred Approaches - guidance*, and which is consistent with the *Special Educational Needs Code of Practice*.
- A multi-agency Transition Group is in place. This could be taken on by an existing group that has developed a multi-agency transition strategy. The group:
 - a) Includes a Transition Champion from the Learning Disability Partnership Board;
 - b) Has representatives from Connexions Service, the local authority including social care, education and housing, the Learning and Skills Council, health, user representatives and voluntary organisations, and
 - c) Assumes responsibility for overseeing transitional arrangements at both strategic and operational level and for agreeing inter-agency protocols;
- Young disabled people aged 16 years and above are supported to use direct payments;

²⁴ DH, *National service framework for children, young people and maternity services: standard 8: disabled children and young people and those with complex health needs*, 2004, ch 7

- Specific arrangements are made for managing the transition of those with high levels of need, those in residential schools/living away from home, looked after young people leaving care, and those with rare conditions;
- Agencies develop local strategies to widen education, training and employment opportunities for disabled young people.'

As a general legal principle, health services for disabled young people must be **suitable for their needs** - for example it will be inappropriate for children to be placed for short break care in a respite unit with older adults. Such an approach may well contravene a young person's rights to private life, which includes personal and psychological integrity.

In terms of the practicalities of delivering good transitions in health, the Children Act guidance stresses the 'crucial' role of GPs through their knowledge of the whole family and their ability to monitor the individual young person's health and well-being. The focus of the Children Act guidance is on ensuring that as far as possible disabled young people are not accommodated in hospital on a long-stay basis.

The good practice guidance for health services in England on transition to adulthood²⁵ emphasises the importance of a **health transition plan**, which should be 'an integral part of the broader transition plan', linked closely to plans held by education and social care. The health plan should be developed by the young person alongside a multi-disciplinary team (including the GP), supported by the most relevant health professional who can review it regularly with them. Planning should start at the latest when the child is 13.²⁶

Valuing People stressed the need for all young people with learning disabilities approaching the end of their secondary schooling to have a **health action plan**, completed with young people by a range of staff, most commonly a community nurse or school nurse.²⁷

Continuing care

²⁵ *Transition: moving on well*

²⁶ *Transition: moving on well*, pp10-11

²⁷ *Valuing people: a new strategy for learning disability for the 21st century*, Circular HSC 2001/016: LAC(2001)23, para 6.15

Where a disabled young person has a significant level of health needs, responsibility for meeting them rests with the responsible health body under the children's continuing care provisions. In relation to disabled adults with substantial health needs, the National Framework for Continuing Healthcare provides an even clearer responsibility on health bodies to take responsibility for *all* their health and social care needs. It provides a single approach to determining eligibility for fully NHS funded continuing care in England, based on the question of whether the person has a 'primary health need'.²⁸

The Continuing Care Framework provides that young people receiving children's continuing care will need to be reassessed against the adult continuing care framework at the age of 17 to ensure an effective adult care package is commissioned in time for the young person's 18th birthday (para 125). In preparation for this, children's continuing care teams should notify adult teams that a child is receiving continuing care at their 14th birthday (for young people with a statement this tallies with the timescale of the Transition Review) , followed up by formal referral for screening at age 16 to the adult NHS continuing healthcare team. There should be consistency in the young person's care package as they move from children's to adult services.

If a young person receiving children's continuing care has been determined by the relevant PCT not to be eligible for adult NHS continuing healthcare, they should be advised of their non-eligibility and of their rights to request an independent review on the same basis as NHS continuing healthcare eligibility decisions regarding adults. Even where a young person is not entitled to adult NHS continuing healthcare, they may have some health needs that fall within the responsibilities of the NHS. In such cases, PCTs should continue to play a full role in transition planning for the young person.²⁹

Palliative care

Young people with life-limiting and life-threatening conditions will have additional support needs at transition to adulthood. As young people with life-limiting conditions are now surviving much longer, this has become³⁰ an important issue. Guidance published through the Transition Support Programme (now disbanded)

²⁸ DH, *National framework for NHS continuing healthcare and NHS-funded nursing care*, 2009 ('Continuing Care Framework'), para 25

²⁹ Continuing Care Framework pp26-28

³⁰ National Transition Support Team, *'How to' guide: moving on to adult care services - young people with life-limiting and life-threatening conditions*, NCB, 2009, available at www.transitionssupportprogramme.org.uk/pdf/ACT.pdf. See also ACT, *Transition care pathway: a framework for the development of integrated multi-agency care pathways for young people with life-threatening and life-limiting conditions*, 2007.

summarises the difficulties faced by these young people in transition to adulthood and suggests good practice ways in which these difficulties can be addressed.

Mental health

The law in relation to meeting the mental health needs of disabled young people is not covered in detail here. Given the high incidence of mental ill-health among disabled young people, particularly those with learning disabilities, it is essential that child and adolescent mental health services (CAMHS) and adult mental health services engage effectively in transition planning, at an individual and strategic level.³¹

10. Housing

Some of the main duties around accommodation/housing that are relevant to transition have been covered under the leaving care duties.

Other relevant provisions are around adaptations to the family home or other accommodation that the young person may move to, providing suitable accommodation for the disabled young person with their family, or providing short breaks or other residential accommodation for the disabled young person.

All of these provisions should also be seen in the context of the local authority's general community care duties to the young person, including those under the Children Act, the CSDPA 1970 s2 (applicable to children and adults) and the National Assistance Act s21.

Issues around adaptations to needed to the home are ones that seem to cause particular problems around the time of transition. This is despite the fact that the main duties to provide adaptations are the same for children and adults. Key provisions include the following:

- Disabled Facilities Grants (DFGs) - grants paid by housing authorities towards the cost of building works which are necessary in order to meet the needs of a disabled occupant. The maximum mandatory grant (see below) is currently £30,000 in England and £36,000 in Wales, although local authorities are empowered to make higher awards.
- s2 Chronically Sick and Disabled Persons Act (CSDPA) 1970 also provides a duty to provide adaptations to the home where this is identified

³¹ See National Transition Support Team, *'How to' guide: How to support young people with learning disabilities and mental health issues*, NCB, 2009, available at www.transitionssupportprogramme.org.uk/pdf/HowTo_FPLD.pdf.

as an eligible community care need on assessment. Where such a need has been identified, social services (children's or adults team) should refer this to the housing authority who will then consider whether a DFG should be made. However, if the housing authority refuses or is unable to approve the grant (for example because the works in question do not come under the mandatory scheme) this does not necessarily absolve the social services of its duty to meet an assessed need under s2 CSDPA. The Local Government Ombudsman has found that it is maladministration for a local authority to fail to appreciate that it may still have a duty to provide adaptations under the 1970 Act regardless of whether the Housing Department will assist.

- NHS bodies have extensive statutory powers to transfer monies to social services and government guidance³² advises that these can be used to facilitate housing adaptation, particularly if in so doing it 'releases beds by expediting discharge'. The NHS has a power to fund or jointly fund adaptations where the need is health related - for example a young person who requires a ceiling track in his/her home before being discharged from hospital.

If a need for housing adaptations has been identified on assessment and has been referred by social services to the housing department, they should assist families with completion of the DFG forms and for arranging the necessary evaluations such as an occupational therapy report. If the young person has complex health needs and the adaptations relate to the provision of health care, the housing authority can request the assistance of the NHS.

While housing authorities have a wide ranging power to give discretionary assistance, in any form, for adaptations or other housing purposes, their mandatory grants can only be applied for more limited purposes; the main purposes for which mandatory grants are made are to facilitate access and provision, i.e. where the primary purpose is one of the following:-

- facilitating a disabled person's access to:
 - the dwelling;
 - a room usable as the principal family room, or for sleeping in;
 - a WC, bath, shower, etc (or the provision of a room for these facilities);
- facilitating the preparation of food by the disabled person;

³² Dept for Communities and Local Govt, *Delivering housing adaptations for disabled people: a good practice guide*, June 2006;

- improving/providing a heating system to meet the disabled person's needs;
- facilitating the disabled person's use of a source of power;
- facilitating access and movement around the home to enable the disabled person to care for someone dependent upon him or her;
- making the dwelling safe for the disabled person and others residing with him or her;
- facilitating the disabled person's access to and from a garden; or
- making access to a garden safe for the disabled person.

Proposals have been considered to enable people entitled to a DFG to receive it as a direct payment and also to choose the contractor to undertake the works.

Where a DFG goes ahead, the housing authority is responsible for the administration through all stages from initial enquiry to post-completion approval. It must decide whether it is reasonable and practicable to carry out the proposed adaptation works, taking account of factors such as the age and condition of the building. It must also decide whether the proposed works are necessary and appropriate to meet the needs of the disabled occupant. In determining what 'meets' the assessed needs of the disabled young person, the housing authority is entitled to consider any possible alternative way of meeting his or her needs.

DFGs will only be available to a disabled child or young person if they live or intend to live in the accommodation as their only or main residence (including rented accommodation). It must be intended that this will be their only or main residence for a period of five years, although in practice this may prove shorter due to health or other reasons. If the young person needs to spend time at another home, for example if parents are separated, adaptations may be necessary in both homes; however a mandatory DFG is only available at the 'main residence'. However if a community care assessment determines that adaptations are also required at the other location it may trigger a duty under s2 CSDPA to facilitate the adaptations.

DFGs are means tested for disabled people aged 19 or over but not for children or young people under 19.