Transition to a positive future Select Committee Report

April 2007

Kent County Council

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FOREWORD

On behalf of the Select Committee I am pleased to present this report on the transition to adulthood of young disabled people including those with learning difficulties.

Growing up should be a time of excitement and increased opportunity for young people; however, transition to adulthood for young disabled people has challenged policy makers over a number of years due to the need to align a broad range of agencies involved in its management. This Select Committee review has itself taken place at a time of immense change amongst those agencies.

In preparing this report and to gain the necessary overview of the topic the Select Committee has held a concentrated series of meetings. We have consulted face to face and in writing with a range of stakeholders including young disabled people, their parents and carers. Members of the Select Committee have had to quickly gain an in-depth knowledge of this subject and have all developed a great and continuing interest. So much so, that we would wish to be involved, along with the Cabinet Portfolio holder in taking forward and sharing our work with stakeholders.

Due to the enormity of the subject we have tried to stick closely to our terms of reference. However, it has become apparent that there are a number of sub-topics that would benefit from further scrutiny including, especially, supported accommodation for young disabled people, support for carers and the possibility of developing in-house resources to address unmet need, for example interpreting services for deaf people.

This report reflects the views of the Select Committee on a totally non-political, cross party basis. I would like to thank my colleagues who served on the Select Committee and especially the Officers who assisted us with particular reference to our Researcher Sue Frampton and Democratic Services Officer, Theresa Grayell. I would also like to thank all of those who contributed to the review by giving of their time, experience and opinions. I would particularly mention in this respect Tracey Riley of Parents Consortium who converted our questionnaire into an accessible format.

I commend this review to your attention and trust it will aid the Authority in delivering a seamless and better service.

Andrew Bowles, Chairman of the Select Committee

1 Executive Summary

1.1 Committee membership

The Select Committee consisted of eight Members of the County Council, five Conservative and two Labour and one Liberal Democrat.

Kent County Council Members (County Councillors)

Mr Andrew Bowles

Mr Robert Burgess

Mrs Valerie Dagger

Mr Clive Hart

Mrs Sarah Hohler

Mr George Koowaree

Mr Tom Maddison

Mr Michael Northey

The participation on the Select Committee of Dr Mike Eddy and Mr Roger Truelove are also acknowledged with thanks.

1.2 The Terms of Reference

The Terms of Reference for this Select Committee Topic Review were, for young disabled people and those with a learning difficulty, (including those In Care), in making the transition to adult life and services, to:-

- identify where KCC (through partnership working) could develop or enhance transition policy to improve the experience of transition;
- incorporate the views of a number of young people aged 14-25 and their parents/carers;
- consider ways of promoting independence and inclusion in community life for these young people; and
- make recommendations that will ensure a more seamless transition to adult life and services and contribute to strategic corporate objectives especially those embodied in ‘Towards 2010’, target 55.

1.3 Evidence gathering

The Committee assembled evidence through desk research and received oral and written evidence from a wide range of stakeholders including Children's Social Services, Adult Social Services, Education, Connexions, the Learning & Skills Council, schools, colleges, charities, parents, carers and young people. Two questionnaire surveys were also sent out. A full list of the witnesses who attended Select Committee hearings is at Appendix 1. A list of those submitting written or supplementary evidence is at Appendix 2.

1.4 Reasons for establishment of the Select Committee

Primarily the Select Committee was formed in response to concerns that some young disabled people including those with learning difficulties were having poor or unplanned transitions and that there was a variation across the county. This was coupled with the knowledge that local organisational change in line with national policy developments presented an opportunity for a fresh look at the topic. The review has looked at:-

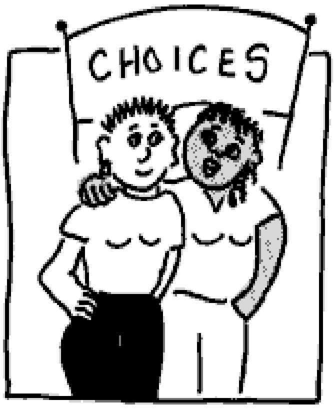
- transition planning
- multi-agency working
- Information and monitoring
- Independence and choice

1.5 Transition policy development

A comprehensive transition policy is currently being developed in Kent and good practice in several other counties including Berkshire and Hampshire has been considered.

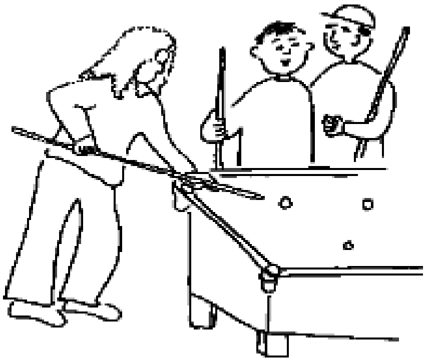
1.6 Easy to read summary

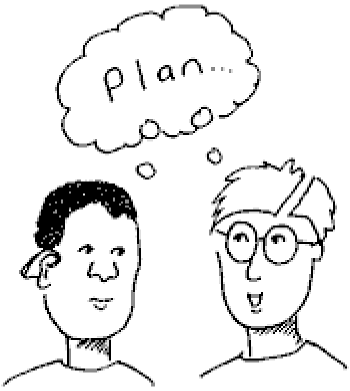
Growing up will be better for young disabled people if they feel part of society, if other people are more aware of the barriers they face and if they and their families or carers can see more positive futures ahead.



It is important that support provided in childhood does not suddenly stop when a young disabled person reaches the age of 18, or good progress made when they were younger can be wasted.

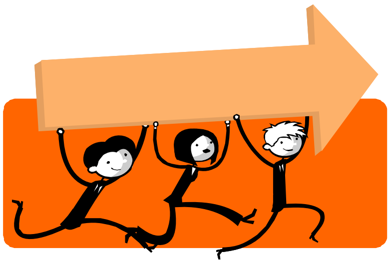
More leisure activities are accessible to young disabled people but they need to know what is available and should have the chance to try things out.

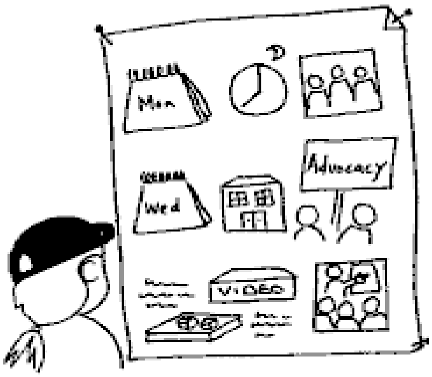




Sometimes teenagers would rather talk to or get support from people of a similar age. If young disabled adults could be employed to provide some of this support it would be good for them and set a really good example to all young people as they grow up.

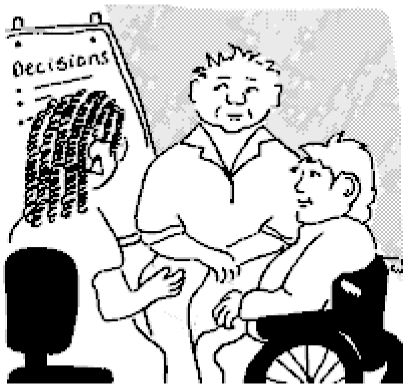
Not all young disabled people have plans for their futures. Planning which takes place for young people with Statements of Special Educational Needs can work well, but only if all the right people are involved.



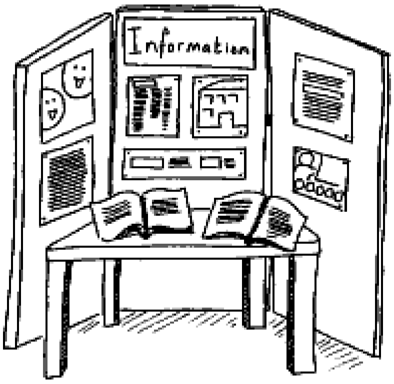


Young people supported by several agencies need plans in place for when they become adults. If plans were monitored, it would be easier to know if things were working out well.

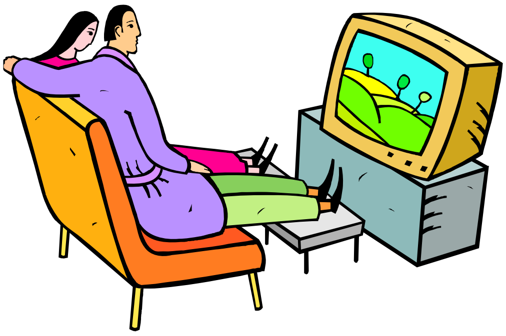
There needs to be a good process for transferring care and support from Children's to Adult Social Services and between other services which are different for children and adults.

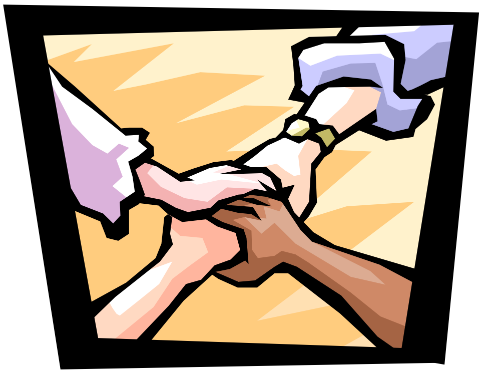


Young disabled people should get the help they need to say or show what they would like to happen as they grow up, since their views and wishes are the most important. They want the same kinds of things as all young people do when they are growing up.



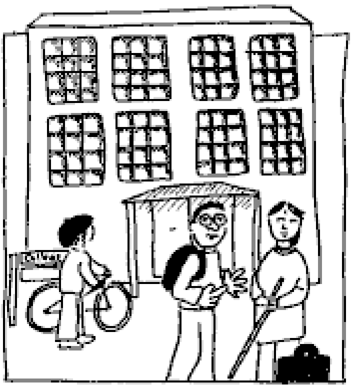
Parents and carers need support too. They need good information to help them plan and they need to know what services are available. They may also need a break from time to time.





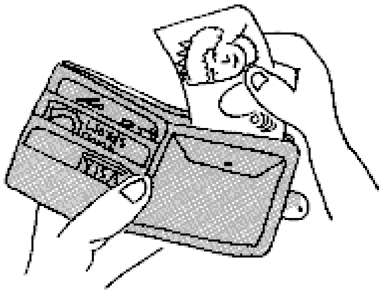
Young disabled people and their families or carers can get support from voluntary organisations as well as the Local Authority.

Sometimes people trying to provide support have too much work to do. This can mean that young disabled people and their families or carers get different services in different parts of Kent and the Select Committee think services should be more even across the county.



New ways of making this happen are being tried out. For example schools are working together to help one another provide support to more young people; charities are getting money so they can plan services into the future.

Young disabled people and their families can spend social care money themselves using Direct Payments and soon they may be able to have an Individual Budget; money collected together from different sources to spend on what they need. The money may be held by different people and this is being tried out to see what works best.



Organisations that provide support to young disabled people have been changing so that they can work better together. It will make a big difference when more people choose how they spend their own money for support. By listening to young disabled people, their families and carers, organisations that provide support services can make sure the right services are available.

Select Committee Recommendations (not prioritised)

1. That KCC work with all providers to increase the availability and choice of leisure facilities for young disabled people and promote and publicise ‘taster sessions’ to encourage participation (page 26).

2. That KCC and schools promote a variety of initiatives to raise disability awareness among peers of young disabled people in mainstream schools and the wider community (page 27).

3. That the Cabinet Members for Children Families & Education and Adult Social Services Directorates are made aware of the Hampshire transition documents and protocols, particularly the new Transition Handbook and Multi-agency Guide, with a view to working towards a similar scheme, for Kent (page 36).

4. That KCC should evaluate the capacity of current data systems to enable strategic monitoring of transition plans (page 40).

5. That the Transition Task Group investigates the potential for the increased use of Trans-active in Kent schools, colleges and other settings (page 43).

6. That KCC should identify the source and type of advocacy available for parents and young people to facilitate better transition planning and make provisions to meet any gaps in service (page 45).

7. To ensure that Children, Families and Education and Adult Social Services’ commissioning strategies are co-ordinated, including the use of jointly-resourced budgets where appropriate, to provide a more graduated and consistent approach to service provision for young disabled people in transition from childhood to adulthood. Such strategies should incorporate Transition Worker roles or demonstrate clearly alternative means of providing similar support (page 49).

8. That the Managing Director of Adult Social Services and the Managing Director of Children, Families and Education must ensure that information about transition and Adult Social Services is available in a range of accessible formats and is brought to the attention of young disabled people and their parents in advance of meetings to enable them to participate in transition planning (page 54).

9. That KCC, Connexions and partners identify how to use available resources more effectively to benefit young disabled people (including those with learning difficulties) in transition (page 61).

10. That individuals identified as Lead Professional for young people in transition to adulthood have the capacity to undertake the function and are provided by KCC and partners with training and support (page 69).

11. That KCC, schools and other partners promote the use of Direct Payments by young people whose social care needs will extend into adulthood, by raising awareness and understanding of Direct Payments among CFE staff and ensuring that Direct Payments are discussed (with the involvement of a peer-mentor or Direct Payment Support Worker/Adviser where possible) as part of transition planning from Year 9 onwards (page 74).

12. That KCC, through Kent Supported Employment and its partners, explore the potential of a programme whereby disabled young adults are employed as peer-mentors to assist with transition planning in schools and elsewhere (page 75).

2 Background Context

2.1 Young disabled people's experience of transition to adulthood has been in the spotlight of national and local government for some time. There has been much policy and guidance relating to disability in general and transition in particular yet determined efforts at joint working sometimes fail to benefit disabled people and their families. There have been consistent reports of poor transition experiences and transition planning has rarely been linked to outcomes for young disabled adults.

2.2 Sir Al Aynsley-Green, Children's Commissioner for England said recently that services for disabled children and their families were a national scandal. For example, Social Services are only able to support around 7.7% of families with a disabled child and school exclusions are a further threat to family life. A recent study found that 80% of families with disabled children were at breaking point due to the amount of care they need to provide[1].

2.3 Changes to Children's Services are underpinned by the government's 'Every Child Matters' agenda which has 5 outcomes: be healthy, stay safe, enjoy and achieve, make a positive contribution and achieve economic well-being. Local authorities are midway through huge organisational changes to facilitate delivery of these outcomes. The Every Disabled Child Matters campaign highlighted the very specific problems of disabled children. Outcomes for disabled children have renewed priority.

2.4 The population is changing; there is a better outlook and survival rate for disabled people with complex needs and more people need adult care later on as their own carers become elderly. The increased demand for Adult Social Services was the subject of a local study. This estimated a rise in Kent's over 60 population of 32% in the 20 years from 2001 and a 10% increase in the number of learning disabled adults needing to be known to services in the same period.[2]

2.5 Adult Social Services have been undergoing modernisation and change; underpinned by the government White Paper, Valuing People. Professionals are trying to promote greater choice, control and independence for adults while at the same time managing a high level of expectation for services, a rising demand for those services and budgetary pressures.

2.6 Definitions of disability

There is no single definition of disability though it is defined in various government Acts which have dictated to some extent the way disability has been viewed over the years, as well as the legal aspects of being disabled. A list of what is meant by various terms when they are used in this report is given at Appendix 3.

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[1] Every Disabled Child Matters website: http://www.edcm.org.uk

[2] Learning Disability Informal Members' Group (IMG) - The implications of the changes in demographics of people with Learning Disabilities and the impact on resources – Final Report 27th February 2006

2.7 Definition of transition

In a statutory sense, the term transition is applied to the process of planning for adulthood, usually between the ages of 14 and 19 for a young person with a Statement of Special Educational Needs. This report also looks more widely at the transition to adulthood of other young people who are not supported by Statements but may be disabled and/or have special educational needs.

> *'It should be acknowledged that transition is an ongoing process rather than a single event.'*[3]

Many people, including young people with learning difficulties, are found generally not to understand the term 'transition', understanding it better as 'growing up' and 'deciding what to do when you are older'.[4]

2.8 Exclusions to this review

Owing to the complexity of the subject and its potential broadness the Select Committee decided to exclude from the review exploration of:-

- 'modernisation of day services for people with a learning disability' and 'demographics of learning disabilities' as these topics were explored in depth by two recent Informal Members' Groups;
- individual disabilities or ethnicity unless as an example of typical transition issues, or
- criminality.

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[3] Alan Milner, Services Director, Parents' Consortium

[4] Road Ahead (The) – Transition Project

3 Legislative and Policy Context

3.1 Legislation

3.1.2 A great deal of legislation and statutory guidance applies to transition planning and this focuses primarily on the reviewing process for young people with Statements of Special Educational Needs. A summary of the main legislation is given as Appendix 4 and the specific roles that different agencies are required to undertake are covered in Section 6.

3.1.2 The Disabled Persons Act 1986 places the responsibility with local authorities to find out from Social Services whether a young person with a Statement is disabled and might need services from the local authority when they have left school. The Children Act 1989 and NHS and Community Care Act 1990 require Social Services to co-ordinate multi-agency assessments and plans for children in need (which includes disabled children). There is also a requirement for a Social Worker to attend the annual review of the Statement for a young person in year 9 (age14) at school so that they can contribute to the transition plan. The Special Educational Needs and Disability Act 2001 and associated SEN Code of Practice provide further statutory guidance regarding assessment and provision of services for young people with special educational needs, incorporating the role of the Connexions Service, which was created in 2000.

3.1.3 The legislation has remained in force for over 20 years, but the policy environment has developed in favour of a multi-agency response to assessment and planning.

3.2 National and local policy developments

3.2.1 There is a shift away from central government management of public services towards decision making closer to local communities. The government's Life Chances[5] report stressed the importance of planning for continuity of services and a 'more transparent and appropriate menu of opportunities and choices'. Life Chances was followed by a consultative Green Paper Independence, Well-being and Choice which set out a vision for the future of adult social care and proposed a key role for Directors of Adult Social Services in improving transition planning and ensuring that 'all young people with disabilities' have the chance to fulfil their potential and benefit from the 7 outcomes set out in the Green Paper:-

"**Improved health:** enjoying good physical and mental health (including protection from abuse and exploitation). Access to appropriate treatment and support in managing long-term conditions independently. Opportunities for physical activity.

Improved quality of life: access to leisure, social activities and life-long learning and to universal, public and commercial services. Security at home, access to transport and confidence in safety outside the home.

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[5] Improving the life chances of disabled people, final report, Prime Minister's Strategy Unit (2005)

Making a positive contribution: active participation in the community through employment or voluntary opportunities. Maintaining involvement in local activities and being involved in policy development and decision making.

Exercise of choice and control: through maximum independence and access to information. Being able to choose and control services. Managing risk in personal life.

Freedom from discrimination or harassment: equality of access to services. Not being subject to abuse.

Economic well-being: access to income and resources sufficient for a good diet, accommodation and participation in family and community life. Ability to meet costs arising from specific individual needs.

Personal dignity: keeping clean and comfortable. Enjoying a clean and orderly environment. Availability of appropriate personal care." [6]

3.2.2 The Local Government Act in 2000 led to the formation of the Kent Partnership, comprising organisations from all sections of the community and led by the Local Authority. The 'Vision for Kent' document detailed the long-term community strategy of the Kent Partnership and 'Active Lives[7]' focused on social care plans, outlining the importance of families and support for disabled children by integrating social care, health and education services. Active Lives acknowledged the difficulties of transition saying that Kent would:-

> *'With Education, Health, and Connexions, develop our transitional services in consultation with users and carers, because the time of transition from childhood to adulthood can be particularly stressful for families who have children with disabilities.'*

3.2.3 Kent groups focusing on the lives of disabled people and in particular the transition to adulthood had already arisen out of partnership working. A Transition Champion was appointed and several strategic groups working independently on transition were drawn together into one multi-agency group, which began to look at various aspects of transition. Multi-agency transition work continues to develop within changing organisational structures and one of the aims is to develop a comprehensive transition policy.

3.2.4 Integrated children's services, in line with the government's Every Child Matters agenda of change for children, took on a more formal structure on 1 April 2006 when there was a complete reorganisation of KCC's Directorate structure merging Education and Children's Social Services to form a new Children, Families and Education Directorate; with Adult Social Services becoming a Directorate in its own right.

3.2.5 The Children's Social Services Annual Operating Plan 2006/7 continued to emphasise the importance of transition planning. It gave particular priority to

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[6] Independence, Well-being and Choice: Our Vision for the Future of Social Care for Adults in England : Department of Health - Publications and statistics

[7] Active Lives: The Future of Social Care in Kent (2004)

the planning process between Children's and Adult Social Services and the need for links between the new Children, Families and Education and Adult Social Services Directorates. The Annual Performance Assessment Plan echoed these aims.

3.2.6 Kent's efforts to improve the transition to adulthood of young disabled people are given a new impetus in the latest policy document 'Towards 2010'. A short-life executive group under the leadership of Oliver Mills, Managing Director of Adult Social Services, has been set up to oversee delivery of Target 55 (Appendix 5) which is:-

> *'To ensure better planning to ease the transition between childhood and adulthood for young people with disabilities and to promote their independence.'*

3.2.7 Other 2010 targets relate to specific areas which impact on transition or its outcomes, such as target 52, which includes supporting disabled people to live independently in their own homes and target 53 on strengthening carers' support.

3.2.8 The Managing Director of Children, Families and Education has statutory responsibility for transition, working closely with the Director of Adult Social Services. The Director of Adult Social Services has a number of specific responsibilities[8], including ensuring that:-

- *(with the Director of Children's Services) 'information about adult services is provided to young people approaching the age where they will make the transition from childhood to adult life, in order to facilitate their involvement in decisions about service provision.'*
- *'all young people with eligible long-term social care needs have been assessed and receive a service which meets their needs throughout their transition to becoming adults'; and*
- *'the Director of Adult Social Services should be responsible for the arrangements to support the transition of service users between different service providers, and between children's and adult's services. He or she should cooperate with the Director of Children's Services to ensure a collaborative approach to the interface between social services for children and social services for adults on the range of issues.'*

In Kent, the Managing Director of Adult Social Services has been given the lead on transition in order to maintain a focus on the outcomes in adulthood for young disabled people.

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[8] Best Practice Guidance on the role of the Director of Adult Social Services, DH (2006)

4 Statistical Data

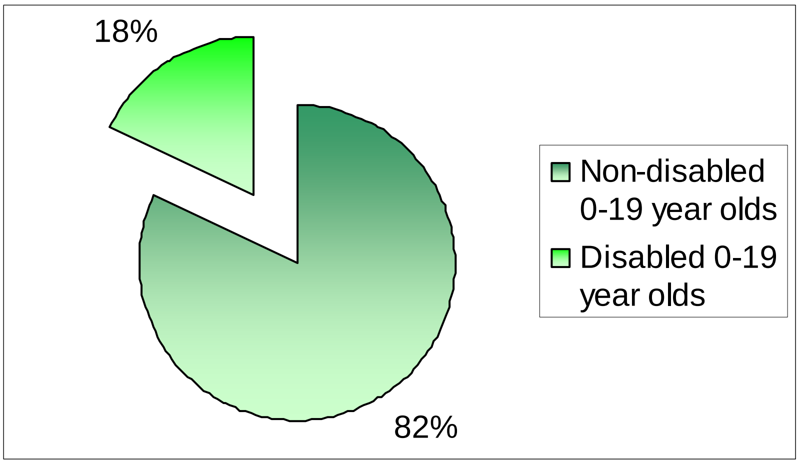
4.1 National context

In the year 2000, 19% of boys and 17% of girls aged 0-19 were reported as having a longstanding illness or disability (including learning difficulty).[9] In that year the most commonly reported conditions among children and adolescents were autistic spectrum disorders and behavioural disorders.[10]

4.2 Local context

4.2.1 From the 2001 Census there were 335,690[11] young people in Kent in the 0-19 age range. Using the proportions indicated in the Office for National Statistics (ONS) Health of Children and Young People data, this would indicate there are around 60,499 disabled children and young people (0-19) in Kent (Chart 1). The ONS statistics excluded undiagnosed conditions and so the true number is probably higher.

Chart 1: What proportion of 0-19 year olds in Kent are disabled?



4.2.2 Much of the data available locally relates to Special Educational Needs (SEN) as the disability data available from the Kent Children's Disability Register is incomplete, owing to the voluntary and confidential nature of registration. Disability statistics and those relating to Special Educational Needs (SEN) are not directly comparable, as many children with SEN are not (or do not consider themselves) disabled and some disabled children do not have Statements. However the two categories overlap.

4.2.3 Nationally, around a quarter of a million children in the state school system have Statements of SEN and a further 1.5 million have special needs not covered by a Statement. The number of Statements maintained by Kent has steadily declined from 8,465 in 2002 to 6,522 in 2006.[12] Data from the Specialist Teaching Service indicates there are 2599 young people with Statements of SEN and 10,583 with SEN but no Statements in special,

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[9] Health of Children and Young People, ONS (2004)

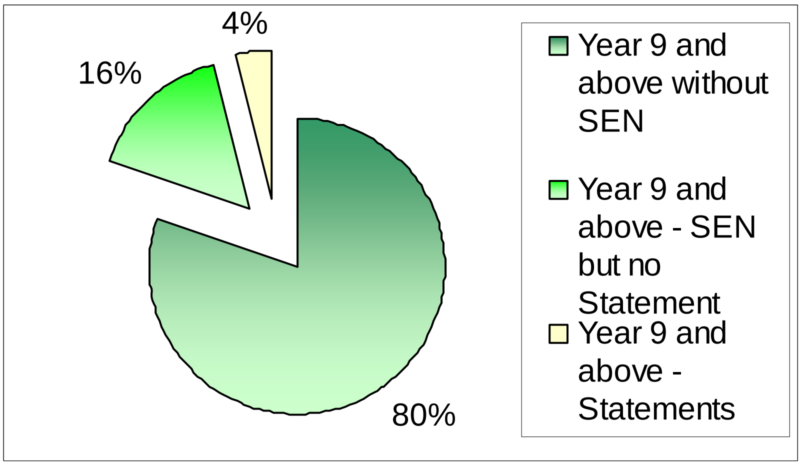
[10] ONS General Household Surveys 1990-2000 (cited in The Health of Children and Young People)

[11] 2001 Census data

[12] KCC Children, Families and Education Facts and Figures 2006

mainstream and other education settings in year 9 and above. The total number of young people with special educational needs, aged 13/14 and above, in Kent schools is therefore 13,182[13] (Chart 2).

Chart 2: How many young people in year 9 and above have SEN?



4.2.4 A significant number (2599) of Kent's young people should therefore have begun statutory transition planning. This represents 19.8% of young people in year 9 and above with special educational needs. Just over half (53.5%) of these 2599 young people are educated in mainstream settings.

4.2.5 As at 30th September 2006, 86 young people aged over 14 with Statements, are in the care of the Local Authority. More children with Statements are known to Children's Services as 'child in need' or 'child protection' cases, but current Social Services computer and data collection systems do not report strategically on the basis of whether a young person has a Statement.

4.2.6 Pupils with special education needs in Year 9 and above are educated in 24 special schools and 101 mainstream schools in Kent. Some mainstream schools have specialist provision available in units and 'designations'. Currently there are 63 such establishments with 757 Statemented pupils (of all age groups) on roll. A further 377 pupils (of all age groups) within mainstream settings have Very Severe and Complex Need funding.[14] There are two specialist colleges in Kent, Westgate College and Dalton College.

4.2.7 Learning and Skills Council data indicate that there are currently 65-70 Kent young people in specialist residential placements within and outside Kent [15] and 8,900 students in Further Education (FE) colleges who declared LDD (learning difficulty and/or disability) needs when they enrolled; 5000 of whom receive Additional Learning Support and other LSC funding.

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[13] KCC Specialist Teaching Service Database

[14] Review of Designated and Specialist Unit Provision - Report to KCC Cabinet (2006)

[15] at a cost of £3.5million per annum for Additional Learning support (ALS)

5 Breaking Down Barriers

5.1 Definitions of disability

There is no single agreed definition of disability and the contributors to this report use a variety of terminology (a glossary is provided at Appendix 3). Learning difficulty is defined in the Education Act 1996 and Special Educational Needs and Disability Act (SENDA) 2001 regarding the assessment and meeting of special educational needs while learning disability is a more recently used term to replace what used to be referred to as 'mental handicap'.

5.2 Models of disability

5.2.1 There are two important models of disability each using a different set of language: the medical model and the social model. A brief comparison of the two models is given here:[16] [17] Both models are used in different circumstances and people may be more familiar with one or the other.

Table 1: Two models of disability

Medical Model	**Social Model**
Sees the person and their 'impairment/s' as the problem	Sees society's inability to meet the person's needs as the problem
Uses this type of language: person with a disability	Uses this type of language: disabled person
Person is adapted to fit the world	World is adapted to fit the person
Is about objectivity and descriptions	Is about giving power and a voice back to the disabled person
Focuses on medically-based responses or 'cures'	Focuses on the disabling factors in society caused by 'oppressive systems'
Types of provision:- • Segregated with professionals in control • Separate with disabled people choosing to be a minority group • Integrated with non-disabled people taking the lead	Type of provision:- • Inclusive, which removes disabling barriers and is open to all.

5.2.2 *'Most carers, professionals and service providers refer to 'learning disabilities', but some self-advocates in UK organisations like People First prefer to*

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[16] Come on in, a practical guide for children's services, Council for Disabled Children (2004)

[17] Role of Language, Alan Milner – Parents' Consortium

describe themselves as having ‘learning difficulties’, and some professionals also use this term…….. Many people believe that using a term like ‘learning disabilities’ is stigmatising. At the same time it would be difficult to organise services and support if there was no way of defining the people for whom they were being provided.’[18]

5.2.3 The multi-agency KCC Task Group working on transition, considered these issues and decided, two years ago, to adopt the social model in its policies and practice. In view of this, the Select Committee decided to look broadly at the transition to adulthood of young disabled people, including young people with learning difficulties and not to concentrate too much on categories of disability, difficulty or impairment.

5.3 Barriers to inclusion

5.3.1 Disabled people can face a number of barriers to their inclusion in society. Legislation has sought to bring greater equality through the Disability Discrimination Act (DDA) 1995 and the DDA 2005, which introduced the Disability Equality Duty. Under this new duty, all public bodies must keep under review how they consult and involve disabled people. Legislation aims to reduce physical barriers in the environment, as well as barriers caused by the attitude of non-disabled people.

5.3.2 Children and young people whose impairments are less obvious can face additional problems through a lack of recognition of the difficulties they face. Early identification of impairments is helping to ensure that intervention can take place sooner, but there remains a need to ensure that services are in place that can provide a continuous response throughout the transition period into adulthood.

5.3.3 The Select Committee received evidence from two young disabled women, on their individual experiences of different aspects of growing up and achieving independence.

C’s Experience (extract):

At my interview for the University of Kent, I felt very comfortable and that I was able to talk to them. I also felt that they would give me the chance to be equal like all their other students even with my disabilities. When I started my summer vacation in 2002, I immediately became very busy communicating with the University and Social Services that have supported me all the way with my care and part of the funding involved, which is a lot I must say and they were behind me all the way……I have 3 Community Service Volunteers from a registered organisation, who provide 24-hour care to help me through the day and also provide friendship with an agency that comes in 3 times a day to help with my personal care.

- volunteers enable me to socialise and anything I need
- there when I need them

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[18] Definitions of Learning Disability - Factsheet, Foundation for people with Learning disabilities

- Education enable help in lectures
- I have to keep communicating my needs to lecturers
- treat me mainly as equal but sometimes a few problems
- good to be in a mainstream environment

I am enjoying my experiences, but it has been hard and I did have some low points. I expect many challenges to come. I do not regret it. Since I have been there they are slowly improving their facilities.

H's experience:

H moved into the mainstream arm of an out-of-county specialist college, with 1:1 support. She and her helper sat in the corner of the classroom, never interacting with other students. She could not mix at break and dinner times as she had to go to the Health unit for assistance with toileting (which her education assistant could not provide). Unable to tolerate this level of exclusion, she returned home to Kent and finished her course at home.

H lived with her parents until she secured a bungalow of her own. Negotiations took two years and there was no consultation on adaptations, some of which were not needed. H has personal assistants 24hrs each day and has her own car from Motability but may have to give it up as some assistants are unable to drive it. H is quite happy to get taxis into town but the toilets in shops don't have hoists so she is unable to manage on her own. In the past some assistants have not wanted H to go out even though she has been capable of going out independently for some time.

Occupational Therapy which H had as a child stopped at 18 and provision now depends on the budget being available. H would like to study for an Open University Degree but can't read books at the moment as she cannot get funding for a page-turner.

H relies a lot on her parents, for things like gardening and changing light bulbs (which assistants can't do) and thinks she will end up in residential care when they are unable to help any more.

5.3.4 These are two sets of experiences among a multitude of other young people's experiences but they also illustrate the point made by many professionals who gave evidence to the Select Committee that progress made early on by young disabled people can be wasted if the appropriate support does not continue on into adult life.

5.4 Access to leisure

5.4.1 Leisure facilities for young disabled people are in great demand and there is a lack of provision in some parts of the county. The Kent Youth Service awaits further funding of around £800k to enable all its centres to meet the requirements of the Disability Discrimination Act (DDA) and parent-led local charities have said that they cannot currently keep up with the requests they get for activities; the more they organise, the more demand there is.

5.4.2 The Youth Service is monitoring use of its facilities by young disabled people as its premises are upgraded or rebuilt to comply with the requirements of the DDA. The Service provides training for its staff to raise disability awareness and challenge established attitudes. It uses positive images of young people in publicity and other materials.

> ☹ **We are not happy just turning up at things when we don't know people**

5.4.3 It is important that providers of mainstream leisure activities and facilities make a positive effort to show they are suitable for disabled young people so they are not 'put off'. Accessibility is as much about feeling confident of a warm welcome and 'fitting in' as it is about the physical accessibility of the environment. In education and work settings young disabled people have been shown to benefit from introductions enabling them to 'try out' and become familiar with a new environment. Parents have suggested that this type of approach would also be valuable with leisure activities. Not all young disabled people are comfortable in integrated settings, so it is important that they can choose what suits them best.

5.4.4 The Select Committee heard that sometimes, where there is local leisure provision suitable for disabled young people, they can miss out if they are not made aware of it. Young disabled people and families would benefit from local publicity advertising newly accessible facilities and from the offer of accompanied introductions or 'taster sessions'.

Recommendation 1

That KCC work with all providers to increase the availability and choice of leisure facilities for young disabled people and promote and publicise 'taster sessions' to encourage participation.

5.5 Raising awareness among peers of disabled young people

5.5.1 A recent survey of public opinion revealed there is still a general lack of understanding about disability and that 75% of the population believe there to be prejudice. Discrimination exists even within organisations committed to fighting it.[19]

5.5.2 A study carried out for the Disability Rights Commission found that both mainstream and special schools were making considerable efforts to enable young disabled people to access the physical environment and the curriculum.[20] Greater inclusion has been shown to improve understanding and reduce prejudice; essential if disabled people are to feel part of society. Special schools make use of the Curriculum, often through Personal, Social and Health Education (PSHE) lessons, to provide independence and other skills.[21] [22] PSHE and Citizenship lessons are used to prepare all young people about behaviour and respect for others and the Select Committee heard evidence that a new strategy is being developed by KCC to make PSHE more inclusive in mainstream schools.[23] The peers of disabled young people can also gain empathy by the use of ‘experiential learning’ where they would, for example, wear a blindfold to simulate being visually impaired or use a wheelchair to gain an appreciation of mobility problems.

5.5.3 As part of the information gathering for this review a group of Members visited a youth centre run for disabled teenagers in West Kent. It was clear that both the young disabled people attending and the volunteers who were organising activities gained greatly from being there and had lots of fun. Many of the volunteers were a similar age to the young people they were supporting; some had come to work at the centre through school initiatives and some of their own accord.

5.5.4 *‘Policies aimed at integrating disabled people more closely into society, not only help disabled people themselves, but serve to reduce prejudice in the long term by fostering greater contact between disabled and non-disabled people.’* [24]

Recommendation 2

That KCC and schools promote a variety of initiatives to raise disability awareness among peers of young disabled people in mainstream schools and the wider community.

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[19] Disabling attitudes? Public perspectives on disabled people’, John Rigg, in British Social Attitudes: the 23rd Report – Perspectives on a changing society, 2007

[20] My school, my family, my life - The Disability Rights Commission (2006)

[21] Diana Robinson, Senior Inclusion and Achievement Adviser, Children, Families and Education

[22] Daniel Lewis, Headteacher, St Nicholas School, Canterbury

[23] Allan Foster, Lead Curriculum Adviser and Subject Adviser for PSHE

[24] Disabling attitudes? Public perspectives on disabled people’, John Rigg, in British Social Attitudes: the 23rd Report – Perspectives on a changing society, 2007

6 Transition Planning – What Should Happen

6.1 Transition planning from the age of 13/14 (year 9 at school) onwards is a legal requirement for young people with Statements of Special Educational Needs. These young people will have severe and complex needs. Statements are reviewed annually and the review in year 9 is known as the Transition Review. Its aim is to draw up a Transition Plan, which is ‘participative, holistic, supportive, evolving, inclusive and collaborative’[25], to be reviewed subsequently along with the Statement. (A brief description of SEN is given as Appendix 6.)

6.2 The process requires the co-operation of a number of agencies, each of whom has specific responsibilities. The roles of key agencies and individuals are outlined below:-

The Local Education Authority (now the Local Authority)

- must send to Connexions a list of all pupils who will require a Year 9 review within two weeks of the start of each school year.

Headteachers

- must invite the Connexions Service to provide written advice and attend the review meeting;
- must invite Social Services to attend the review so that 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;
- must ensure that a Transition Plan is drawn up, in consultation with the Connexions Service and
- facilitate the transfer of information to enable specialist help to be provided for continuing education or training.

The Local Authority (through its 16plus Service)

- must ensure that young people in care on their 16th birthday (and are ‘Eligible’ under the Leaving Care Act) have a Pathway Plan; equivalent to a Transition Plan or Connexions Action Plan.

Connexions

- must attend the review in year 9 (as a condition of grant);
- must assist the young person and parents/carers to identify post 16 provision, provide counselling and support;
- should attend subsequent reviews particularly to update the transition plan in year 11 and oversee its delivery;
- must complete assessments (Section 140 Assessments under the Learning and Skills Act) for young people with learning difficulties and

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[25] SEN Code of Practice

disabilities (LDD) when they are undertaking or likely to undertake post-16 education, training or higher education (mandatory for young people with Statements, discretionary for certain others);
- must ensure the transfer of information to post-16 providers, Social Services and the Learning and Skills Council
- must continue planning post-16;
- must arrange transfer to adult support.

Health

- must ensure that professionals involved in the young person's care contribute to the transition plan and attend the year 9 transition review if possible;
- must ensure that young people with special education or complex needs have a health action plan to facilitate the move into adult services.

The Learning and Skills Council (LSC)

- must have regard to the needs of young people with complex or special educational needs when developing, planning and funding post 16 provision;
- must take into account the Section 140 Assessments carried out by Connexions for young people with complex or special educational needs.

Social Services[26]

- should ensure they attend the year 9 review and contribute to the transition plan in year 9 if a child is in care, or in need; the definition of the latter being covered by the Children Act 1989 and including disabled children;
- must offer an assessment to young people with Statements who are disabled and may require adult social services;
- must carry out an assessment and formulate a care plan for young people who will need to access adult social services;
- should ensure transition plans are person-centred.

6.3 Example of good transition policy and practice: Hampshire[27]

Hampshire County Council have developed a comprehensive multi-agency guide for professionals and a handbook for families, which covers what happens at age 14-16, 17-19 and 19-25 years. It specifies roles and responsibilities, how to prepare for meetings, what is discussed and what happens afterwards. It covers care planning; charging policy for services; the complaints procedure; carers' assessments; access to equipment and housing adaptations. It describes options such as where to live, work, leisure, travel, money and relationships.

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[26] Please note the legislation was written before the division of Children's Social Services and Adult Social Services.

[27] Mark Surtees, Services Manager – Learning Disabilities, Hampshire County Council

There are 7 dedicated area-based transition workers in a virtual team, guided by a protocol and led by a Services Manager. They work with young people of 14-25 with learning disabilities, physical disabilities, mental health issues or who are otherwise 'vulnerable adults' and eligible to receive a service.

The transition worker has a specific role (as additional worker) and attends transition reviews, contributes to assessments, identifies service needs and liaises with other professionals, as well as contributing to monitoring and service development.

Young people with learning disabilities need the most support. Hampshire County Council uses the Disability Register to ensure that young people are offered an assessment, which may be carried out either by Children's or Adult Social Services. Young people not qualifying for services are signposted to other sources of help.

Transition Panels facilitate the transfer from Children's to Adult Social Services of young people with severe and complex needs who require multi-agency input. Panels consider young people when they reach 16-16½ to ensure a smooth transfer at 18. The Committee heard how the Panel process had been a 'leap forward'.

6.3.1 The procedures that Hampshire County Council has put in places link the parallel processes of transition planning in school for young people with special educational needs; assessments carried out by Social Services and the planned transfer of cases from Children's to Adult Social care teams.

7 Transition Planning in Kent

7.1 Separate processes

7.1.1 The Select Committee gained the view that the transfer of cases from Children's to Adult Social Services in Kent is seen by some professionals to be a process unrelated to the statutory transition planning which takes place in school from year 9 onwards. This differs, for example, to practice in Hampshire where Transition Workers (based within Adult Social Services) provide a link between the two processes by attending and contributing to transition reviews in school as well as co-ordinating the transfer of cases from the Children's to Adult Disability Teams.

7.1.2 The 'separateness' of the two processes in Kent has been enhanced by the fact that the data collection systems of partner agencies (including Education and Children's Social Services which are now within the same KCC Directorate) are different and do not work in parallel. For example, the Children and Families information system has not been able to report on which of the young people Social Services is working with have Statements. A new system, Swift, may provide this opportunity.

7.2 Transition planning in school

7.2.1 KCC's Additional Educational Needs & Resources (AEN&R) team assists schools by reminding them each school term, of the children with Statements, for whom they need to conduct transition reviews. The onus is then on schools to arrange meetings and invite agencies to attend. The Select Committee heard that the administration of reviews is a heavy bureaucratic burden, particularly on special schools, which have many reviews (including transition) to organise. [28]

7.2.2 There is anecdotal evidence to suggest that statutory transition planning is not always very effective.[29] Attendance at transition reviews has not been sufficiently prioritised by agencies and professionals who should be involved, as they do not see transition planning as a joint task.[30] As a result, agencies often fail to send reports, attend meetings, or both. Without strategic monitoring it is impossible to know how well the system is working either for young people with a Statement or young people with special educational needs but no Statement.

7.2.3 A young person's transition review is most effective when it is well attended by all the agencies involved. This ensures they work and plan together and avoids the risk of several agencies working at cross-purposes or duplicating effort. It also helps to ensure that the young person, parents and/or carers gain a view of all the options available to them. It is an effective use of agencies' resources if a meeting results in a jointly constructed 'letter' that is agreed by the young person and parents.[31]

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[28] Joanna Wainwright, Director Commissioning (Specialist Services)
[29] Marlene Morrissey, County AEN Manager
[30] Des Sowerby, Joint Director – Learning Disabilities (Adult Services)
[31] Justine Croft, LDD Co-ordinator, Connexions

7.2.4 The Select Committee heard that the future housing and employment needs of young people are often overlooked in planning. Young people, families, carers and service commissioners could benefit from the involvement of, for example, housing charities or supported employment providers (such as Kent Supported Employment) in transition planning from age 14. This would give time for providers to build relationships with young people and families and plan ahead to meet identified needs. It would also help to avoid emergency situations; the Select Committee heard of one example where a young person had left school and a housing charity had 9 days' notice to find suitable accommodation.[32]

> *'We need to move away from transition planning in schools that focuses on education – there needs to be a discussion of options including housing, employment; 'the real world'*.[33]

7.3 Children's Social Services

7.3.1 The Select Committee learned that Children's Social Services will usually only attend transition reviews for a child in the care of the Authority or for a child who is already designated as a Child in Need. In some cases Children's Social Services may be represented by a Duty Social Worker, who does not know the young person. This could, for example, cause delays in drawing together a plan as decisions on social care funding would have to be made outside of the meeting**.**[34]

7.3.2 It is important to remember that Children's Social Services are in touch with far fewer children and young people than those dealt with by the Education Assessment Service via statementing. Only children and young people with high levels of need or permanent, long-term disabling conditions meet the Children's Social Services' criteria (Appendix 8). Intervention only takes place when families need support over and above normal parenting responsibilities. Specialist Disability Teams work with children and young people with permanent, long-term disabling conditions and the majority of support is through grants from voluntary organisations. These Teams retain cases until young people reach the age of 18. So a young person at that age, with ongoing social care needs would transfer to an Adult Team (on meeting their criteria)[35]. It is acknowledged that planned transfers are not taking place consistently across the county.

7.3.3 There are particular challenges to effective planning for young people in out-of-county residential placements. Adult Social Services' involvement is important where there needs to be a planned return to the KCC area. There remain unresolved issues about which Local Authority takes responsibility for ongoing services where young people intend to remain in their out-of-county placements post 18.

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[32] Gordon Boxall, Chief Executive, MCCH
[33] Alan Milner, Services Director, Parents' Consortium
[34] Royal School for Deaf Children, Margate: Written Evidence
[35] Rose Dillon, Strategic Development Manager, Disabled Children

7.4 Adult Social Services – Transition Worker role

7.4.1 Transition Workers based in Adult Social Services can provide continuity by working with young people and families/carers across the period between childhood and adulthood. They have the potential to provide a range of assistance to young people and families (as additional workers) since, for example, Social Workers from the specialist Children's Disability Teams cannot allocate time to attending transition reviews as the majority of young people do not meet their eligibility criteria. The location of the post within the adult sector is felt to be important to promote the culture of moving towards greater independence while supporting young people to make informed choices about education, housing and employment. Currently the pressure of funding Transition Workers is with Adult Social Services.[36]

7.4.2 Transition Worker posts across Kent, including at least one jointly-funded between Social Services and Health (50/50) have ended over time, mainly because of funding pressures.[37] [38] There is now one dedicated Transition Worker covering the Canterbury Area and in other Districts there are Care Managers with special responsibility for transition. The dedicated worker's remit is to work with young people aged 16 and over and there is not enough capacity to work with young people from age 14. Much of the initial work related to parents' need for information rather than a service and parents were pleased and reassured to know they had a point of contact in relation to transition.

7.4.3 Although attached to an Adult Learning Disability Team, the post is inclusive of young people with all types of disability. It is co-located with the Children's Disability Team and specialist health colleagues in a multi-disciplinary setting. The absence of Transition Workers elsewhere can cause a problem when working with schools and colleges as, for example, some young people would have a Transition Worker while others would not, on the basis of where they live.[39] This has been described to the Select Committee as a 'postcode lottery' for young people, parents and carers. Ideally there should be sufficient workers to cover the County and aligning posts with school 'clusters'[40] would avoid discontinuity.

7.4.4 The Select Committee heard evidence confirming that generally, planning for adult social care takes place for young people who are in the care of the Local Authority and that due to resources being stretched very thinly Adult Social Services often do not get involved with young people's planning until 'late in the day'.

7.5 Transition planning in school for young people without Statements

7.5.1 There is no legal requirement for transition planning for young people without a Statement and research indicates that young physically disabled people are among those without Statements who can experience a poor handover to

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[36] Des Sowerby, Joint Director – Learning Disabilities (Adult Services)

[37] Greg Gibbins, Transition Worker, Canterbury Adult Learning Disabilities Team

[38] Caroline Baker, Senior Practitioner, Senior Practitioner, Children With Disabilities Team, West Kent

[39] Greg Gibbins, Transition Worker, Canterbury Adult Learning Disabilities Team

[40] Group of schools who work together supportively and share expertise

Adult Social Services, particularly as a period away at college can interrupt contact with Social Services. [41] An audit carried out by KCC in 2004 found there was insufficient information available to assess transition processes for young people with different types of disability though it was felt at that time that, as well as young people with severe and complex needs, those with serious physical disabilities had poor transition processes. There is still a lack of strategic monitoring to enable an objective assessment of the current situation.

7.5.2 Approximately 80% of Kent young people with special educational needs (in year 9 and above) are supported in school at School Action and School Action Plus, which means the school, not the Local Authority must meet and fund their needs. Schools have in-house processes for reviewing support and progress and many young people will have Individual Education Plans. The extent of transition planning that takes place in schools is not monitored strategically.

7.5.3 *'Children with Statements are better placed to allow for effective transition planning to take place. However, the fact that their needs are more complex and severe and they require more specialised provision/services and are often placed out-of-county at a distance from home, can make planning more problematic and harder to manage. For children without statements, there is less legal protection but the fact that they are usually in school locally makes planning easier to manage.'* [42]

7.5.4 It is therefore vital that Children, Families and Education and Adult Social Services jointly explore ways to ensure that the cases of all young people who will require social care into adulthood have been identified well in advance and that planning for the transfer to, or commencement of, adult social care is started prior to young people leaving school. A high priority should be given to those young people placed out-of-county. A related recommendation is given at the end of Section 9. The parents and carers of all young disabled people in transition will be better supported by the consistent provision of information and a recommendation in this regard is made at the end of Section 10. The Select Committee was impressed by the quality of information provided by Hampshire County Council.

Recommendation 3

That the Cabinet Members for Children Families & Education, and Adult Social Services Directorates are made aware of the Hampshire transition documents and protocols, particularly the new Transition Handbook and Multi-agency Guide, with a view to working towards a similar scheme, for Kent.

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[41] Fiorentino, L., et al. Transition from school to adult life for physically disabled young people, Arch Dis Child 1998;79:306-311

[42] Marlene Morrissey, County AEN Manager

7.6 The views of young people, parents and carers about transition planning

7.6.1 Questionnaires were sent out to families with disabled children and young people aged 14-19 who were in touch with two parent-led organisations in Kent; Parents' Consortium in Hextable and Special Needs Advisory and Activities Project (SNAAP) in Canterbury. We asked questions about different aspects of transition planning and also whether the young person had a Statement. A total of 42 responses were received, a response rate of around 15%. Summarised results are given at Appendix 7.[43] [44]

7.6.2 From the responses:-

- 18 out of 42 (43%) young people had no plan at all for their future and this figure included several with Statements of SEN, one of whom was severely autistic and blind;
- the level of agency involvement in the transition planning that took place varied from the school and parent being present, to the involvement of several agencies. Connexions were usually but not always present;
- the content of plans was variable with many not considering a range of issues about the young person's future;
- the majority of young people (92%) who had plans felt their views and wishes had been listened to when making the plan;
- most young people who had transition plans were happy with them (84%).

7.6.3 Some of the views expressed by parents:-

> **'We have no plan! Very worried about future and lack of info.'**
>
> *Parent of young person aged 14*

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[43] Questionnaires were devised using a system of symbols known as Widget, to be accessible to young people with learning difficulties, with the help Parents' Consortium. Families were accessed via Parents Consortium and SNAAP and the identities of respondents have been kept confidential.

[44] The response rate means these views may not reflect accurately the full range of experience of transition planning; and questionnaires may not have been sensitive to a range of issues faced by young disabled people and their parents.

> ***'Would like to know more about employment opportunities available, and sheltered accommodation.'***
>
> *Parent of D aged 17*

> ***'Information (should be) more readily available, rather than have to find out for yourself including benefits, …clubs, discounts available, changes of allowances at different ages….'***
>
> *Parent of C aged 18*

> ***'We have completed a moving on plan for T to move into College but no plan after that – living independently.'***
>
> *Parent of T aged 15*

7.6.4 Young people were asked what had made them happy when growing up and comments reflected a huge range of personal feelings, activities and interests as well as the love and support of family members, for example:-

Playstation!

Drawing and art projects

Feeling safe and secure

Making friends at school

Seeing my friends

Things that made young people sad when growing up were just as personal and varied. Young people spoke of feeling ‘too disabled’ or ‘not disabled enough’ to join in with things; about the lack of suitable facilities and (through parents) about the fight to obtain education and respite.

Finding school work hard

I don’t like loud noises

Going away to boarding school …

People don’t want to mix with me as I am disabled

7.7 Monitoring transition planning

7.7.1 The use of person-centred transition plans helps to ensure that young people’s wishes and aspirations are monitored and kept central to the planning process, on a continuous basis.

7.7.2 It will be difficult to ensure there is a consistent and ‘joined up approach to the assessment and support of young people’s needs at an early stage (i.e. age 14-17)’[45] without a strategic monitoring system to link these processes. Currently, there is no system in place to link assessments with transition planning or to monitor the effectiveness of transition planning for young people with special educational needs either with, or without Statements.[46] A quality review was to be carried out by the Additional Education Needs & Resources division two years ago but this work was discontinued.[47]

7.7.3 Elements of good transition planning can be found in parts of Kent but not consistently across the county.[48] A national survey[49] found that most Local Authorities do not feel that monitoring of transition planning and outcomes is important. The Select Committee also heard that currently there is no tracking of post-school destinations for disabled young people (including those with learning difficulties). However, the Learning and Skills Council are aware that

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[45] Transition Planning for disabled children and young people and their families: Report to DMT, March 2006

[46] Marlene Morrissey, County AEN Manager

[47] Andrea White, Specialist Teaching Service

[48] Justine Croft, Connexions

[49] Growing up matters - Better transition planning for young people with complex needs, CSCI (2007)

there could be a more effective use of information gained from Section 140 Assessments[50] (currently carried out by Connexions Personal Advisers for young people with Statements) and it is their intention that in future better strategic use will be made of this information.

7.7.4 Evidence received by the Select Committee indicates that the absence of any monitoring linked at strategic level between the Specialist Teaching Service, schools and Social Services, makes it difficult for Social Services to track their own involvement in the statutory transition planning process, at anything other than local level.

Recommendation 4

That KCC should evaluate the capacity of current data systems to enable strategic monitoring of transition plans.

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[50] David Le Breton, Learning and Skills Council

8 Focus on the Young Person

8.1 Person-centred planning

8.1.1 The White Paper Valuing People set clear goals and objectives relating to transition, including an expectation that person-centred planning would be introduced for all young people moving from children's to adult services by 2003. Person-centred planning focuses not only on services available, but on the wishes and aspirations of the young person concerned and therefore provides an individual focus on the 'invisible transition' from child to adult status.[51]

8.1.2 Person-centred planning was evident in the special schools we asked to help with this review and is also well embedded in Adult Learning Disability Services. Within Disabled Children's Services there has tended to be a family rather than an individual child focus but there is now a move towards helping young disabled people to take a more active role in planning for their future.[52]

8.2 Example of local good practice in person-centred planning: St Nicholas (Special) School and Canterbury College[53]

St Nicholas School's 16-19 unit is based on the College campus. The multi-agency transition model was set up in 2003 in partnership with the NHS-funded Services for Children with Learning Disabilities and Challenging Behaviour (LDCB) Team based at the Royal Queen Victoria Hospital in Folkestone, which has an administrator and Transition Nurse to assist families through the process. It began with selected students aged 16-19 and now all pupils from year 9 onwards have person-centred transition plans.

Parents and pupils are prepared for the transition review with information, meetings, workshops and workbooks so that they are ready to participate in a person-centred review focusing on the pupil's wishes and dreams, as set out in their workbook. Information about Connexions and the Local Authority is provided before the review.

The experience of St Nicholas School has shown them that working in a person-centred way changes the whole structure of transition planning, as its meetings are approached in a way that ensures the young person is the central focus. There are no side-meetings to discuss particular issues; there is one meeting which is inclusive and structured so that everyone understands what is happening.

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[51] Hudson, B., Making and missing connections: learning disability services and the transition from adolescence to adulthood (2006) Disability and Society, Volume 21, No 1, 47-60

[52] Rose Dillon, Strategic Development Manager, Disabled Children

[53] Daniel Lewis, Headteacher, St Nicholas School and Lut Stewart, Director of Student Support Services, Canterbury College

8.3 Example of national good practice in person-centred planning: Trans-active by MENCAP[54]

Trans-active was launched in 2003 with the aim of supporting all young disabled people to participate in their own person-centred transition planning. It is used in more than 80 schools, colleges and more recently 16plus and Connexions settings. It links to the national curriculum through Citizenship, Personal, Social and Health Education (PSHE) and Information Technology.

Over 1000 young people now have a ‘transition passport’, a brightly coloured document which they help to create online - by adding pictures representing their needs, wishes and preferences. They are helped by supporters of the same age who also gain from the experience. Trans-active has an accompanying website http://www.trans-active.org.uk with information for parents and young people about all stages of the transition process, signposting to organisations and resources.

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[54] Lewis Perkins, Project Manager – Trans-active, MENCAP

The front page of a transition passport:

8.3.1 An increased use of this type of person-centred planning in schools and other settings would ensure that young people had plenty of time to think about what they would like to do in the future throughout the period of their transition to adulthood. Their ideas could be developed and taken forward at annual transition or other reviews by a Transition Worker, or other co-ordinating worker, to ensure they fed into future multi-agency service planning.

Recommendation 5

That the Transition Task Group investigates the potential for the increased use of Trans-active in Kent schools, colleges and other settings.

8.4 Enabling participation

8.4.1 Valuing People focused on Person-Centred Planning for people with learning difficulties. However the principle can and should be applied to all young disabled people such as those with physical or sensory disabilities.[55]

8.4.2 A recent study found that more attention needed to be focused on participation of disabled young people and that policy should recognise the time and skills

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[55] Alan Milner, Services Director, Parents' Consortium

needed by staff to facilitate it.[56] The communication needs of young people with communication impairments and/or complex needs should be taken into account and a greater awareness is needed among professionals about what constitutes participation at an appropriate level.

> *'Even the most severely disabled children can communicate in some way; it's up to other people to work out how.'* [57]

8.4.3 Communication for young people with sensory impairment can be slow; for a young person who is deafblind, for example, considerable time would be needed in order to prepare. Enabling participation might involve providing information in Braille or arranging the services of a sign language interpreter. The Select Committee heard that it could be difficult to engage interpreters as 'they are in short supply'. It is therefore imperative that transition reviews and other meetings with young people are planned far enough (in the case of interpreting services – 1 month) in advance to ensure the appropriate professionals are present to enable the young person to participate in their own planning.

8.4.4 It was also highlighted to the Select Committee that the issuing of fewer Statements to deaf children and young people had resulted in a decline in referrals to the Deaf Services Bureau who were now less likely to be invited to transition and other reviews. Without this input, reviews could become less accessible to some young people and vitally important child protection issues could be poorly addressed.[58] The message from a range of professionals to the Select Committee is that Person-Centred Planning needs to start early so that young people have the opportunity to make choices before they leave school. It should be led by the young person with support from independent advocates or facilitators to ensure that the focus is on what the young person wants and not what other people want.[59]

8.5 Advocacy

8.5.1 The Select Committee heard from a number of sources about the importance of advocacy during transition. The Royal School for Deaf Children provided written evidence about the difficulty they have accessing the available advocacy service and for this reason they view parents as young people's main advocates whereas, for example, St Nicholas School use advocates known to young people such as a Social Worker or member of staff that they know well, or a Connexions Personal Adviser.

8.5.2 The Select Committee received evidence that over-reliance on parents as advocates during young people's transition to adulthood can lead to difficulties. This is due to the natural conflicts that may arise as teenagers begin to develop ideas and wants that differ from those of their parents. Young people need to have their own views heard and taken into account.[60]

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[56] Franklin A., and Sloper, P., (2007) Supporting the Participation of Disabled Children and Young People and Decision Making

[57] Kent parent/carer

[58] Beryl Palmer, Occupational Therapy and Sensory Disabilities Unit

[59] The Skillnet Group: Written Evidence

[60] Louise Watch, Direct Payments Co-ordinator

Situations where parents' and young people's views differ about what should happen in the future need to be managed very sensitively by professionals.

8.5.3 For families receiving services from Children's Disability Teams, the involvement of Adult Social Services from 14 is necessary to allay parents' fears and concerns about what will happen in the future. Independent advocacy for children in care can significantly improve the transition process because of the conflict for Social Workers between their advocacy role and their directions to work within cash limits when demand exceeds supply.[61]

8.5.4 Advocacy services are available from different organisations such as Parents' Consortium, Skillnet and agencies such as SENSE or RNID, but currently do not permeate Kent's practice as fully as in some other authorities such as Essex, where advocacy is well embedded in service provision.[62] Some Local Authorities contract-out the advocacy role to an independent organisation.[63]

8.5.5 Advocacy services struggle to meet the existing demand. The 12 Kent (Adult) Districts currently had been given £28,000 for advocacy project work but individual cases could be expensive.[64] Some providers offer services to the over 18s only. There is also a self-advocacy project 'Voice for Kent' which requires further funding.

8.5.6 The importance of peer-group mentoring was raised as something that could be of immense value to young people who need to relate to their peer group and not always to their parents, as they grow up[65]. The use of mentoring was noted earlier in relation to the Trans-active method of person-centred planning.

Recommendation 6

That KCC should identify the source and type of advocacy available for parents and young people to facilitate better transition planning and make provision to meet any gaps in service.

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[61] Gwen Kidd, Fostering Social Worker

[62] Louise Watch' Direct Payments Co-ordinator

[63] Royal School for Deaf Children: Written Evidence

[64] Des Sowerby, Joint Director – Learning Disabilities (Adult Services)

[65] Carrie Johnson, Special Needs Activities and Advisory Project

9 Support for Carers

9.1 Raised profile for carers

9.1.1 The government's New Deal for Carers, announced on 21st February 2007, recognises the vital role of carers in society and pledges a new package of support and services. Local Authorities will receive £33 million broken down into £25 million for emergency support, £3 million on national advice and information (helpline) and £5 million on training. KCC is planning to set up a network among voluntary carers' organisations to share information and identify where good support exists. Analysis of this work will take place later in 2007 and enable Adult Social Services to work more closely with its partners in the voluntary sector.

9.2 Training

9.2.1 KCC Adult Social Services have begun to offer training to carers through work jointly funded with Adult Education, Northwest Kent Carers' Support and Gravesham and Swanley MIND. An Expert Carers' Programme will be developed so that the control and management of support rests with the real 'experts'; the individuals concerned rather than providers of services. Other training is offered or planned through use of the Carers' Grant to the voluntary sector. Across Kent; carers' organisations run 70 schemes which provide training under the headings of: information, breaks, emotional support, maintaining carer's own health and having a voice.

9.3 Assessments

9.3.1 Carers have the right to an assessment of their own needs under the Carers Recognition and Services Act 1995 and the Carers & Disabled Children's Act 2000; The Assessment & Carers (Equal Opportunities) Act 2004 placed a duty on councils to inform carers of the right to an assessment. This type of assessment enables a carer to discuss with Social Services the help they might need in caring, maintaining their own health, work-life balance and coping with family commitments. It can either be carried out separately or combined with assessment and review of the young person's needs.

9.3.2 KCC commissions Carers First to carry out some assessments, but the service is not available across the county. Alternatively a carer providing 'regular and substantial care' but who needs support or a break can also submit a self-assessment which can be done online or on paper. The criteria for obtaining an assessment are low; all carers have the right to an assessment though not all will be eligible for a service.

9.4 Information

9.4.1 It is significant to note that many parents do not consider themselves to be 'carers' and so information aimed at carers needs to be clearly explained. It was highlighted to the Select Committee that Adult Social Services have identified a need for clear communication about, firstly, the right of carers to an assessment and, secondly, about the assessment itself as some carers have had an assessment and not known, specifically, that this has taken place.

☹ More information for carers needed

9.5 Charging policy

9.5.1 The policy of Adult Social Services is not to charge carers for the services they receive. However a carer might have been used to receiving services for a young person free of charge from Children's Social Services and find that an equivalent service from Adult Social Services (when the young person reaches 18) attracts a charge, although voluntary organisations such as Crossroads would provide support free of charge.

9.5.2 Help provided in the home (domiciliary care) by Children's Social Services or Health would be free. Once a young disabled person reaches the age of 18 Adult Social Services apply their Fairer Charging Policy. The charges and rates of both Children's and Adult Social Services are clearly presented in two concise booklets available online.[66]

9.6 Family Respite Scheme

9.6.1 This scheme, which provides specialist foster placements for disabled children and young people, has developed in recognition of the fact that in most cases a family setting is preferable to residential care. There are also substantial cost-savings to be made. The scheme offers day care and emergency care. Respite foster carers recruited to the scheme are often parents of disabled children themselves and therefore have a great deal of expertise and experience to offer. This is backed up by comprehensive training. The scheme has developed most successfully in East Kent where respite is provided to over 80 children and young people and in addition there are 17 young people in permanent foster care. To qualify for the scheme, children and young people must meet the criteria of the Children's Disability Teams and cases are presented at a respite panel where the level of respite is agreed. This is usually 24 nights per year to begin with.

9.6.2 As the Family Respite Scheme expands to meet needs in other parts of the county, benefits would result from links being made with the Adult Placement Scheme. Currently, for example, family respite carers have to repeat components of training if they continue to provide care for a young person when they reach the age of 18.

9.6.3 There is also a disparity in the level of inspection between the Children's and Adult schemes with the potential for adult protection issues to be overlooked.

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[66] Social Services rates and charges 2006/07

A child respite placement is reviewed by a Team Leader or Practice Supervisor from the Children's Disability Team using the same protocols as the review process for a child in the care of the Authority; visits are also made every 4-6 weeks. A respite carer, on joining the equivalent Adult Scheme in order to continue caring for a young person, told the Select Committee that the frequency of visits then dropped considerably.

9.7 Other types of provision

9.7.1 KCC is exploring innovative ways of offering support and respite through parent-led resource centres based on the model of the Parents' Consortium in West Kent. The Select Committee was told that young disabled people often do not want to access holiday schemes or respite provision at their schools.[67] However, there may be merit in exploring such extended provision where there are separate premises on a school site, away from what young people consider to be their educational environment.

Recommendation 7

To ensure that Children, Families and Education and Adult Social Services' commissioning strategies are co-ordinated, including the use of jointly-resourced budgets where appropriate, to provide a more graduated and consistent approach to service provision for young disabled people in transition from childhood to adulthood. Such strategies should incorporate Transition Worker roles or demonstrate clearly alternative means of providing similar support.

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[67] Rose Dillon, Strategic Development Manager, Disabled Children

10 Information about Transition

10.1 What information is needed?

10.1.1 The Road Ahead transition project[68] found that young people, their parents and supporters (including voluntary) needed information on:-

- the process of transition; roles, rights and entitlements;
- local resources and services including person-centred planning;
- the young person's rights and responsibilities as an adult including information on self-advocacy, empowerment, risk taking and keeping safe;
- changes and choices.

The study found that young people wanted a range of information on: work, going to college, where and how to live, money and benefits, friends, sex and relationships, safety, independence skills, rights and responsibilities, healthy living, emotional changes and having fun.

10.1.2 The Select Committee heard evidence from Parents' Consortium, an organisation in touch with families of disabled children and young people. From his experience as a parent and of working with families, the Services Director indicated that a separate guide to services covering the transition period is needed. Without one, parents have to consult a variety of other documents to 'pull the threads together'. Such a guide could also direct families to national as well as local information resources.

10.1.3 As well as specific information targeted at young people and parents who will be taking part in statutory or other formal transition planning, there is a need for a universal set of information so that no young person, parent or carer has insufficient information to plan for the future. There is a need for information to be made consistently available by KCC and its partners.

10.2 What information is there already?

10.2.1 KCC's AEN & Resources Team provide leaflets and a website about special and additional education needs. Partnership with Parents (PwP) provide a one-page summary about statutory transition planning. The NHS project outlined in Section 8 has developed a comprehensive set of booklets about transition available for the Dover/Shepway; and Canterbury/Herne Bay/Whitstable areas. A West Kent transition group has focused on information provision and produced a bright and accessible multi-agency leaflet for the Tunbridge Wells area, which has been circulated by Connexions to young people over 14 at their annual reviews. Transition is referred to in numerous other leaflets and online resources.

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[68] Road Ahead (The) – Transition Project

10.3 When is information needed?

10.3.1 Despite a range of information being available; it still does not reach everyone in time:

> ***'I didn't even know till after the meeting that it was a transition review. It was there in the small print but I hadn't noticed it, so I couldn't prepare. Knowing what to expect (about transition) would eliminate a lot of worry.'***
>
> *Parent of C, aged 14*

10.3.2 Information provided in advance would be of more benefit to parents; helping them to prepare for meetings. Information distributed more widely or made universally available would assist parents in participating in all types of future planning (including their own informal planning for their child's future). A number of people who gave evidence to the Select Committee said they thought a local website dedicated to transition would be useful. Existing resources such as the Direct Payments Support Scheme website and the Supported Employment Scheme website have the potential to be developed to include more information on transition.

> ***'Services need to seek families who need them, not the other way round.'***[69]

10.4 Children not in school

10.4.1 The Select Committee also heard evidence regarding a small proportion of the 600 children educated at home in Kent.[70] Those who have attended a school and have Statements in force have a statutory requirement for transition planning and are provided with information by the Children Educated at Home Co-ordinator to help them through the process, with the assistance of Connexions.

10.5 Accessible information

10.5.1 Information should be accessible to all young people, parents and carers including those who have sensory disabilities. This is outlined in a range of guidance, including Connexions' Information Advice and Guidance Quality

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[69] Carrie Johnson, Special Needs Activities and Advisory Project

[70] Tim Fox, Children Educated at Home Co-ordinator

Standards, to ensure that: *'Transition routes to adult services are explained to young people and information is available in a variety of media and formats.'*

10.6 Children's Disability Registers

10.6.1 There are children's disability registers (set up under the Children Act 1989) in West and East Kent each with a Co-ordinator who acts as an information conduit for families of disabled children and young people aged 0-19. Mid Kent has had no co-ordinator for some time but the work has been covered as well as possible in the other areas. The Service in West Kent is co-located with Parents' Consortium and in East Kent with the Disabled Children's Service.[71]

10.6.2 Registration is completely voluntary and the co-ordinators keep confidential the information provided by parents. The Register is currently used to disseminate information about services and events via 6-monthly newsletters. There is no website for the service.

10.6.3 The Register Service also gathers information, by district, including age, type of disability; future housing requirements and support service used. The latter includes services in education, health and leisure.

10.7 Information for professionals

10.7.1 It is important that professionals are supported with information about transition and services available to parents from different agencies and KCC Directorates even if they are not directly involved with transition work. A lack of this knowledge can lead to parents being pushed 'from pillar to post' to find out what they need.

10.7.2 Raising general awareness of transition issues among professionals will also help to ensure that they can advise correctly young people who may become disabled later in their lives; directing them to the appropriate source of support.

10.7.3 Key points arising from evidence are that:-

- a variety of information about transition is already available but not yet consistently across the county;

- parents of young people with special educational needs but no Statement may not have equal access to information about transition to help with other (including their own) planning;

- proactive provision of information would save parents' time and energy in seeking it out;

- information needs to be concise and accessible; available in a variety of formats and languages;

- a strategic and multi-agency approach to information provision would provide greater consistency and avoid duplication of work;

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[71] Sue Snooks, Children's Disability Register Co-ordinator, West Kent

- The Children's Disability Register is currently an under-used resource. It could be used to disseminate information about transition (though this would only reach those who have voluntarily registered). Development of a Register website would help the Service to reach and benefit more families of disabled children and young people.

10.8 Strategic considerations

10.8.1 Guidance on Section 12 of the new Childcare Act suggests three possible models of information provision: a central hub linked to frontline provision via 'kiosks', telephone hotlines, outreach visits and surgeries; a one-stop shop; a call-centre or combination of the three models. This work will be led and co-ordinated by the Children's Trust and could incorporate the information requirements of disabled young people, parents and carers as young people make the transition to adulthood.

10.8.2 Some of the advice covered by the legislation is already being provided by the Partnership with Parents Service (PwP). Their service provision is focused on the primary-secondary school transfer but could be extended to provide better information and signposting on referral and access to social care services during the transition to adulthood. PwP currently provide information to parents via a helpline and a new focus on transition to adulthood would make the service more holistic in line with its original remit to balance the level of support given to parents of children and young people with special educational needs but no Statements. [72]

10.8.3 The Select Committee intends that its recommendation on information provision will link in with the work of KCC's User/carer involvement group and other transition work-streams and the awaited Transition Guide from the Council for Disabled Children.[73] It is also consistent with the Guidance for directors of Adult Social Services on information provision.[74]

Recommendation 8

That the Managing Director of Adult Social Services and the Managing Director of Children, Families and Education must ensure that information about transition and Adult Social Services is available in a range of accessible formats and is brought to the attention of young disabled people and their parents in advance of meetings to enable them to participate in transition planning.

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[72] Linda Baker, Partnership with Parents

[73] Debra Cooney: Written evidence

[74] Best Practice Guidance on the role of the Director of Adult Social Services, DH (2006)

11 Strategic Multi-Agency Work and Developments

11.1 *'A key solution to the challenges around transition is effective co-ordination of multi-agency services'.*[75]'

11.2 Strategic Transition Groups

11.2.1 KCC has a history of multi-agency work aimed at improving transition. In 2004 the Service Development Partnership for Disabled Children was formed to continue the work of previous groups; with the backing and representation of senior managers from key Kent agencies and organisations, including Social Services, Health, Education, Connexions, the Learning and Skills Council, the Children's Fund, voluntary sector and parents. The Select Committee was informed about the work of the group by the Project Manager for Disabled children who was appointed in 2004 to develop a multi-agency strategy on community based services for disabled children and their families.[76]

11.2.2 Five task groups were formed including one to focus on key transition periods for disabled children and young people aged 0-25. There was a clear need for the Transition Task Group to work jointly with Adult Social Services and it amalgamated with an existing County Transition Group under the new leadership of the Transition Champion. The group is accountable to the Service Development Partnership and reports to the Kent Partnership Board (Learning Disabilities). The Task Group decided to focus on the child to adulthood transition (14-25 age range) and in adopting the social model of disability, to be inclusive of young people with learning difficulties.

11.2.3 Following the publication of KCC's Towards 2010 document containing Target 55 on transition, a new 2010 Executive group was formed under the leadership of Oliver Mills, Managing Director of Adult Social Services. The Managing Director will oversee progress and the joint 2010 leads from Children's and Adult Social Services will report to this Group. A new Senior Manager, Angela Graham, has been appointed to project manage transition from the perspective of both Children's and Adult Social Services.

11.3 Children's Trust arrangements

11.3.1 *'We need to establish new cultures in the workplace so that individual professionals work horizontally across professional boundaries rather than vertically in professional hierarchies'* [77]

11.3.2 The Children Act 2004 placed a duty on local authorities to lead on the development of integrated children's services. Local partnership arrangements have undergone development and the Kent Partnership is now known as the Kent Children's Trust; whose function will be to commission and provide services to children and young people. The Children's Trust will provide the framework for integrated front-line delivery of services, including the development of children's centres and extended schools.

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[75] Parliamentary Hearings on Services for Disabled Children, October 2006

[76] Debra Cooney, Project Manager – Disabled Children

[77] Every Child Matters (2003)

11.3.3 The Children Act 2004 outlines a clear 'duty to co-operate' and that services will be brought together 'in an area'. 35 Authorities, known as Pathfinders, have been piloting integrated services, concentrating on:-[78]

- disabilities and mental health
- disabilities
- disabilities and looked after
- mental health
- early years[79]

11.3.4 The Managing Director of the Children Families and Education Directorate is the chairman of the Trust and its membership is shown in Table 2 below:

Table 2: Membership of the Kent Children's Trust

KCC officers from Children, Families and Education Directorate
KCC officers from Communities Directorate
KCC Cabinet Member
Chief Executives of the new Primary Care Trusts
Associate Director of Public Health
District Council representation
Kent Police
Kent Fire and Rescue Service
Kent Area Probation Service
Youth Offending Service
Chief Executive of Connexions
Learning and Skills Council
Canterbury Christ Church University College
Voluntary and Community Sector
Headteachers
The Church
Kent Children's Fund

11.3.5 Children's Trusts should be able to work with young disabled people up to the age of 25[80], however in the initial stages of Children's Trust arrangements in Kent the role such a Trust will have with disabled 20-25 year olds is unclear.[81] Currently, the statutory responsibility of Connexions extends to the age of 25 for young people with learning difficulties and/or disabilities (LDD) but the Committee heard evidence that the future role of Connexions in providing information, advice and guidance, when funding is given direct to Local Authorities, could not yet be confirmed.[82]

11.3.6 The Committee felt that, in order to ensure effective joint work on transition, the Director of Adult Social Services should be included in the Trust membership, particularly in view of guidance indicating that he should maximise the contribution of children's service providers to the planning of

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[78] O'Brien, M., Developing Integrated Services for Children in England: Emerging Messages from Children's Trust pathfinders

[79] Children's Trust Arrangements in Kent - Report to Cabinet (2006)

[80] Children Act 2004

[81] Joanna Wainwright, Director Commissioning (Specialist Services)

[82] Gordon Bernard, Chief Executive, Connexions Kent & Medway

Adult Social Services. The Committee is pleased to note that prompt action has already been taken and that the Managing Director of Adult Social Services is, by the time of writing, a Member of the Children's Trust Board[83]

11.4 Directorate and agency reorganisations

11.4.1 From 1st April 2006 Adult Social Services and Children's Social Services separated and Children's Social Services amalgamated with Education under the new Children, Families and Education (CFE) Directorate. Children's Social Services and the Adult Social Services Directorate each have a Managing Director; respectively Bill Anderson and Oliver Mills and the new Children, Families and Education Directorate is led by Managing Director, Graham Badman. These changes take place as a result of the Every Child Matters agenda to facilitate more effective joint working.

11.4.2 On 1st April 2006 Adult Social Services was reorganised from three into two Areas: East and West Kent. Operationally, work retains its focus on the 12 Kent districts while the Children, Families and Education Directorate is increasingly shifting towards work focused on 'clusters'.

11.4.3 Children's Social Services retain their division into three Areas: East, Mid and West Kent, divided into Districts and Teams from whom caseloads are drawn except that the Disabled Children's Service, previously managed within each of the three Areas, is now being restructured (at November 2006) into two Areas: East and West Kent, with a discrete management structure under the leadership of a Specialist Services Manager, in order to align it better with Adult Social Services and new Primary Care Trust (Health) boundaries.[84]

11.4.4 Education is also divided into East, Mid and West Kent Areas and in addition schools work together in 23 'Clusters'. Following a 2003 review of special schools in Kent, a further review of 'Units and Designations' within mainstream schools took place.[85] Funding will be allocated to 'Cluster Lead Schools'. Implementation is proposed for September 2007 and a key aim is building expertise so that the needs of a range of children can be met locally, as well as providing additional places for young people with autism. It is possible that new autism provision with outreach support will be developed in South West Kent though other options are also being considered.[86]

11.4.5 A new strategic Health Authority was formed from Surrey, Sussex and Kent on 1st July 2006[87] and five of the Kent Primary Care Trusts in mid and east Kent were merged to form a new Eastern and Coastal Kent PCT based in Whitstable. West Kent PCT has its base in Tonbridge. The commissioning of a range of services offered to children and adults has been changing over time from a county to a locally based culture and pooled budgets are in use between Health and Adult Social Care to fund services and specific posts

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[83] Blog: Oliver Mills, February 2007

[84] Liz Totman, Head of Specialist Services

[85] This included children and young people in receipt of Very Severe and Complex Need funding in those settings

[86] Review of Designated and Specialist Unit Provision - Report to KCC Cabinet (2006)

[87] NHS continuing healthcare: transitional arrangements following NHS reorganisation and pending national framework implementation : DH (2006)

such as the Joint Director, Learning Disabilities. As General Practitioners develop their roles as commissioners, they and PCTs will be faced with the challenge of aligning with the district-based Adult Social Services' provision and the increasingly cluster-based organisation of Children's Social care and Education provision.

11.5 The Learning and Skills Council (LSC)

11.5.1 Following a National reorganisation of the LSC into 9 regions, the Kent and Medway local partnership is now one of 6 in the South East handling services including finance. Local partnership teams' work will include developing strategic relationships with Local Authorities and other stakeholders and partners; leading the 14-19 agenda and tailoring national priorities to local needs. The LSC provide government funding locally to (eligible) young people aged 16+ in mainstream schools, in special schools and all young people in the Further Education (college) sector.

11.6 The Third Sector

11.6.1 A review of the role of community and voluntary organisations in social and economic regeneration began in May 2006 and a final report is expected in March 2007. Building on government initiatives to acknowledge and support the important role of these organisations in delivering public services and building locally sustainable communities, from 2008 there will be a three-year (rather than one-year) funding arrangement through local councils and the Select Committee heard how this would, for example, benefit small organisations supporting disabled children and young people and their families, offering more security and the ability to plan ahead.[88] [89]

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[88] Carrie Johnson, Project Manager, Special Needs Activities and Advisory Project

[89] NCVO - Briefing on the future role of the third sector in social and economic regeneration: interim report (2006)

12 Connexions

12.1 National issues

12.1.1 Prior to the government's creation of Connexions in 2000, studies showed that 75% of young people with Statements left compulsory education with no transition plan. By 2003, replacing the old Careers Service, Connexions, had national partnership bases which were to provide information, advice and guidance to all young people aged 13-19 and support for certain young people with Learning Difficulties and/or Disabilities (LDD) up to age 25, provided by personal advisers (PAs). PAs provide guidance from town-centre Connexions Access Points (CAPs) and others are based in schools and elsewhere.

12.1.2 Connexions define a person with 'LDD' as:-

- having a significantly greater difficulty in learning than the majority of persons their age;
- having a disability which prevents or hinders making use of facilities generally provided by institutions providing post-16 education or training[90].

12.1.3 In 2004, through consultation with schools and other agencies, East of England partnerships arrived at 7 principles for effective transition planning (given as Appendix 8) and identified that:-

- Personal Advisers (PAs) needed more resources to support them in carrying out their role as advocates for young people, as well as their statutory obligations in transition to participate in planning and assessment;
- more time needs to be allocated to supporting young people with LDD;
- parents need one key person as a point of contact and support throughout transition, before planning starts in year 9 'until an appropriate lifestyle has been developed after school';
- PAs must support the formal transition process for young people with Statements but need support themselves to be able to work with all young people with SEN, who do not have statements (those on School Action or School Action Plus).

12.1.4 Connexions support is tiered according to need from intensive and sustained support to provision of information, advice, guidance and the review of career/learning/employment/personal development choices. The remit of Connexions is therefore very broad and the 'Life Chances' report[91] indicates that the level of funding received from the government in the form of a grant, was less than expected.

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[90] S140 of the Learning and Skills Act 2000 Revised guidance to Connexions Partnerships (2004)

[91] Improving the life chances of disabled people, final report, Prime Minister's Strategy Unit (2005)

12.2 Connexions Kent & Medway

12.2.1 Connexions have a specialist team to work with young people with learning difficulties and/or disabilities (LDD). The Committee learned from the Co-ordinator that the specialist service works with Statemented children in special schools and not with Statemented children in mainstream schools. There are Guidance PAs based in mainstream schools and these schools are supported with in-house training. This could mean that there may currently be less expertise available to young people with a Statement in mainstream schools, in terms of statutory transition planning at age 14 onwards.

12.2.2 There are capacity issues and the specialist service is not able to attend all Year 9 reviews. Better liaison with and between schools would enable Connexions PAs to attend more transition reviews; it is easiest when reviews are held in series for a group of children within a school but some local schools hold their reviews at the same time, which makes it impossible for the designated PA to attend both.[92]

12.2.3 From September 2008 there will be more pressure on PAs due to young people having a new entitlement to study 1 of 14 diploma lines, available at 3 levels, which will provide increased choice. It is unlikely that any one establishment could provide all 14 and as a result there will be more movement between locations that will need to be planned.[93]

12.2.4 The Select Committee received evidence to suggest that Connexions are viewed by some stakeholders as providers of mainstream services, which could indicate their activities to support disabled young people might benefit from a higher profile and recognition.

12.3 Connexions and Rainer Kent

12.3.1 Rainer Kent provide leaving and after care services to young people who have been in care (and meet certain requirements under the Leaving Care Act). The Select Committee heard that Connexions PAs could provide the most useful support to Care Leavers[94] with mild learning difficulties if they were based within the 16plus offices, but Connexions PAs were so far placed in only one of the 16plus offices across the county. There is, however, a strong possibility that PAs will be co-located with the 16plus Teams in the near future.

12.4 Connexions and funding for specialist placements

12.4.1 Independent specialist colleges are nationally available and often residential. The two local specialist colleges in Kent cannot cater for all the hearing impaired (HI) or visually impaired (VI) young people who would like to attend. The Select Committee heard that it is preferable for local provision to be identified, to avoid young people becoming disengaged from their local community and supports. This also places considerably less of a burden on

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[92] Justine Croft, Learning Difficulty and/or Disability Co-ordinator, Connexions Kent & Medway

[93] Gordon Bernard, Chief Executive, Connexions Kent & Medway

[94] Please note the Rainer 16plus teams work with all young care leavers not just those with learning difficulties.

professionals who need to participate in ongoing reviews. Connexions have reciprocal arrangements for attending out-of-county reviews.

12.4.2 The LSC must fund places for students under 19 who cannot be catered for in their local community and can also fund places for 19-25 year olds in the absence of local provision. It can take 4 days of a Connexions Personal Adviser's time to complete the paperwork necessary to obtain LSC funding for a specialist placement.[95] Obtaining funding then takes 3-4 months and in some cases up to a year. With a massive shortfall of available places some applications are inevitably unsuccessful and these delays can therefore substantially affect young people's ability to gain the place of their choice.[96]

☹ **It is impossible to plan for the future until we know if we have funding for college**

12.5 Developing the Connexions Service

12.5.1 Under Children's Trust arrangements, in the near future the careers service may go out to tender and Connexions hope to be awarded the contract. By this time they are likely to have charitable status. Funding for Information, Advice and Guidance will be devolved to the LA.

12.5.2 ECOTEC[97] evaluated the alignment of Connexions with Children's Trusts in November 2005[98] for the Department for Education and Skills (DfES) and indicated that Connexions Personal Advisers (PAs) under Children's Trusts were likely to become employees of the Local Authority. Should this be the case, there is the potential for increased joint-work, training and a reduction in duplication between roles. However the Connexions Kent & Medway Chief Executive informed the Committee that these new arrangements had the potential to raise the costs of KCC in terms of, for example, pension rights and this could ultimately lead to a reduction in Connexions' service provision.

Recommendation 9

That KCC, Connexions and partners identify how to use available resources more effectively to benefit young disabled people (including those with learning difficulties) in transition.

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[95] Gordon Bernard, Chief Executive, Connexions Kent & Medway

[96] Justine Croft, Learning Difficulty and/or Disability Co-ordinator, Connexions Kent & Medway

[97] Specialists in economic and social development

[98] Connexions Moving Towards Children's Trusts, ECOTEC (2005)

13 Towards an Integrated System

13.1 Discontinuities in service

13.1.1 The Select Committee heard evidence from a number of sources that led them to appreciate that the traditional way of working in vertical teams and hierarchies had made the co-ordination, commissioning, and provision of services for disabled children and young people more difficult, particularly across periods of transition, despite a history of joint working between agencies. Discontinuities have developed between children's and adult service boundaries and in some cases there is a gap in service.

Table 3: Boundaries between child and adult services

for paediatric to adult health services – **16**
for child (CAMHS) to adult mental health services – **16-18**
for (severely) disabled children's to adult Social Services – **18**
for other disabled children with 16plus teams – **16-21**
school life ends between **16 and 19**
education-based specialist provision ends with schooling between **16 and 19**
Connexions services end between **19 and 25**

13.1.2 Evidence received indicated that this system serves least well those young people who are 'borderline' cases either in terms of the degree of their disability, or of meeting the criteria set by various parts of agencies' service in order to manage their finite resources. Some young people are either 'not disabled enough', or 'too disabled' to benefit from the services that exist.[99]

Example 1:

Rainer 16plus Services support young people between 16 and 21 who are leaving care, some of whom have mild to moderate disabilities not severe enough to have warranted services from the specialist Disabled Children's Service. These disabilities are often compounded by mental health problems due to 'early life trauma which led to them coming into care'.

At a time when they are already coping with growing up and seeking more independence, it is very difficult to identify appropriate support. Many are assessed as having an IQ of around 70, which means they cannot access any community services (Adult Social Services).

This is coupled with a gap in mental health services between CAMHS (Child and Adolescent Mental Health Services) and Adult Mental Health at 16/17. So, even young people who have been able to access appropriate support from CAMHS up to age 16, find it is not available when they need it most.
Adult mental health services are available at 18 but they are less responsive to young people's needs since they focus on testing and diagnosis rather than support.

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[99] Rose Dillon, Strategic Development Manager, Disabled Children

If they have behavioural problems or have come into contact with the Youth Offending Teams there is even less chance that 16plus will be able to help them access appropriate housing or employment. The only way of accessing help, for one or two cases, will be when they enter the Criminal Justice system.

13.1.3 Young people with learning difficulties and mental health needs should be able to access the Child and Adolescent Mental Health Service (CAMHS) up to age 18[100], but the equivalent support at 16/17 is not available. Kent's Commissioning strategy for mental health acknowledges this, saying that '*poor links can exacerbate a young person's mental health problems'.*

Example 2: [101]

Moira is blind, has cerebral palsy, epilepsy and uses a wheelchair; being totally dependent for personal care needs. At 16, mainstream college was not an option and her parents could not find a school to meet her needs. The plan was to approach the LSC to fund Moira's further education. A college was found through which to channel the request but funding could not be obtained because Moira needed to attend and be part of the college body. The costs to Social Services rose to £480 per week as a result.

Moira's parents asked Children's Services to support a Charity they set up to provide Community-based care and education. The Charity used a method of 'gentle teaching' where every step of progress (like the distance of the spoon from Moira's hand at mealtimes and how many times she could feed herself) was part of her education process.

It was difficult to persuade anyone that the above measures of progress were 'education' but eventually the team managed to negotiate a complex set of funding split between 4 agencies.

13.1.4 From witness evidence it was apparent that professionals who are not necessarily specialists in disability, are having to manage, plan or make funding decisions for young people with a range of disabilities or other significant needs and that even where person-centred approaches are being used to benefit young people's transition planning, the same organisational barriers have been in place for disabled young people when they reach what is considered to be 'the normal time' to end school, college, or another aspect of service provision.[102]

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[100] National Service Framework for Children, Young People and Maternity Services: The mental health and psychological wellbeing of children and young people : DH (2004)

[101] Caroline Baker, Senior Practitioner, Children With Disabilities Team, West Kent and John Moore, Care Manager, B. Unit Learning Disabilities Team

[102] Mick McCarthy, County Manager, Rainer Kent

13.2 Service provision graduated into adulthood

13.2.1 Disabled young people may learn at a different pace to their non-disabled peers because of their disability. The beginning of a disabled child's education process is the meeting of basic needs in terms of language, communication, feeding, or whatever those needs are. What is normally thought of as 'education' might start later and for many disabled children this is a time of exploration and extending their experience of the world. Real engagement and expectation may not start until 16-18 at which time the kinds of support previously available generally stop, when there is a need for them to continue.[103]

13.2.2 The Select Committee heard compelling evidence that for some young people who have been in care it is essential that the safeguards of Corporate Parenting extend into adulthood to ensure services are available to mitigate the effects of earlier difficulties.

13.2.3 Many young people on the autistic spectrum will require fewer services as they mature and gain experience and skills, but a responsive service should be continuous throughout the period of need and perhaps tapered should the need decline, rather than suddenly end because of an imposed boundary which is largely arbitrary.

13.2.4 It is also clear from evidence that although special education is available up to age 19 and Connexions provide support up to 25 for some young people there is inconsistency in the availability of a variety of services across that period for a number of young people who require support for longer (for a variety of reasons).

13.2.5 The Select Committee heard that a solution to providing services across transition would be the use of a pooled budget between KCC and external funders.[104] Other Authorities, for example Kingston-upon-Thames had used such a budget with contributions from Connexions and the Learning and Skills Council to fund a central team of care workers. The Life Chances report highlights the importance of overlapping services to ensure smoother transition to adulthood. The Select Committee feel it is important that disabled young people can access services appropriate to their needs rather than age as they become young adults.

13.2.6 It is envisaged that individual budgets will in time enable young people to access services more seamlessly. However the opportunity exists to address any gaps in service as well as improving communication between equivalent services based within the Children's and Adult Directorates (such as the Fostering Respite Scheme and Adult Placement Schemes); as well as extending services so they taper off according to need.

13.3 Late awareness of Adult Social Services support needs

13.3.1 Adult Social Services are concerned that 'surprise cases' can sometimes emerge as requiring support (having perhaps been known to another agency

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[103] Gwen Kidd, Fostering Social Worker

[104] Alan Milner, Services Director, Parents' Consortium

or part of the CFE Directorate).[105] In the short term it will be necessary for KCC to work in close partnership with Primary Care Trusts in Kent to overcome the difficulties of young people entering the county via health processes, so that early notification to Adult Social Services can take place. A greater awareness among professionals of transition processes will also help to ensure that, for example, when a young person becomes disabled in later life the need for transition planning can be addressed promptly.

13.4 Local commissioning

13.4.1 An increasingly integrated approach to commissioning, planning and providing services will be made possible by the developments taking place in order to deliver the 5 outcomes of the Every Child Matters agenda. This is discussed further in paragraph 13.8 in relation to Lead Professionals.

13.4.3 Increased local commissioning of services will ensure that communities are developed to meet diverse needs. The not-for-profit sector will make an increasing contribution to the planning and developing of services to meet local needs, particularly in the housing sector.

13.4.4 Developments in local commissioning and integrated working are underpinned by an improved capacity for agencies to share data and this will facilitate joint work to support and ensure services are available for children and young people who require interventions from a number of agencies.

13.5 Definitions and the sharing of data

13.5.1 The Select Committee's research and evidence from witnesses indicates that the different definitions used by agencies have been a stumbling block to effective joint working, data sharing and the commissioning and planning of services. It has been difficult for agencies to know exactly which children and young people their individual data sets are describing. Consequently, families of children and young people requiring support from a range of agencies have to contend with multiple assessments, plans and reviews which could include Social Services child in need (Section 17) assessments; child protection (Section 47) assessments; care planning and reviews for children in care as well as health and in-school reviews. Connexions also carry out 'Section 140' assessments for young people with Statements moving on to Further or Higher Education without this information yet being used to facilitate better planning in that sector. There may be two or more distinct transition plans used within schools, which are updated separately.[106] Parents or carers have to relate the same information many times in different circumstances and to different professionals.

13.5.2 National developments which must be in place by March 2008 are intended to address this situation;[107] including increased sharing of data collected by key agencies including health, education, social care and youth justice. This is underpinned by the Learning and Skills Act 2000 to allow identification of young people who may have 'barriers to learning'. In October 2006 the

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[105] Michael Thomas-Sam, Head Of Policy And Service Development (Adult Services)

[106] Gillian Wills, Chief Executive, Royal School for Deaf Children: Written Evidence

[107] Joanna Wainwright, Director Commissioning (Specialist Services)

Department for Education and Skills (DfES) handed over responsibility for integrated working to the Children's Workforce Development Council (CWDC) for Information sharing, Common Assessment Framework, Lead Professional and multi-agency working.

13.6 Common Assessment Framework (CAF)

13.6.1 The CAF will mean that parents and children over 12 will be able to consent to assessment data being shared between partner agencies. This voluntary process will mean that a professional beginning to work, for example with a disabled child or young person would be able to see whether other assessments had already been undertaken and use the data to inform their own assessments. A government plan for information sharing in the public sector is expected in April 2007. KCC has protocols in place for information sharing between partner organisations and this is continually revised in light of government policy and guidance.[108] While there are likely to be initial barriers to overcome in terms of technology and resources, this framework will lead to each child or young person having one instead of many assessments and a single integrated plan for support co-ordinated by a Lead Professional.

13.7 ContactPoint

13.7.1 ContactPoint is a national database, formerly known as the Children's Information Sharing Index (ISI), which by 2008 will hold information about all children, including the name of any services being provided. Local Authorities (LAs) will decide who sees any information on the database and disclosure of 'sensitive' data will require additional consent from the individual. Some organisations will be *required* to supply information to the database and others can *choose* to. Every LA can decide who has access (for example in social care, education, health, Connexions, school) and anyone who has access is required to have training and to have undergone a Criminal Records Bureau (CRB) check.[109]

13.8 Lead Professional (LP)

13.8.1 This function will fall to a member of an integrated 'team around the child' and the person chosen will be a point of contact for the family of a child or young person requiring support from a range of services. The Lead Professional would be the person with the most appropriate skills in relation to the needs of the child and could be from the voluntary sector if this was where most support came from. This should help to avoid the necessity for parents to constantly update a series of professionals with the same information. The function would facilitate more successful transitions throughout life since a snapshot of current support would be available at any given time to facilitate effective planning and service provision.

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[108] KCC Three Tier Model for Information Sharing

[109] Every Child Matters

The Children's Trust 'team around the child' approach, to support children who require multi-agency input has been piloted in Kent through its Early Support programme for children aged 0-5 with developmental delay.

The lessons learned are being extended, bringing in an existing Adult Social Services Transition Project, to test integrated team working for young people in transition to adulthood.

A new project in Ashford provides the opportunity to focus on and monitor the outcomes of a discrete group of young people in transition, using person-centred planning. It also presents an opportunity to link with work on Direct Payments and Individual Budgets to give young people and their families much greater choice and control.[110]

13.8.2 With the 'team around the child' model, each young person has a different Team, according to their needs. This model is seen as an alternative to the Transition Worker model of support. The Select Committee has not had the opportunity to consider this approach in detail. Some professionals are concerned that investing the contact with parents and co-ordinating role in one person such as a Transition Worker, there could lead to discontinuity if that person leaves. However, the Transition Worker model does allow for a systematic feedback process to Adult Social Services to assist with future planning.

13.8.3 Every Child Matters guidance considers a spectrum of need, which helps to focus on a wider range of children and young people than those with a Statement of Special Educational Needs. It anticipates that:

- the needs of most children and young people with additional education needs (AEN) would be met by universal services available to all children (no Lead Professional required);

- those children and young people requiring an integrated package of support would have a Lead Professional to co-ordinate it from the early years onwards;

- children and young people with more significant needs (those needing specialist or statutory services which might include children in care; children subject to child protection procedures; disabled children; Statemented children and those involved with the Youth Offending Service would also need a Lead Professional (who may be the worker already allocated by the specialist or statutory service).

13.8.4 For children known to Social Services, the Lead Professional function would probably rest with the Social Worker. As well as acting as a conduit for other professionals' contact with parents, in relation to transition to adulthood the Select Committee were told that the Lead Professional would be responsible for overseeing the delivery of the transition plan from age 14. This would

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[110] Debra Cooney, Project Manager, Disabled Children

involve co-ordination, time keeping and ensuring that ‘what was supposed to happen did happen’.[111]

13.8.5 It is not possible to estimate at this time how many cases a Lead Professional may be required to co-ordinate for disabled young people in transition to adulthood.

13.8.6 The Select Committee was told that it is good practice for young people to choose who they would like to lead their transition reviews. If the young person is hearing or visually impaired this often falls to a Specialist Teacher since this is the person most familiar to them.

13.8.7 The Select Committee has some concerns that if the Lead Professional function falls to a Social Worker; given that it has been necessary for a Duty Social Worker to attend transition reviews,[112] it may not be possible to provide the continuity intended for disabled young people and their families if other commitments need to be prioritised over, for example, attendance at transition reviews. The Lead Professional would have their own role to fulfil as well as taking on this additional function through the transition period. Evidence heard by the Select Committee indicates that, where dedicated Transition Worker posts exist or have existed, the capacity to work with young people in transition and their families is already stretched to the limit.

13.8.8 There will need to be a careful consideration of the capacity of a nominated Lead Professional to focus on the move to adulthood. This focus has been effectively provided by Adult Social Services’ involvement early on, enabling planning processes to link with different sources of adult service provision from in-house and other sectors.

13.8.9 Pilot schemes are in operation in 15 Local Authorities until April 2008, to evaluate Lead Professionals as budget-holders. This would enable the Lead Professional for a child or young person to purchase services in response to a crisis, or to meet a planned-for need. This method of funding could contribute to seamless transition to adulthood for a small number of young disabled people and others with significant needs as described in paragraph 13.8.3 and elsewhere in this report, by avoiding the immediate need to meet eligibility criteria in order to obtain a service.

Recommendation 10

That individuals identified as Lead Professional for young people in transition to adulthood have the capacity to undertake the function and are provided by KCC and partners with training and support.

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[111] Joanna Wainwright, Director Commissioning (Specialist Services)
[112] Gillian Wills, Chief Executive, Royal School for Deaf Children

14 Independence and Choice

14.1 Direct Payments

14.1.1 Direct Payments (DP) were introduced by the Community Care (Direct Payments) Act in 1996. They are a form of self-directed support, designed to promote independence, choice and inclusion for disabled people by enabling them to purchase support or equipment of their own choice. DP are given as cash payments in place of the assistance that would otherwise have been given by Social Services following a community care assessment by Children's or Adult Social Services. The offer of Direct Payments following such an assessment (on meeting eligibility criteria) was made mandatory by the Health and Social Care Act 2001, effective from April 2003.

14.1.2 DP can be made to the parents of a disabled child or young person until the young person reaches 18; directly to a disabled young person aged 16 or 17, or to a carer. Kent has developed a 'Kent Card' as one method of receiving and spending the funds. It can be used like a bank debit card with the added advantage of providing an automatic record of purchases, reducing the burden of administration for the individual. Under current legislation, Direct Payments provided by a Local Authority cannot be used to purchase services from that Authority.

14.1.3 A support scheme was set up by KCC to offer free information, advice and advocacy to people who are considering the use of, or already using DP. The Select Committee learned that 862 people in Kent were in receipt of Direct Payments at the end of March 2006[113]; including around 100 children and young people; 7 of whom are in the 16-18 age group. The latter are very poorly young people for whom trust funds have been set up in order to secure payments into adulthood. A second DP Service is currently being developed for children and young people under 18 and this is being run by the service-user and parent led organisation Parents' Consortium to ensure that it is completely responsive to the needs of disabled children, young people and their families. The new scheme is initially basing its workers alongside the established (adult) scheme in order to share and benefit from the expertise already developed.

14.1.4 Usage of the Direct Payments Website indicates that there is a high level of interest in the scheme and the steady increase in uptake (so far mainly by adults) is shown in Chart 3 on the next page. Figures given are 'snapshots' and many more people will have received Direct Payments, including one-off payments, during each year. It should, however, be acknowledged that Direct Payments have impacted on social care budgets, for example, where people who did not previously opt to receive a service have chosen to take advantage of Direct Payments. There is a further potential impact on Children's Social Services, who have invested in developing services which may not be purchased with Direct Payments.

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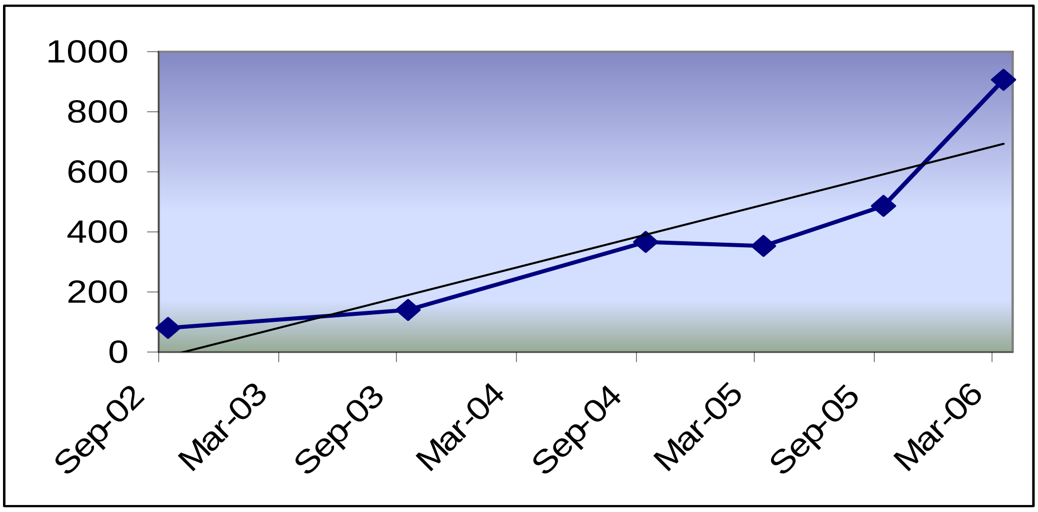
[113] KCC Performance Review Report

Chart 3: The number of people in receipt of Direct Payments[114]



14.1.5 DP have been used successfully by some 'knowledgeable' parents, for example, to purchase respite care from outside KCC but there is a need for clear and concise information about the range of local resources from which young people and their parents can choose. (This links to an earlier recommendation regarding the provision of information).

14.1.6 The Select Committee heard that some parents had been incorrectly informed about their entitlement to Direct Payments. However, DP have yet to become fully 'embedded' among children's service providers, and there is a need to raise the level of awareness of the DP Scheme.[115] More families and young people might consider using DP if they were introduced to the concept at year 9 transition reviews[116] and this would be most effective if the topic could be explained by a peer-mentor or other expert. Kent's Support Scheme already encourages peer-networking both in person and via the internet. Earlier use of DP would help to prepare young people for greater independence in adulthood.

14.1.7 Highlighted by the development of a separate children's Direct Payment service, is the need for continuity across the transition period. Two anomalies in the system relating to personal assistance were highlighted to the Select Committee:-

- a need for parity in the rates of pay for personal assistants across Children's and Adult Social Services;

- the fact that young people with Asperger's syndrome (high functioning autism) might receive Direct Payments up to the age of 17 for personal assistance then become ineligible for similar assistance on reaching the age of 18. Adult Learning Disability Services are currently limited to people with an IQ (Intelligence Quotient) of below 70.

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[114] Data from KCC Performance Monitoring Team
[115] Carrie Johnson, Special Needs Activities and Advisory Project
[116] Louise Watch, Direct Payments Co-ordinator

14.2 'In-Control'

14.2.1 In-Control is a form of self-directed support, being piloted and developed across England and Scotland as a result of collaboration between disabled people and their families, central and local government, service providers, charities and other organisations. It enables a disabled person (regardless of disability) to take control of their own social welfare and represents a major shift in the way social welfare is managed.[117]

14.2.2 This model is being piloted nationally and is likely to be available in Kent in the near future. It is based on 7 ethical principles[118]:-

- the Right to Independent Living

  'I can get the support I need to be an independent citizen.'

- the Right to an Individual Budget

  'I know how much money I can use for my support.'

- the Right to Self-Determination

  'I have the authority, support or representation to make my own decisions.'

- the Right to Accessibility

  'I can understand the rules and systems and am able to get help easily.'

- the Right to Flexible Funding

  'I can use my money flexibly and creatively.'

- Accountability Principle

  ' I should tell people how I used my money and anything I've learnt.'

- Capacity Principle

  'Give me enough help, but not too much; I've got something to contribute too.'

14.2.3 KCC is at the forefront of taking this forward nationally. Learning disabled people in Kent are developing a DVD to help others to understand the system and the benefits to be derived from it.[119]

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[117] Des Sowerby, Joint Director, Learning Disabilities (Adult Services)

[118] In producing this report KCC acknowledges its adaptation of materials produced by in Control (www.in-control.org.uk)'.

[119] Des Sowerby, Joint Director, Learning Disabilities (Adult Services)

14.2.4 An individual will assess the level of practical help and support needed using a points system and the 'value of a point' can be calculated on available resources and converted to money. Under this system, a person eligible for social care, would know from the start how much money they have to spend on what could be a mixture of external and in-house support and this could be funded using Direct Payments or another method.

14.2.5 In the event of a disagreement about support between a disabled person and their carer, the support can be brokered. A Care Manager would undertake a Carer's Impact Assessment. Care Manager roles would change[120] but in the event of a planned package not proving successful there is always the option for the disabled individual to opt for traditional care planning, which would exist as a safety net.[121]

14.2.6 Pending the availability of In-Control, which should enable more people to access self-directed support, as noted in 14.1.6, awareness of and uptake of Direct Payments could be increased by introducing them to young people likely to need Adult Social Services, early on. This would be facilitated by developing the knowledge base of the workforce and supporting the county-wide initiatives for better provision of information.

Recommendation 11

That KCC, schools and other partners promote the use of Direct Payments by young people whose social care needs will extend into adulthood, by raising awareness and understanding of Direct Payments among CFE staff and ensuring that Direct Payments are discussed (with the involvement of a peer-mentor or Direct Payment Support Worker/Adviser where possible) as part of transition planning from Year 9 onwards.

14.3 Kent Supported Employment (KSE)

14.3.1 KSE has developed within Adult Social Services to support disabled people into meaningful employment. It is an inclusive scheme, working for example with young people leaving care. Currently the scheme supports around 700 people each year through its partnership work with organisations such as Focus to Work Trust, Sunlight Plus, Royal British Legion Industries (Employment Solutions), Connexions and Job Centre Plus. Job Centre Plus approves referrals to the scheme from all sources though most come through Connexions. Currently referrals are routed through Adult Social Services Learning Disability and Promoting Independence Teams and consequently KSE does not become involved in transition planning for young people, though this would have clear benefits. There have been informal links with schools which were very useful and could be strengthened.

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[120] Michael Thomas-Sam, Head Of Policy And Service Development

[121] In-Control website: http:\\ www.in-control.org.uk

14.3.2 The Scheme's funding is complex. Support is received from KCC, Job Centre Plus and the European Union Equal Programme. There is also a project jointly funded with the Learning and Skills Council for young disabled people from the age of 16. A simplification of funding streams would enable a more flexible approach to service provision.

14.4 Supported employment and peer-mentoring

14.4.1 The Select Committee has heard a range of evidence which demonstrates the value of peer-mentoring and peer-support of disabled young people by disabled and non-disabled peers whereby groups of young people of similar ages are brought together in a creative way. These ideas have emerged independently, in the context of leisure, person-centred planning, advocacy and school-based informal sessions to promote understanding of Direct Payments, employment and other opportunities.

14.4.2 It has become clear that there are benefits to be derived from the development and formalisation of such schemes since they have the potential to:-

- foster a climate of understanding and contribute to inclusion;
- increase opportunities for both mentors and mentees;
- provide positive role-models to disabled young people and their families and/or carers;
- enable young disabled people and their families to become familiar with new situations, services (such as the Direct Payments Scheme) or environments with the aid of a 'buddy';
- increase independence.

14.4.3 A scheme which combined the provision of meaningful employment with the benefits noted would convey a powerful message; bringing disabled people into schools in a way that '*focuses on the positive contribution disabled people make to the world, as well as raising conventional disability awareness*.'[122] Such a scheme could build upon the work with schools of District Partnership Groups, the Direct Payment Support Scheme and other initiatives.

Recommendation 12

That KCC, through Kent Supported Employment and its partners, explore the potential of a programme whereby disabled young adults are employed as peer-mentors to assist with transition planning in schools and elsewhere.

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[122] Des Sowerby, Joint Director, Learning Disabilities (Adult Services)

Appendix 1 – Oral Evidence

The following witnesses gave oral evidence to the Committee in a series of Hearings.

1. 26 October 2006

Gordon Bernard, Chief Executive and Justine Croft, Learning Difficulty and/or Disability Co-ordinator, Connexions

2. 1 November 2006

Louise Watch, Direct Payments Co-ordinator

Carrie Johnson, Project Manager, SNAAP (Special Needs Advisory and Activities Project)

Alan Milner, Services Director, Parents' Consortium

3. 10 November 2006

Des Sowerby, Joint Director – Learning Disabilities (Adult Social Services)

Michael Thomas-Sam, Head of Policy and Service Development (Adult Social Services)

Gordon Boxall, Chief Executive, MCCH

4. 16 November 2006

Greg Gibbins, Transition Worker, Canterbury and District Adult Social Services Learning Disabilities Team

Caroline Baker, Senior Practitioner, Tonbridge Disabled Children's Team (Children, Families and Education) and John Moore, Care Manager, Tunbridge Wells Adult Social Services Learning Disabilities Team

Kathy Melling, Group Manager, Social Economy and Supported Employment Unit (SESEU)

5. 6 December 2006

Andrea White, Specialist Teaching Services Manager

Tim Fox, Children Educated at Home Co-ordinator

Mick McCarthy, County Manager, Rainer Kent and Steve Lines, Mental Health Specialist, Rainer Kent

6. **13 December 2006**

David Waggett and David Le Breton, Learning and Skills Council

Mark Surtees, Hampshire County Council

7. **19 December 2006**

Linda Baker, Partnership with Parents

Diane Robinson, Senior Inclusion and Achievement Adviser; Allan Foster, Lead Curriculum Adviser and Subject Adviser for PSHE

8. **20 December 2006**

Joanna Wainwright, Director Commissioning (Specialist Services)

Liz Totman, Head of Specialist Services and Rose Dillon

Lut Stewart, Director of Student Support Services – Canterbury College and Daniel Lewis, Headteacher, St Nicholas School, Canterbury

Beryl Palmer, Sensory Disabilities Manager, Adult Social Services

Appendix 2 – Written Evidence

Andrew Ross, Tadworth College

Camilla Khanna, Graduate

Christopher Robertson, Lecturer in Inclusive and Special Education, University of Birmingham

David Abbot, Nora Fry Research Centre, University of Bristol

Debra Cooney, Project Manager, Disabled Children

Dr Pauline Heslop, Nora Fry Research Centre, University of Bristol

Gary Forde, Diversity Manager, Youth Service)

Gillian Wills, Chief Executive, Royal School for Deaf Children

Jo Kidd, Skillnet Group

Lewis Perkins, MENCAP

Marlene Morrissey, County AEN Manager

Maurice Harker, Housing Options

Royal London Society for the Blind, Lesley Morris, Educational Support Services Manager

Sandie Howard, Transition Nurse, Services for Children with Learning Disabilities and Challenging Behaviour (LDCB) Team

Sheelagh Smith, Independent Consultant

Tim Pethybridge, parent

Young people, parents and carers who responded to questionnaires

Supplementary evidence was received from:

A number of KCC Officers, including particularly Dawn Holroyd and Sue Snooks, Children's Disability Register Co-ordinators and Liz Piper, Team Manager, Learning Disabilities Team, Tunbridge Wells Adult Social Services

Young people, parents and carers who assisted the review with the help of Gwen Kidd, Fostering Social Worker

Visit

17th January 2007: Visit to Youth Centre, run by Parents' Consortium in Hextable, by Mrs Hohler, Mr Koowaree and Mr Maddison.

Appendix 3 – Glossary of Terms and Acronyms

Advocate	Someone who is able to speak on someone else's behalf
AEN	Additional Educational Needs (term more commonly used now than 'special educational needs'
Assessment of Children in Need and their Families	A Framework used by Social Services to systematically analyse, understand and record what is happening to children and young people within their families and wider community. It enables professional judgements to be made, including of whether the child is in need.
Care Plan	Document drawn up as a result of consultation between Social Services and the young person and their family showing the ways in which services will meet the young person's needs.
CIN	Child in Need
Community Care Assessment	The process by which a local authority determines whether a person needs services and whether his needs call for provision to be made.
Complex Needs	This includes young people with medical conditions, high support needs, behavioural problems and/or learning difficulties
CP	Child Protection
CPA	Connexions Personal Adviser
DCS	Director of Children's Services
DAS or DASS	Director of Adult (Social) Services
'in Control'	A form of self-directed support being developed by national and local government in partnership with disabled people and various organisations.
LA	Local Authority
LAC	'Looked After Child' – a child in the care of the Local Authority (may also be referred to as a 'child in care')
LDD	Learning difficulty and/or disability Defined in the Learning and Skills Act and used by Connexions
Learning Difficulty	Defined in the Education Act 1996 regarding a person having 'significantly greater difficulty in learning than the majority of persons of his age, or .. a disability which either prevents or hinders him from making use of facilities of a kind generally provided … for persons of his age.'

Learning Disability	Lifelong neurological disorder (difficulty reading, writing, spelling, reasoning, recalling or organising information) Example: dyslexia.
LSA	Learning and Skills Act (2000)
LSC	Learning and Skills Council
NEET	Not in education, employment, or training
PCP	Person-Centred Planning
PSHE	Personal, Social and Health Education
PwP	Partnership with Parents – organisation funded by and working at 'arms length' to KCC which provides mediation, a helpline and other information and advice to parents, carers and schools regarding special educational needs
School Action (SA)	Additional or different action within school or setting to enable independent learning and curriculum access.
School Action Plus	Builds on SA[123] with co-ordinated action and identified outcomes for the school, the service(s) and the pupil.
SEN (Special Educational Needs)	Covers many conditions including autism, Asperger's syndrome, ADHD, dyslexia, dyspraxia, behavioural difficulties and physical disabilities
Transition Plan	Document drawn up at the Year 9 review and updated at subsequent annual reviews which sets out the steps to address the young person's needs when they leave school.
Transition Review	The review of a Statement in Year 9 of schooling which begins the transition planning process.

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[123] or Early Years Action

Appendix 4: Legislation - overview

Chronically Sick and Disabled Persons Act 1970
Section 2 lists various services, and if a need for any of these services is assessed under the Disabled Persons Act, Social Services must ensure these needs are met.

Disabled Persons (Services, Consultation & Representation) Act 1986 (Sections 5 & 6)
Local Authorities (LAs) must seek information from Social Services to determine whether a young person with a Statement is disabled and may need services from the LA as an adult. The duty is to offer an assessment (before the young person leaves school). If parents object to a home visit, social and health services must still give an opinion. The Children Act 1989 outlines how this assessment should not duplicate but be in tandem with other reviews such as the statutory review of a child in care; annual education review; now under the Education Act 1996, or review of an Individual Education Plan.

The Children Act 1989
Requires LAs to provide support services for a new category of children 'in need' including disabled children; to keep a register of disabled children; to identify the level of need in the LA area; to ensure that the services available are publicised; to promote inter-agency working and facilitate service provision by independent providers.

NHS and Community Care Act 1990
Entitles young people in transition to adulthood to an assessment of their needs (which they can decline). It makes LAs responsible for the co-ordination, planning, assessment and provision of services for the health and social care of adults.

Carers Recognition and Services Act 1995
Gives parents/carers the right to an assessment of their own needs.

Disability Discrimination Act (DDA) 1995
Says you are disabled if you have a mental or physical impairment; this has an adverse effect on your ability to carry out normal day-to-day activities; the adverse effect is substantial and the adverse effect is long-term (meaning it has lasted for 12 months, or is likely to last for more than 12 months or for the rest of your life).

Community Care (Direct Payments) Act 1996
Introduced the power for Local Authorities to make Direct Payments to individuals as a way of making services more flexible and responsive.

Education Act 1996

States that a child with special educational needs (SEN) should be educated in a mainstream school provided his own needs can be met without adversely affecting his peers and with an efficient use of resources.

Carers and Disabled Children Act 2000

Enables LAs to provide Direct Payments rather than services to parents of disabled children and to disabled 16 and 17 year olds. Carers can also receive services and the social needs of the family are given greater consideration for example with a voucher scheme to enable short-term respite breaks.

The Health Act 2000

Allows one agency to fund another to provide services e.g. health can fund Social Services to provide a service to a disabled child and their family.

The Children (Leaving Care) Act 2000

Specifies that the needs of disabled young people must be taken into account in preparing them for leaving care and providing aftercare. Adult Social Services should be included in the pathway planning process to ensure a smooth transition from Children's to Adult Social Services. Social Services Departments must take account of any transition plan drawn up under the SEN Code of Practice.

Learning and Skills Act 2000

The National Learning and Skills Council (LSC) replaced the Further Education Funding Council, becoming responsible for planning and funding post-16 education. Section 140 of the Act places a power and a duty on the Secretary of State to make arrangements for the assessment of young people with learning difficulties and/or disabilities (LDD) when they are undertaking or likely to undertake post-16 education, training or higher education. Connexions Partnerships will deliver this responsibility. It requires the LSC to have regard to the needs of young people with LDD and to any report of an assessment carried out under Section 140. It also sets out the reasons for seeking a specialist residential placement.

White Paper 'Valuing People: A New Strategy for Learning Disability for the 21st Century'

Published in 2001, this was the first White Paper on learning disability for 30 years. It said that there should be effective links between children's and adult health and Social Services and set out

> '*an expectation that all local services should have introduced person-centred planning for all young people moving from children's to adult services by 2003. It also requires Learning Disability Partnership Boards to identify a member with lead responsibility for transition issues, who will work with the Connexions Service to ensure effective joint working.'*

SEN Code of Practice 2001

The Education Act 1993 placed a duty on the Secretary of State to issue a Code of Practice and the power to revise it (this revised the 1994 code). It provides advice to LAs, maintained schools and others on their statutory duty to identify, assess and provide for children's special educational needs. It sets out the transition planning process for young people with special educational needs and gives a number of specific statutory duties to headteachers and Connexions. It also states that the Connexions Action Plan, transition plan and pathway plan (where there is one) should be the same, not separate documents.

Special Educational Needs and Disability Act (SENDA) 2001

Amends the Education Act 1996 and the Disability Discrimination Act 1995. It applies to education up to and after age 16 and makes it illegal to treat a disabled person less favourably because of their disability, without justification. It requires reasonable adjustments to be made for disabled students so they are not substantially disadvantaged. It applies to higher and further education establishments, and youth services; not Connexions or training providers which are covered by Disability Discrimination Act (DDA).

Health and Social Care Act 2001

Effective from April 2003, gave LAs the duty rather than power to make Direct Payments instead of providing services to those requesting them and who meet criteria.

'Every Child Matters' and Children Act 2004

Sets out the new framework for universal children's services under 5 key outcomes: be healthy, stay safe, enjoy and achieve, make a positive contribution and achieve economic well-being. It lays the foundations for children's service providers to work together in partnerships called Children's Trusts, sharing information to provide greater protection, at the same time giving children and young people a greater say. It created the role of Director of Adult Social Services (DASS) and provided statutory guidance to the Director of Children's Services (DCS) and Lead Member for Children's Services, directing them to work closely with the DASS. The Act extends the 0-19 remit up to age 25 for young adults with a learning difficulty, who is receiving services under the Learning and Skills Act.

National Service Framework for Children, Young People and Maternity Services 2004

Sets out five standards for Local Authorities, Health and partners to ensure quality service for children, young people, parents and carers. Standard 8 looks at transition for young people with complex health needs focusing on:

- person-centred planning
- multi-agency transition groups
- Direct Payments
- support for those with high level needs e.g. children in care
- development of local strategies for education, training and employment of disabled young people

- development of adolescent health services

Improving the Life Chances of Disabled People Final Report 2005
This built on previous projects and analyses; recognising and identifying the reasons for poor outcomes experienced by disabled people. Its vision was to ensure that disabled people have full opportunities and choices as equal members of society, by 2025. It covers independent living, early years and family support, transition to adulthood and employment. On transition it identified three key areas of support:

- planning based on individual needs
- continuous service provision
- access to more transparent and appropriate menu of opportunities and choices

Green Paper Independence, Well-being and Choice: Our vision for the future of social care for adults in England 2005
The Green Paper, a consultation document, set out a vision for adult social care in the next 10-15 years. It focused on 7 key outcomes: improved health; improved quality of life; making a positive contribution; exercise of choice and control; freedom from discrimination and harassment; economic well being and personal dignity. It proposed a key role for the Director of Adult Social Services in improving transition planning.

Disability Discrimination Act 2005
The Act says that public authorities should eliminate discrimination and harassment of disabled people; promote equality of opportunity, taking account of disability (even by treating disabled people more favourably); promote positive attitudes towards disabled people and encourage their participation in public life.

White Paper Our Health, Our Care, Our Say: a new direction for community services 2006
The White Paper confirmed the vision of good quality social care and NHS services provided in local communities as set out in the Department of Health Green Paper, Independence, Well-being and Choice. It introduced a new role of Practitioner with Special Interests and proposed pilot roles for adolescent health (likely to focus on disabled children in transition to adulthood).

Childcare Act 2006
Covers the duty to provide information, advice and assistance for parents of children aged 0-19. Focuses on childcare services for younger children but makes provision for vulnerable groups including disabled children and makes particular reference to information about the transition of disabled young people to adulthood.

Appendix 5: Extract from ‘Towards 2010’ – Target 55 on Transition

‘Ensure better planning to ease the transition between childhood and adulthood for young people with disabilities and to promote their independence’.

Why is this a priority for action?
Growing up, leaving school and learning to become independent is a challenge for all young people. But for young people with disabilities it can be harder still, and we need to ensure that the right support is available to enable them to be as independent as possible. If we get it wrong, there is a danger that they will not achieve their potential or the quality of life that they are capable of having. We want to make the transition experience better and to enable young people to live as independent adults.

What have we done so far?

We have strong processes in place for transition planning but feedback from our service users demonstrates that transition planning needs to be further improved for young people with disabilities and their families. The following are now in place:

- We have established a working group which involves Health, Education, Social Care, Connexions and the Learning and Skills Council to improve service planning and the delivery of education, social care and health services.

- All the partner organisations have signed up to a common set of key principles and values which will inform how we would improve services for young people with disabilities.

What extra work will we need to do between now and 2010? We will:

- improve partnership working to ensure all organisations have information on all young people with disabilities who will be becoming independent.

- work with young people with disabilities and their families to make transition more integrated and tailored to individual needs.

- ensure that there is continuity of care and support for disabled children and young people which enables them to have equality of opportunity with their peers to participate in education, training and employment opportunities.

- encourage the take-up of Direct Payments, as this is becoming popular with young adults because of the flexibility and control it gives them over their lives to enable them to live independently.

- work with housing departments and associations, employers and training providers (including training in independent living) are all key elements of this target. Key partners in delivering this target include the Learning Skills Council, District Councils, Connexions, Social Enterprise and Supported Employment schemes and other voluntary and community sector partners (such as RPS Rayner (16+) and Upfront).

- ensure that the outcomes are supported by other targets particularly: listen to young people's views and opinions and develop their ideas to improve life in Kent (no.14), increase the number of people to supported to live independently in their own homes (no.52), and strengthen the support provided to people caring for relatives and friends (no.53).

What will it mean for you?

Better experiences for young people with disabilities and their families through the transition period, resulting in greater opportunities for their independent living and participation in community life.

For further information, please contact Michael Thomas-Sam, Head of Policy and Service Development in Adult Social Services (01622 694843) or Colin Feltham (Head of Additional Educational Needs and Resources in Children, Families and Education (01622 605729).

Appendix 6: Special Educational Needs – brief description

Special Educational Needs are those that are 'additional or different' to needs normally met in the classroom. The SEN Code of Practice (2001) provides the definitive guidance. It groups SEN under the following headings:

- Cognition and learning
- Behaviour, emotional and social
- Communication and interaction (including autistic spectrum disorders and speech and language difficulties)
- Sensory and Physical (including hearing impairment, visual impairment, physical and medical difficulties)

SEN covers conditions including autistic spectrum disorders, Asperger's syndrome, dyslexia, dyspraxia, Attention Deficit Hyperactive Disorder (ADHD), behavioural problems and physical disabilities.[124]

Failure to progress dictates whether action is required and then intervention at one of three levels takes place: School Action, School Action Plus, or Statutory Action (the issuing of a Statement of SEN); the latter requires the local authority to take over responsibility from the school for provision and its monitoring and review, up to age 19.

The statement of a young person leaving school between 16 and 19 may lapse, in which case, the transition plan should provide continuity by specifying arrangements agreed with parents for meeting a young person's special needs in further or higher education, or Social Services provision.

All young people educated in special schools must have a Statement. The Statements of all young people whether in special or mainstream schools must be reviewed annually and the first review of the Statement in Year 9 is a Transition Review.

Special Educational Needs are increasingly referred to as Additional Educational Needs.

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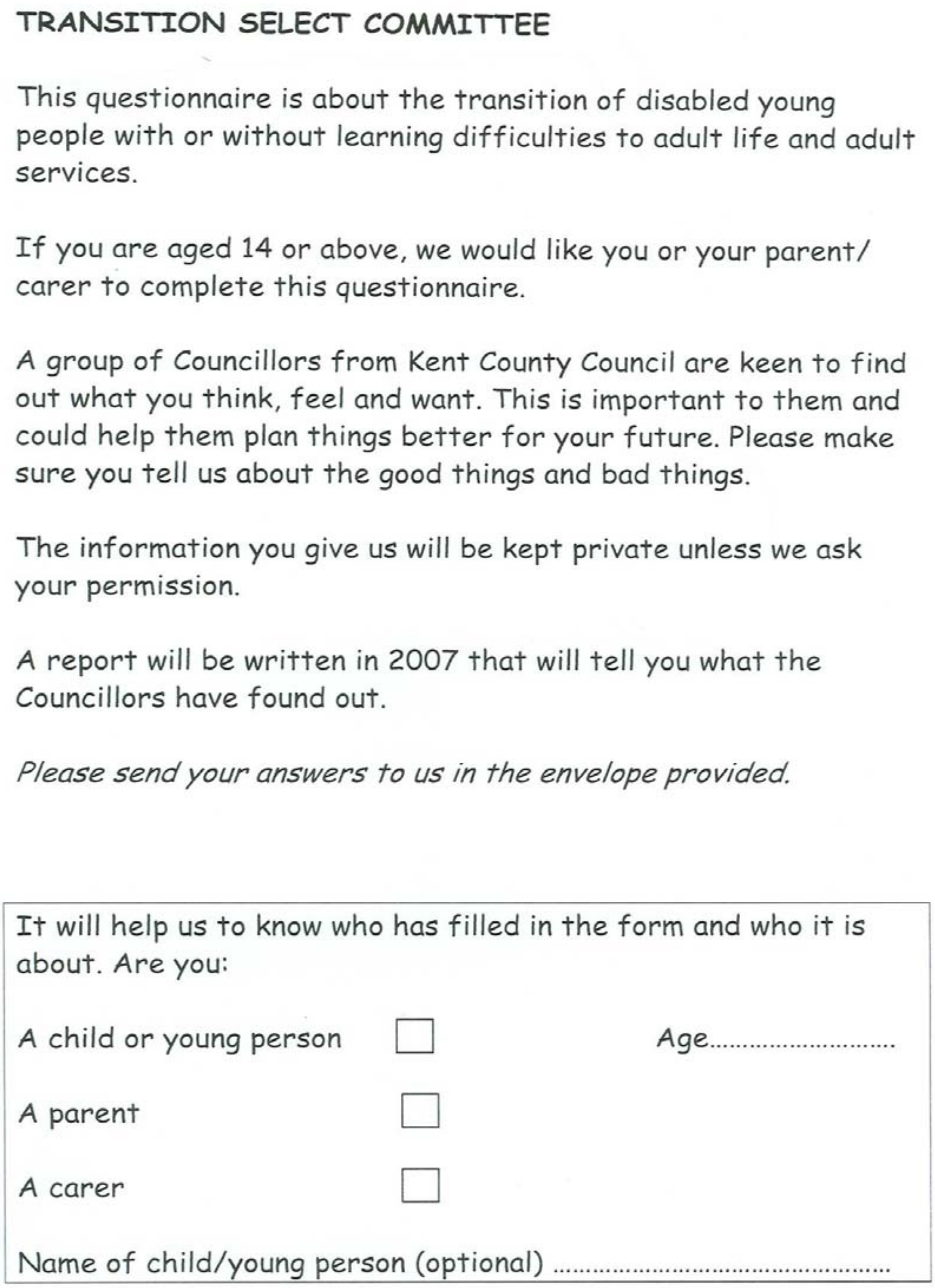
[124] House of Commons Education and Skills Committee Report, DfES (2006)

Appendix 7: Questionnaire and Summary of responses



TRANSITION SELECT COMMITTEE

This questionnaire is about the transition of disabled young people with or without learning difficulties to adult life and adult services.

If you are aged 14 or above, we would like you or your parent/ carer to complete this questionnaire.

A group of Councillors from Kent County Council are keen to find out what you think, feel and want. This is important to them and could help them plan things better for your future. Please make sure you tell us about the good things and bad things.

The information you give us will be kept private unless we ask your permission.

A report will be written in 2007 that will tell you what the Councillors have found out.

Please send your answers to us in the envelope provided.

It will help us to know who has filled in the form and who it is about. Are you:

A child or young person ☐ Age............................

A parent ☐

A carer ☐

Name of child/young person (optional) ....

QUESTIONNAIRE

1

1. Do you have a statement of Special Education Needs?

Yes ____ No ____

2

2. Do you have a transition plan (made at school in year 9 and reviewed each year) or other type of plan for your future?

Transition plan ____ Other plan ____ No plan ____

If no plan, please go to question 5

If yes, when you made your plan, did you feel your views and wishes were listened to?

Yes ______ No ______

3

3. Who came to your review and helped you make your plan?

Someone from school Yes ___ No ___

Someone from Connexions Yes ___ No ___

Someone from Social Services Yes ___ No ___

Someone from health Yes ___ No ___

Others (please tell us who)

____

4

4. Are you happy with the plan for your future?

Yes ______ No ______

If no, please tell us what you are unhappy about?

____

5

5. Have you started to plan about things like:

Where you will live Yes ___ No ___

What kind of support you will need Yes ___ No ___

Any equipment you might need Yes ___ No ___

Any benefits you might receive Yes ___ No ___

Who will help you Yes ___ No ___

6

6. Do you receive a service from Social Services?

Yes ___ No ___

If yes, do you know about Direct Payments?

Yes ___ No ___

AND FOR PARENT/CARERS:

7

7. Have you had an assessment of your own needs as a carer?

Yes ___ No ___

Please use this page to tell us in a few words:

Things that have made me happy when growing up

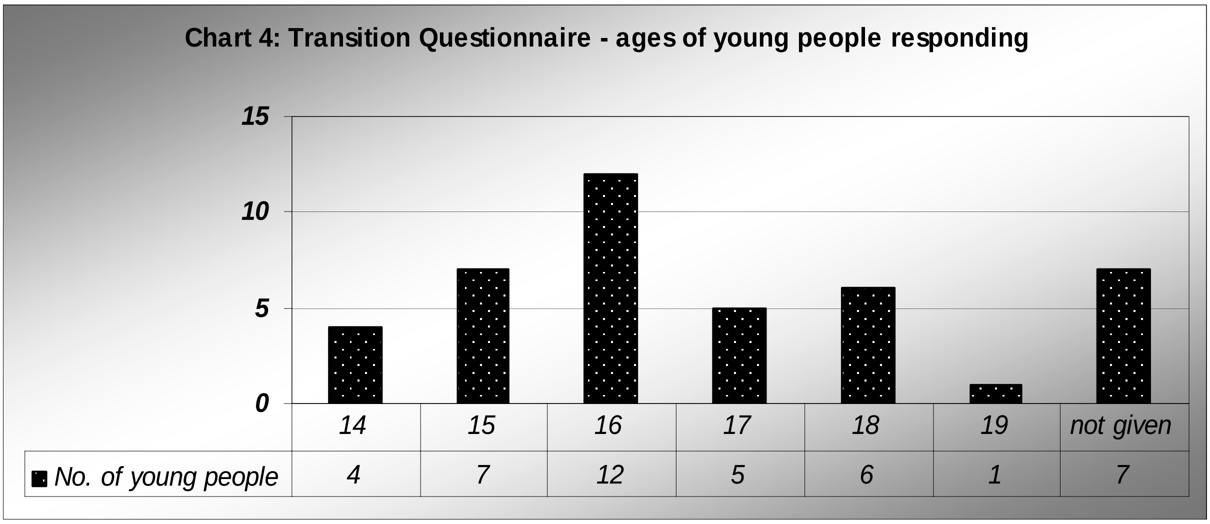
Things that have made me unhappy when growing up

Thank you very much for helping with this: There is a prepaid envelope with this questionnaire for your return

(Questionnaires were sent out via Parents Consortium in Hextable and SNAAP in Canterbury to families of young disabled people aged 14 - 19)

Summary of responses:

Responses were received from 42 young people whose ages are shown below in Chart 4.



Not all young people were able to respond for themselves; 13 (31%) did so, the remaining 29 (61%) were completed on the young person's behalf by a parent or carer.

Q1 37 (88%) of the young people had a Statement of Special Education Needs and the remaining 5 (12%) had no Statement.

Q2 22 (52%) young people had a Transition Plan, a further 2 young people (5%) had another type of plan for the future and 18 young people (43%) had no plan for the future.

Of those young people with a Transition or other type of plan, the majority; 22 (92%) said they felt their views and wishes had been listened to when the Plan was made.

Q3 Those having a Transition plan were asked who attended their Transition Review to help make the plan. The level of agency involvement varied. It is not known whether reports were sent by other agencies nor can it be commented upon whether the attendance of other agencies was desirable or if they were invited.[125] Results are shown in Table 1 below:

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[125] Some parents may not have thought to list themselves under 'other'.

Table 1: Attendance at Transition Reviews

School	2
Social Services	1
School, Connexions	7
School, Social Services	1
School, Connexions, Parent	6
School, Connexions, Social Services, Foster Carer	1
School, Connexions, Social Services, Education	1
School, Connexions, parent, speech therapist	1
Social Services, Transition Nurse, Footprints Carers	1
School, Connexions, Social Services, Health	2
Not answered	1
Total	**24**

Q4 The majority of young people who had a plan for the future were happy with it – 20 of 24 (83%). Two young people were unhappy; one would be happy if they could go to the College of their choice and one was unsure.

The parents of both young people who were unhappy noted: *'not sure what's going to happen with my son when he reaches 19 years of age'*

The young person who was unsure said they '*would like to know more about employment opportunities available and sheltered accommodation*' and also '*what happens after college*'.

Q5 All 42 respondents were asked whether they had started to plan about where they would like, what kind of support they would need, any equipment they might need, any benefits they might receive and who would help them.

11	not started any planning at all
4	had started to plan about all these aspects

For those who had begun to plan the following had been considered:

Table 2: Planning

Where you will live	15
What kind of support you will need	15
Any equipment you might need	10
Any benefits you might receive	20
Who will help you	20

It should be noted that equipment was noted as being not applicable to four respondents.

Q6 Respondents were asked whether they were in receipt of a service from Social Services – 11 (26%) received a service and 31 (74%) did not.

Of the 11 in receipt of a service, 5 (45%) were aware of Direct Payments (as were some other respondents not receiving a service.

Q7 Parents/Carers were asked if they had received an assessment of their own needs as a carer and 2 (5%) had received an assessment. This question was not answered by one respondent and another young person's questionnaire was completed on their behalf by a carer at a residential care home.

Additional Information

13 young people had Statements but no Transition Plan. This included two young people with severe autism, one of whom was also blind. Some young people had started their own plans for the future.

One young person with a transition plan answered no to all aspects in Question 5 (i.e. plan did not consider where to live, support, equipment, benefits or help).

Additional Comments and concerns from parents

- Difficulties obtaining funding for transport
- Inappropriate suspensions and isolations due to disability not being connected with behaviour
- Detrimental effect of worry on carer's health
- School is not proactive in arranging statement reviews
- 'We have completed a moving on plan for T to move into College but no plan after that – living independently.'
- 'Information (should be) more readily available, rather than have to find out for yourself including benefits, RADAR key, clubs, discounts available, changes of allowances at different ages…'
- 'We have no plan! Very worried about future and lack of info.'

Young people were asked what kinds of things had made them happy and sad when growing up and their answers are shown below.

'**Things that have made me happy when growing up'**

- Lego
- Playstation
- School successes
- Family around me
- Feeling safe and secure
- Lots of help and support at school
- 'Don't know – happy doing everything I want'
- Love and Support from my family
- 'Having a statement of Educational Needs made a huge improvement to A's well being, both at school and at home.'
- Christmas, holidays, family, friends

- Clubs, VSU, Horseriding, Little Miss Club
- Going to school, going out to places, holiday, clubs
- Going to Kidscamp – finishes at 18 – haven't tried any Adult leisure services yet.
- Help from mum and dad (2)
- School holidays with my family – swimming, playing football
- My mum letting me try out activities that I like the sound of
- My parents
- Sport
- Writing stories
- Drawing and art projects
- ICT and internet
- Using the gym
- Xbox
- My mum
- Cooking pancakes
- Relaxing, School and college
- When growing up I have had the support of my loving family, as well as wonderful grandmother (may she rest in peace), which helped me to get through some troublesome times in my childhood.
- Meet lots of people being at school and further education, going to Kidscamp has been lots of fun
- Being at home
- School
- Playstation!
- Spending time with my mum and family
- Playing outdoors
- Going to school
- Seeing my friends
- Going on holiday
- Being active
- Getting support from parents and school
- Making friends at school
- Horse riding, collecting transformers, being with my mum, Christmas
- Living with my foster carers all the time in the same family
- Pilgrims Way Primary School
- Music, my family, holidays, brothers, Christmas
- Getting EMA
- Visiting the Fortune Centre
- Being loved and well cared for
- Being given games and toys that I can enjoy playing with and learn at the same time
- Going to schools where I have had 1-1 care and help
- Now I am in a bigger school, where I am learning to experience a lot of activities that I had not seen before
- Having a very supportive family
- Going out with my family, trips to the seaside or for a picnic, on the swings

Things that have made me sad when growing up:

- No friends, places to go to socialise, lack of independence
- Nothing!
- I don’t like things that I don’t understand
- I don’t like too many people around me
- I don’t like loud noises
- New experiences have to be introduced gradually
- Being in hospital
- Being away from my family, especially my mum
- Being bullied
- My parents wrapping me in cotton wool
- No friends after school, nowhere to go with my mum
- Thinking about leaving school
- Having to face new challenges
- Finding school work hard
- Difficulty making friends
- [Teacher’s name]
- Clowns
- PE
- Nearly losing my brother in a fire
- My pet dog getting dognapped in the woods
- Scalded when younger by mum (not now the carer)
- Going away to boarding school to meet special needs
- Felt let down by system (parent)
- Fight for travel assistance to school
- Fight for DLA
- More information for carers needed
- Bullying
- Not enough facilities available for me
- Not enough support for my parents
- My sister being annoying
- Some people are not nice
- That my mum has to fight for everything for me (education, respite, etc)
- Having to wash my hair and going to school
- Getting out of bed
- Lack of resources for children who find school ‘difficult’
- People who don’t understand my difficulties and cause offence by their ignorance
- Not going out with friends on my own
- Leaving my school
- Being bullied
- Death of people I know
- Alternative curriculum does not always work
- Who checks up on pupils doing permanent work experience – the school showed little interest
- No transitional review took place in year 11
- No one seemed to care – out of sight, out of mind.
- Social isolation due to a lack of appropriate leisure activities (as A’s parent I found that, because A’s difficulties were considered ‘moderate’, he was excluded or ineligible for help, as only the ‘severe’ needs were catered for, although he was

not ‘able’ enough to access mainstream activities. The Parents Consortium provided A’s only social activities, but the needs of these ‘in between’ children were not adequately met when A was younger.

- Bullying from less understanding children who judge me before they try to get to know me is a big problem.
- My brother going away to university
- It is impossible to plan for the future until we know if we have funding for College.
- Not seeing my friends when on school holidays because they live too far away
- Having fits
- Having no-one to play with
- People don’t want to mix with me as I am disabled
- Not seeing my dad for 2 years
- I have missed having company. I don’t have any brothers and sisters or friends at school or near where I live. All the clubs offered to people like me – or the support groups for my mum, are never near where we live. Sometimes I feel too disabled to join in things or I am not disabled enough. (From mum: we hear about clubs and support groups etc., but timings are usually bad as I work. We are not happy about just ‘turning up’ at things when we don’t know people. More 1-1 before (home visits maybe?) would be nice.
- Happy with plan but – I am at school until 19 years so hope at my annual review next year 2007 there will be more talk of adult placements and my choices.
- People being horrible, finding it hard to make friends out of school hours, not being able to go places with my friends, having to have an adult with me at all times.

Appendix 8: Criteria for receiving services from Children’s Social Services

Disabled children and young people fall into two broad groups: those with health or development needs and those with severe or profound disabilities.

Children and young people with health or developmental needs may include those presenting with the following difficulties not in conjunction with a profound learning, communication or physical disability:

- behavioural problems;
- Attention Deficit Hyperactive Disorder (ADHD) or Attention Deficit Disorder (ADD);
- mental health difficulties;
- specific learning difficulty, e.g. dyslexia, dyspraxia;
- where the primary need is assessed as relating to social factors e.g. parenting difficulties or difficulties with siblings.

Kent Children’s Social Services (CSS) have developed a Child in Need Matrix as an aid to determining the threshold for intervention. CSS will only become directly involved where it is clear that there is high level of need.

Kent CSS also provide a specialist service for children with severe or profound disabilities and to be eligible for this service the child or young person must have a disability that is permanent or long term and meets at least one of the following criteria:

- severe or profound learning disability;
- severe or profound physical disability;
- significant or profound sensory disability;
- complex medical needs or long term condition expected to disable the child for more than one year;
- life threatening illness;
- severe communication disabilities or behavioural difficulties related to the child’s disability (e.g. autism);
- severe developmental delay;
- combination of disabilities, which individually are not severe but together cause as much stress as a very severe disability;
- diagnosis of deafness.

Children's Social Services hold Child in Need and Child Protection cases until the young person reaches 18. Kent's Looked after Children, apart from those managed within the specialist Disabled Children's Service, transfer to the 16plus Service (Rainer Kent) at 16.

Appendix 9: Seven principles for effective transition planning devised by East of England Connexions Partnerships in 2004

1. Multi-agency work to be established through the development of protocols ensuring shared understanding of transition.

2. Each stage of assessment and planning should inform the next.

3. Clarity about Health professionals' role is essential.

4. Young People must be prepared for their reviews so that they can take a lead role.

5. Parents must be helped to understand the transition planning process and the roles of those involved and to be aware of the options open to the young people before the review in Year 9.

6. Reviews should provide a supportive and comfortable structure so that young people and their parents or carers feel able to contribute; adequate time must be devoted to transition planning.

7. Young people need access to curriculum activities, role models and other outside activities that raise their aspirations and encourage them to feel positive about their potential and their future opportunities.

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Acknowledgements

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Transition to a Positive Future Select Committee
April 2007