

EAST SUSSEX **JOINT AGENCY TRANSITION POLICY AND** **PROTOCOL FOR DISABLED YOUNG PEOPLE**

1. Purpose

This policy and protocol document aims to make explicit the planning and review processes for young disabled people to support their move from adolescence to adulthood, ensuring a smooth transfer from children's to adult services.

2. Scope

This process relates to children and young people aged between 13 and 25 years, who are resident in East Sussex and are disabled (the definition under Section 17 of the Children Act applies)¹.

This includes children and young people whose:

- disability is permanent and substantial and which impacts adversely on their daily life
- development is significantly impaired and who need to receive significantly more personal care and supervision than children without disabilities of similar age and circumstances.

The majority of disabled children will have a statement of special educational needs under the Special Educational Needs Code of Practice. However not all children who have a statement are disabled.

The focus on inclusion within education settings means that disabled children are increasingly having their educational needs met in mainstream schools and may not have a statement. It is important therefore that these children and young people are also identified within the transition planning process.

3. Legislation

The legislative framework for young people with disabilities is complex and there are numerous requirements to take into account from different pieces of legislation:

- ❖ The Children Act 1989
- ❖ The Chronically Sick and Disabled Persons Act 1970

¹ 'A child is disabled if he is blind, deaf or dumb or suffers from mental disorder of any kind or is substantially and permanently handicapped by illness, injury or congenital deformity or other such disability'. Children Act S17 (11)

- ❖ Disabled Persons (Services, Consultation and Representation) Act 1986
- ❖ The NHS and Community Care Act 1990
- ❖ The Education Act 1993
- ❖ The Special Educational Needs Code of Practice 2001
- ❖ Human Rights Act 1998
- ❖ The Carers (Recognition and Services) Act 1995
- ❖ Carers and Disabled Children Act 2000
- ❖ The Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2003
- ❖ Children (Leaving Care) Act 2000
- ❖ Disability Discrimination Act 1995
- ❖ Special Educational Needs and Disability Act 2001
- ❖ Health & Social Care Act 2001
- ❖ Learning and Skills Act 2000

4. Values and Principles

Government policy as a whole and the Valuing People White Paper in particular places an emphasis on the need to develop services for vulnerable people in their own communities and to limit the use of residential or nursing home care to those situations where it is unavoidable. Government expects Social Services Departments to develop a range of provision that promotes independence, maximises the opportunities available to those that need support and improves access to housing, employment, education and leisure activities.

The following values and principles inform this document:

Children in Need

Disabled children are 'children in need' and are therefore entitled to an assessment of their needs and the provision of services to safeguard and promote their welfare. As stated in the Children Act children with disabilities are children first and as such are entitled to the same services as other children. Services should be designed to enable disabled children to live as normal a life as possible.

Adult Status

At the age of 18 years, all people, regardless of disability, legally gain adult status. It is important that the adult status of people with disabilities and in particular, people with learning disabilities, is recognised and reinforced.

Individuals mature at different rates and have different cognitive and functional abilities, and therefore the availability of continued support and guidance to help in decision making and the exercise of rights is important. Some family carers may also need support to develop awareness and

acceptance of their son or daughter's status as an adult, their role in protecting them and the potential change in the parent/child relationship.

Valuing People

'Valuing People' introduces four key principles of Rights, Independence, Choice and Inclusion for all people with learning disabilities, backed up by national objectives for services and supported by targets and performance indicators. Valuing People acknowledges that Transition can be a particularly difficult process for disabled young people and their parents and carers. One of the objectives in Valuing People specifically focuses on support for families with disabled children and their needs at Transition.

Valuing People Objective 2: Transition into Adult Life

'As young people with learning disabilities move into adulthood, to ensure continuity of care and support for the young person and their family; and to provide equality of opportunity in order to enable as many disabled young people as possible to participate in education, training and employment'.

By:

- 'Ensuring that each Connexions partnership provides a full service to learning disabled people by identifying them, deploying sufficient staff with the right competencies and co-ordinating the delivery of appropriate supports and opportunities'.
- 'Ensuring effective links are in place within and between children's and adults services in both health and social services'.

Social Model of Disability

The social model of disability is based on a positive view of disability that focuses on ability rather than disability. It challenges society to identify and take action to remove the barriers that prevent disabled people from taking their rightful part in the normal life of the community. This calls for all agencies to work together to address inequalities across health, education, employment housing, access, transport, sport and leisure.

5. Looked After Children

Under the provisions of the Leaving Care Act 2000, every eligible young person who is looked after by a local authority on their 16th birthday must have a Pathway Plan. This plan should build on the young person's Care and Individual or Personal Education Plans, mapping out a pathway to independence, including education, training and employment. Care leavers should also have access to a personal adviser, who will usually also take on the role as Connexions personal adviser.

6. Health Action Planning

Of particular concern for families at transition is the loss of co-ordinated health services that were previously available through school and child health services. Families often report difficulties in accessing relevant medical/healthcare information and support at transition. Meeting the needs of young people with complex health care needs is especially important – for such young people early and co-ordinated planning and service design by health professionals in collaboration with partner agencies is needed to ensure that competent and appropriate adult services replace children's provision.

The introduction of health action plans should support the continuity of health care for young people moving on to adult services. Valuing People makes the recommendation that young people going through transition should be a priority for health action planning.

7. Young People with Complex Needs

For some young people with multiple and complex needs it is not sufficient await the outcome of their individual assessment before securing the services to meet assessed need, as there will not be adequate time to make the arrangements and in some cases the services will not exist. It is therefore necessary to identify future need for these young people at least two years in advance in order to make suitable budgetary and service planning arrangements.

8. Involvement of Young People and their Carers

It is essential to involve young people and their carers in assessments and service planning. Young people should be encouraged to contribute to their annual reviews, transition plans and make positive decisions about their future. They should be given an opportunity to express their hopes and aspirations, and how these can be met. Person Centred Planning (see below) may help facilitate this.

9. Person Centred Planning and Approaches

Valuing People requires us to develop person centred approaches and person centred planning.

Person centred approaches are ways of commissioning, providing and organising services rooted in listening to what people want, to help them live in their communities as they choose. They look to mainstream services and community resources for assistance and do not limit themselves to what is available within social care services. People are not simply placed in pre-existing services and expected to adjust, rather the service strives to adjust to the person. They work to build a person centred organisational culture.

Person centred planning is a process for listening and learning, focused on what is important to someone now and for the future, and acting upon this in alliance with family and friends. PCP is used to understand a person's capacities and choices and is a basis for problem solving and negotiation to mobilise the resources necessary to pursue the person's aspirations. These resources may be obtained from a person's personal network, from service agencies or from a range of non-specialist and non-service sources.

Valuing people requires that person centred planning is introduced for all young people moving into adulthood from 2003. Some young people and their families can be supported to lead their own planning, for others a nominated worker will need to be available to support planning with the young person. What is most important is that transition plans are person centred and developed in a partnership between young people, their families, children's and adult services.

10. Direct Payments

The Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2003 require local authorities to offer direct payments to all individuals who are eligible. This includes:

- Disabled people aged 16 and over
- People with parental responsibility for a disabled child who provide or intend to provide a substantial amount of care on a regular basis for their child.

Direct payments are important at transition as they enable young people to make more decisions for themselves and provide opportunities for them to have more control over their lives.

If a parent is receiving a direct payment to support the care of their son or daughter, at the point when the young person reaches 16 a decision will need to be made as to whether it is appropriate to continue with that arrangement or for the young person to receive a direct payment in their own right. Alternatively the parent may want to consider sharing and gradually relinquishing responsibility for the management of part or the entire care package. They will therefore continue to manage some elements of the care package whilst the young person manages a proportion. This decision should be informed by the young person's transition plan.

Whatever decision is made it is important that parents are made aware that they may not continue to receive direct payments to purchase services to meet the needs of their child once their child reaches their 18th birthday. However if they plan to continue in their caring role, they may be entitled to receive direct payments as an alternative to local authority directly provided carers services under the provisions of the Carers and Disabled Children Act 2000.

If a young person is unable to manage a direct payment then at age 18 it may be possible for an indirect payment to be set up or a user-controlled trust.

11. Information

It is essential that young people and their families can access information on services that are appropriate for them at this stage of their lives and for the future. Both the Children Act and the NHS and Community Care Act require the production of information targeted at families most likely to benefit from services.

Consultation with MENCAP and family carers has identified the following information needs as essential to the success of the transition from children's to adult services:

- The transition process – role and purpose, and access routes.
- An overview of the full range of adult services, including housing options, day services, education, employment opportunities etc. It is important to explain that access to services is based on a needs led assessment.
- Realistic and complete information on service availability (e.g respite) to enable advance planning.
- Eligibility for community care services, (FACS guidance) and the potential for change for the individual that may result from differences in eligibility criteria between children's and adult services.
- Information relating to the rights and responsibilities associated with adult status, and the responsibility of the department to protect and uphold those rights, and to promote and support independence and empowerment.
- Information on eligibility for all benefits and funding opportunities, to include Independent Living Fund and Supporting People Grant.
- Information on Supporting People services available to support independent living.
- Information on person centred planning.
- Information on appropriate support networks.
- A named contact individual.
- Information on the progress of work in hand for each individual, advance information to enable thorough planning, and peace of mind for the individuals and their parents or family carers.

12. Shared Responsibility

Implementing this policy and ensuring transition processes are as smooth as possible is not the responsibility of one individual. All staff working in integrated and family support teams and provider services for disabled adults and children share responsibility for implementation. Key responsibilities at each stage are identified in the protocol, however in summary:

- Staff working with disabled children must ensure that information on future need is shared with adult teams.
- Adult teams must be involved in key decisions for disabled young people that are likely to impact into adulthood. Early involvement is crucial, especially in regard to disabled young people who are looked after (either through the making of a Care Order or accommodated by agreement with parents) and eligible for support as care leavers under the Children (Leaving Care) Act 2000.
- Adult teams must allocate a worker to begin joint work with children's services at the latest **one year** before a young person is due to transfer to adult services (i.e. by their 17th or 18th birthday, dependent on school leaving date).
- Adult services have a responsibility to ensure that information on adult services and policy is shared with staff working with children.
- Services to young people and their families should not be affected in any way by inter service negotiations.

TRANSITION PROTOCOL

The aim and purpose of this Transition Protocol is to:

- 1) ensure a smooth transition for disabled young people from children's services to community care services on their 18th or 19th birthday, and
- 2) Identify at an early stage the likely need for services for these young people after full time education.

The procedures in this protocol cover the transition process from the Year 9 Transition Plan Review (14+) through subsequent annual reviews and the school leaver's review as well as the transfer from children's services to adult services on a young persons' 18th or 19th birthday.

1. Year 9 Transition Review Meeting

A transition plan must be prepared for all young people with a statement of special educational needs following their Year 9 Annual Review. It should draw together information from a range of individuals within and beyond the school in order to plan coherently with the young person for their transition to adult life. It should be updated on at least an annual basis.

Not all young people who begin the transition planning process at Year 9 will be disabled and require support from adult services.

The responsibility for ensuring that the transition plan is written lies with the Head teacher. It will be their responsibility to decide who should draw up the plan, based on the available resources within the school.

The Year 9 Review meeting should involve the agencies that may play a major role in the young person's life in the post school years and must involve the Connexions service who **must** attend (see section 2).

The Head teacher must also invite a representative from social services so that any parallel assessments under other legislation (e.g. under the Disabled Persons (Services, Consultation and Representation) Act 1986, or as a child in need under the Children Act 1989) can contribute to and draw information from the review process.

The following people should also be invited to take part in the meeting:

- The child's parents, or if the child is looked after, the child's social worker, residential care worker or foster parents as appropriate
- A relevant teacher, who may be the child's class teacher, year tutor or SENCO

- A representative of the LEA
- Any person specified by the LEA or whom the head teacher considers appropriate.

For young people who are allocated to a social worker it is expected that the social worker will attend the Year 9 Annual Review meeting for all children with statements of special educational need who are looked after or receiving services as a child in need.

If the young person does not have an allocated worker or has not previously been known to social services, the invitation should go to the Disabled Children's Duty and Assessment team who will liaise with the parents and Head teacher. A decision should be made as to whether the young person may be a child in need under the Children Act 1989 and a duty social worker needs to attend the Year 9 Annual Review.

Following the Year 9 Review meeting a copy of the transition plan should be sent to the child's social worker to be placed on the child's file or if the child has not previously been known to social services sent to the Disabled Children's Duty and Assessment Team, Sorrel Drive, Eastbourne.

A copy of all Transition Plans should be forwarded to the Senior Practitioner (Transition) for information (Dorset Road, Bexhill).

2. Role of Connexions

Connexions is a national initiative that brings together advice and support for young people aged 16-19 (and up to 25 for young adults with special educational needs) through a network of Personal Advisers. These Personal Advisers will be linked with mainstream and special schools as well as Connexions Centres and Access Points.

Sussex Connexions has contracted Sussex Careers as the lead partner to support the transition process for young people with special educational needs and to undertake the Personal Adviser role for pupils with statements of educational needs as outlined in the SEN Code of Practice. The Personal Adviser role includes providing impartial individual guidance, advice and information including the identification of appropriate learning and employment opportunities, assessing a young person's holistic needs and advocating on their behalf. With the consent of young people and their parents/carers the Personal Adviser will refer to statutory services and the voluntary sector to highlight an individual's need for an assessment or service.

An important aspect of the role is to highlight the future learning needs of individual young people with East Sussex Local Education Authority and Sussex Learning and Skills Council in order for longer term planning to take place. The Lead Personal Adviser (Special Needs) based in each Operational area has a co-ordinating role.

These processes will need to be carried out in partnership with the LEA's SEN Officers and those professionals who know the young person well.

Activities taking place that will include the Personal Adviser:

- Meeting with the young person during Year 9
- Attending the Year 9 Annual Review and other Annual reviews as appropriate.
- Co-ordinating the Transition Plan started at the Year 9 Annual review
- Undertaking a Section 140 Assessment to support the young person's transition to their next learning based placement. This applies to young people who have a statement of educational need, are placed on a school's special educational needs register as school action plus or are otherwise deemed to benefit from this process.
- With consent transferring information to colleges, training providers and social services as appropriate
- Maintaining contact to support an individual's transition to the relevant adult based service.

3. The Learning and Skills Council (LSC)

Sussex LSC is one of 47 local Learning and Skills Councils and is responsible for planning and funding post-16 education and training in colleges, school sixth forms and work based learning. They also check to see if it is of high quality. The Learning and Skills Act 2000 requires the LSC to consider the needs of people with learning difficulties and/or disabilities.

Sussex LSC will attend a planning meeting each term with the LEA, Connexions and other agencies to gather information and plan for the future. This means that college provision should be better able to meet the needs of young people.

4. Supporting People

Supporting People is the Government's long term policy to enable local authorities to plan, commission and provide quality support services which help vulnerable people to live independently in the community. Appropriate Supporting People services should be included in planning and reviews when considering options for housing related support.

5. Annual Planning Meetings

In September of each academic year the transition leads (see section 10) across children's and adult services will arrange and co-ordinate a planning meeting. The aim of this meeting is to collate information to inform forward planning and ensure that transition plans are underway for all young people who are likely to require community care services. **Do not delay sending a**

referral for a young person to adult services (see section 8) until after an Annual Planning Meeting. The purpose of the Annual Planning Meeting is largely strategic and it is not a substitute for individual case planning meetings.

Prior to this meeting information will be collated from the LEA, Connexions and social services in regard to disabled young people who will be:

1. School/college leavers in the following summer term (in the main these will be young people in Year 14 who will be reaching their 19th birthday).
2. Reaching the age of 18 in the following financial year (from 1 April to 31 March) and who will be transferring to adult services at age 18 or 19.
3. Rising 16 year olds with high care needs who will almost certainly require substantial care packages from adult services once they have left full time education.
4. Disabled young people who are looked after and will be reaching their 16th birthday during the following academic year.

Information should be supplied to the Planning meeting via a completed Transition Planning Form (Appendix 1). This should be sent in good time prior to the meeting to the Senior Practitioner (Transition) based at Dorset Road, Bexhill.

Professionals who may attend the Planning meeting include:

Operations Manager, Disabled Children's Service
Practice Managers, Disabled Children's Teams
Practice Manager, Disabled Children's Duty and Assessment Team
Managers, Community Learning Disability Teams
Practice Managers Independent Living Teams
Manager, Sensory Impairment Team
Head of Occupational Therapy
Careers/Connexions Representatives
Operations Manager, Leaving Care
LEA representative
Employment services representative
Learning and Skills Council representative
Health representatives
Transition leads (May represent Practice Managers as appropriate).

The meeting will be jointly chaired by the Head of Specialist Services (Children's) and Head of Learning Disability (Adults).

The aim of the planning meeting is to address the needs of the different groups of young people as below:

1. School/college leavers

- If the young person is open to the disabled children's team ensure an assessor from the appropriate adult's team has been identified to begin joint work. If the case has not yet been allocated by adult services **the team responsible for this should be agreed at the planning meeting.**
- If the young person has not previously been known to the disabled children's team or their case has been closed, a referral will be made to the disabled children's duty and assessment team who will offer a school leavers assessment under the Disabled Persons (Services, Consultation and Representation) Act. This assessment is to be undertaken no earlier than 12 months and no later than 8 months before the young person is expected to leave full time education, whether from school or college. Dependent on the outcome of this assessment a referral may then be made to the appropriate adult's team. Alternatively a joint assessment may be undertaken.

To provide an indication of service need for each young person the planning meeting will also:

- Identify the type of package likely to be required on leaving school or college.
- Identify the role of other agencies and action required to ensure a smooth transition.

Individual case planning meetings will be the forum for deciding specific plans for young people.

2. Rising 18 year olds

- If the young person is likely to require ongoing adult services the planning meeting will agree which adults team will be responsible for that young person's future care including completion of any assessment.
- Identify the latest date when an assessor should be allocated to begin joint working (for young people open to the disabled children's team).
- Identify the possible resource required at the time of transfer and estimated level of support required at school leaving age. (Indicative information only – individual case planning meetings will be the forum for deciding specific plans for young people).
- Clarify the type of information the young person and parents may need and agree who will responsible for providing this.
- Identify areas of work appropriate to other agencies e.g. Health, Connexions.

3. Rising 16 year olds with high care needs

- To provide early warning for adult services teams.
- Identify an adult service team to begin joint working.
- Identify the resource and estimated level of support required at school leaving age. (Indicative information only – individual case planning meetings will be the forum for deciding specific plans for young people).
- Identify the areas of work that will need to be addressed over the next 3 years and who will be responsible.

4. 16 + Care Leavers

- Alert Leaving Care Team to enable a Personal advisor to be allocated and Pathway planning begun.
- Identify an adult services team to begin joint working.
- Identify the resource and estimated level of support required at school leaving age.
- Identify the areas of work that will need to be addressed over the next 3 years and who will be responsible.

5. Action after the planning meeting

1. To identify at an early stage the likely numbers and support needs of young people who will be transferring in the next financial year.
2. To identify the potential requirement for both in-house and agency resources.
3. To identify budget pressures.
4. To feed the information into the planning process.
5. To liase with other agencies as appropriate.
6. Within 6 weeks of the planning meeting the young person, parents, school/college and Connexions service to be advised of the name of the allocated adult services worker and contact number. This applies to both young people who will be reaching their 18th or 19th birthdays and transferring into community care services, as well as those young people rising 16 where a need for early joint working with adult services has been identified.

7. To follow up the annual planning meeting a further meeting will be held in January to check progress and ensure actions are being carried out.

6. Annual Reviews in Years 10, 11, 12, 13, & 14

At subsequent annual reviews until the young person leaves school, the Head teacher is responsible for ensuring that the young person's transition plan is reviewed and updated.

When the pupil enters their final year at school, the Connexions Personal Adviser (PA) is required to draw up an action plan with the young person and relevant agencies that takes forward the transition plan when the LEA's involvement ceases (S.140 assessment). The Connexions PA should attend the final year review.

It is not usually necessary for a social worker from the disabled children's team to attend reviews in years 10, 11, 12 and 13 unless it is a school leaver's review or the young person is looked after.

If a young person is likely to require ongoing support services into adulthood, in their final year in school or college social services attendance at their school leaver's review is **essential**. If the young person is under 19 this is the responsibility of the social worker from the Disabled Children's Team, although preferably an adult services assessor should also attend.

7. School Leavers Assessment

In accordance with the Disabled Persons (Services, Consultation and Representation) Act 1986 social services are required to identify disabled children and assess their needs and those of their carers during their final year in full time education.

The assessment should include consideration of the need for:

- Information about training in independent living skills.
- Counselling.
- Appropriately designed or adapted housing.
- Aids and equipment to assist in independent living.
- Assistance with personal or social requirements.
- Accessible forms of transport.
- The removal of environmental barriers to the person's social integration.
- Any other services whether provided by the local authority or otherwise in particular for further education, training, employment, health, and leisure.
- Carers' assessment.
- Management of any identified risks.

8. Procedure for Case Referral and Transfer

Case and financial responsibility will transfer from children's to adult services on a young person's **19th birthday** (if still in full time education) or **18th birthday** if they have left school (or intend to leave school by the end of Year 13).

Prior to this point case and financial responsibility remains with children's services. It is therefore important that cases of young people going through transition should not be closed until all paperwork is completed and sent to the appropriate adult's team (see below) and transfer agreed.

When a referral is made to request joint working for a young person from the Disabled Children's Team to an Adult Services team (i.e. at least one year before case transfer) the referral should be made via a completed C1 form.

If a recent assessment of the young person has been undertaken by children's services (i.e. within the last two years, and providing there have been no significant changes) this may be attached to the C1 referral form.

If a recent assessment is not available, an initial or updated assessment should be completed (if the young person is under 18) or the first section of the adult's Social Care Assessment. This assessment should include information on the family/young person's background, their disability, effect this has on their quality of life, information on daily routines, health needs, and details of services provided. (Note: it is **not** sufficient to send a copy of the young person's last service review).

Do not delay sending the C1 form if an updated assessment or Social Care Assessment has not yet been completed. This can be sent on later.

The second part of the Social Care Assessment (Summary of Assessed Needs) will be completed by Adult Services. This should be explained to families.

A CF3 transfer summary updating on any recent changes should be included on the file when the case is finally transferred.

9. Individual Case Planning Meetings

Following a referral to an adult services team, it is the responsibility of the social worker from the disabled children's team to set up an individual case planning meeting for that young person. This meeting should include a representative from adult services (preferably the allocated worker but if this is not possible the transition lead, a duty worker or other representative may attend); other key professionals involved in the young person's life; their parents or carers and if appropriate the young person themselves.

This meeting could be combined with an already existing review meeting e.g. a LAC or service review, or school annual review.

The purpose of the meeting is to agree plans and identify actions required over the next year to facilitate a smooth transfer for the young person from children's to adult services, as well as provide information to parents and carers.

10. Role of Transition Leads

Each adult service Community Learning Disability Team, Independent Living Team and Disabled Children's Team will identify an individual who will be the Transition Lead within that team.

It is not expected that the Transition Lead will take on case responsibility for all young people coming through transition in their team. Their role will be to:

- Support and enable information flow between the children and adult's teams.
- Ensure that they are well informed on children's and adult's services policies and provision, and make information available to other members of staff.
- Work with their Team Manager to ensure cases are allocated at the appropriate time and link with local service providers to develop provision.
- Link with external agencies such as Connexions and the Learning & Skills Council.
- Provide information on future need to their management team.
- Support and advise case holders on all relevant issues.
- Act as a local 'transition champion'.

It will be the responsibility of the Team Manager to ensure that plans for individual young people are progressed and that the Transition Lead is appropriately supported.

It is planned that these key posts will become a 'virtual team' of operational staff who can work together to improve communication, support the development of new and existing services and raise the profile of the needs of young people and their families at transition. Regular liaison meetings will be held.

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