



Health Transitions in Brighton & Hove – Young People with a Learning Disability



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Introduction

The Transitions Forum of the Brighton & Hove Learning Disability Partnership Board commissioned a piece of work to look into health transitions for young people with a learning disability in the City. This report is an account of that work and its findings.

The main aims of the work:

- to scope current local practice in relation to health transition
- to research national policy, good practice guidance and existing good practice
- to produce a report which provides recommendations for potential improvements in local practice
- if possible, to develop a pathway or protocol promoting good joint working
- if possible, to produce clear and accessible information about health transitions for people with a learning disability and their carers

The work focussed primarily on transition between specialist services provided at Seaside View Child Development Centre & associated professionals for children and young people with developmental needs/disabilities, and the Community Learning Disability Team for adults, plus local GP's and some acute services.

Any recommendations made in this document would apply to all young learning disabled people who have a statement of special educational needs and are eligible for statutory transition planning, and good practice would extend this further to all young people with a learning disability.

Brighton & Hove Transition Protocol (April 2010)

A transition protocol for young people who have disabilities and special needs has recently been agreed in Brighton & Hove. That document sets out the transition process for those young people who have a statement of special educational needs and for whom there is a legal requirement to have transition reviews, and for those young people who have a significant or long term health or mental health difficulty where formal planning would be beneficial. It outlines who may be involved in transition planning, and the process of formal transition planning.

In summary, that formal process will usually follow these stages:

Year 8 – Special educational needs team produces a list of young people who require transition planning to begin in year 9

Year 9 – the first transition planning meeting takes place as part of the year 9 review. Locally either a Connexions PA or Transitions Team worker will be in attendance and make sure plans are being followed up.

Year 10 – the annual review is a transition planning meeting, to look at what has been achieved so far and update the plan

Year 11 to Year 14 – final annual review takes place in the year the young person leaves education. Referrals are made to adult social services when the young person is 16 years old.

The Transitions Team in Brighton & Hove is a multi-agency team that oversees the social services transition process for young people attending Downs View School



Hillside School and Downs View Link College. The team may be involved with a young person from the age of 14 years until 25 years of age.

Definition of Learning Disability

Valuing People (Dept of Health, 2001) offered the following definition of learning disability:

Learning Disability includes the presence of:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with:
- a reduced ability to cope independently (impaired social functioning);
- which started before adulthood, with lasting effect on development

IQ scores have also historically been used to indicate the presence of learning disability, with a score below 70 usually being accepted as determining eligibility for specialist services. It is not currently commonplace for IQ assessments to be carried out however, any assessment of an individual should take into account social functioning and communication skills as well. The typical needs and abilities of individuals vary greatly and are often categorised within mild, moderate, severe and profound levels of learning disability.

Learning Disability and Health

It is well evidenced that people with a learning disability have higher levels of health need, and higher levels of unmet health needs. Research reveals higher prevalence of obesity in the learning disability population compared to the general population, as well as higher prevalence of mental health problems, sensory impairments, epilepsy, cerebral palsy, speech and language disorders, and swallowing disorders. People with a learning disability are 4 times more likely to die of preventable causes, and are 58 times more likely to die before the age of 50 compared to the general population.

There are increasing numbers of children and young people with complex and multiples disabilities surviving into adulthood. A number of factors are influencing the increases in life expectancy, including higher survival rates of premature babies, improved treatment and interventions for life limiting illness and improvements in medical technology.

Reports such as Treat Me Right! (Mencap, 2004), Death by Indifference (Mencap, 2007), Health Care for All (Michael, 2008) all highlighted examples of where mainstream health services have failed to adequately meet the health needs of people with learning disabilities. Improving the health and well being of the learning disability population is currently a key national and local priority, alongside ensuring safe, appropriate and equal access to mainstream health services.



Specialist learning disability health service provision for children and adults in Brighton & Hove

Specialist learning disability health service provision in the City for children and young people is primarily provided by the Seaside View Child Development Centre. The team includes social workers, paediatricians, occupational therapists, physiotherapists, psychologists, specialist nurses and speech and language therapists. In addition to this, some children and young people with a learning disability will be accessing child and adolescent mental health services (CAMHS).

For adults, specialist learning disability health services are provided by the Community Learning Disability Team (CLDT). The team includes social workers, psychiatry, psychology, learning disability nurses, physiotherapy, speech and language therapy, behaviour support and occupational therapy.

As well as the core services at CLDT, there is a Learning Disability Liaison Team based at the Royal Sussex County Hospital, who provide support in ensuring access to good health care for all adults with a learning disability using Brighton & Sussex University Hospitals NHS Trust services. This includes the Royal Sussex County Hospital, Princess Royal Hospital, Eye Hospital and Hurstwood Park Neurological Hospital. More recently, a new post has been established in mainstream mental health services for a learning disability nurse to ensure appropriate access to the range of mental health services for adults with a learning disability who also have mental health needs.

Adults with a learning disability in the City (i.e. those aged 18 and over) are now entitled to an annual health check and health action plan from their GP practice. People can receive their annual health check even if they are still receiving health service input from any of the Children & Young People Trust services.

In addition to specialist services, children, young people and adults with a learning disability access local primary and community health care services such as GPs and dentists, as well as hospital based services such as those provided at the Royal Alexandra and Royal Sussex County Hospitals in Brighton.



National Good Practice Guidance – measuring guidance against current local practice

Health services responsibilities in Year 9

Special Education Needs Code Of Practice (DfSE, 2001) – recommendations for Year 9 Annual Review

‘Health professionals involved in the management and care of the young person should provide advice towards transition plans in writing and, wherever possible, should attend the annual review meeting in Year 9 ... advise on the services that are likely to be required ... discuss arrangements for transfer to adult health services with the young person, their parent and their GP. They should facilitate any referrals and transfers of records...’

A Transition Guide for All Services (DCSF & DoH, 2007)

‘Prepare information to feed into transition review (re-assess if necessary)’

‘All young people who have a learning disability should be offered a health action plan (HAP)’

In terms of local practice, Year 9 reviews are used as the starting point for transition planning, however, the input into annual reviews from the various health professionals involved varies between the disciplines.

- The specialist SALT reports routinely completing written reports for consideration as part of the annual/transition reviews.
- Specialist school nurses reported completing AR4 medical advice forms regularly for children at Hillside and Patcham House, and have a template for use when contributing to the Common Assessment Framework (CAF).
- Health OT report rarely being asked to contribute to annual/transition reviews, and having little input into the CAF.
- Consultant Paediatricians do not have a secure route for contributing to the e-CAF

Attendance at Year 9 reviews and later reviews by health professionals is not commonplace, mostly due to restrictions in their time and capacity. In addition, health professionals do not currently have a secure way to share health information electronically with social care and education staff as a way of contributing to annual reviews.

While the individual clinicians may have care plans for their patients, currently these are not centrally combined into a meaningful Health Action Plan that is used to co-ordinate health care, inform transition planning or to be shared with other health professionals e.g. a young person’s GP.



Health services responsibilities in Year 10 & 11

A Transition Guide for All Services (DCSF & DoH, 2007)

'Health professionals should begin to introduce the concept of transition ... the young person could be seen by themselves ... or with someone of their own choice ...'

'...consider information transfer ...paediatric teams should liaise with adult teams to ask what information is most useful ... ensuring GPs are kept fully informed ...'

INFORMATION TRANSFER

Feedback suggests that information transfer is an issue. Adult teams report that valuable information about a young person's history can be lost when they move into adult services, and professionals in CYPT report concerns at not having a designated individual to pass records onto in adult services. Feedback from local GP's suggests they do not always receive comprehensive information from paediatric services, although they do report regularly receiving copies of clinic letters and letters to other clinicians.

There are also practical issues such as ownership of records – records are 'owned' by a service and therefore not handed over in full to adult services once the child leaves a service.

There may also be a number of documents and assessments within which information is contained about a young person's health. Examples may include:

- Common Assessment Framework
- Health care plans – used by individual disciplines e.g. school nurses
- Transitions Assessment and Plan (based on CAF) – used by transitions team
- Continuing health care assessments
- Statement of special educational need

In addition, each specialty will have their own file for the child e.g. paediatrician, CAMHS, OT etc, and these are not centrally combined. Information transfer to adult services will be difficult when records are held in many places.

THE CONCEPT OF TRANSITION

Whether or not the young person is seen by themselves for appointments, or accompanied by a person of their choosing, is dependent on the needs and abilities of the young person. More able young people may be seen alone if they wish, however professionals have reported that in many cases a parent/carer is present for appointments as the young person is not able to communicate their health needs for themselves. The venue in which appointments take place is also a factor, for example, the specialist children's SALT reports usually seeing their patients alone or in groups as interventions usually take place in school.

Information about the process of transition is available in relation to the processes for education and social care, from a number of sources. This includes the Brighton & Hove Transition Protocol (2010), and 'Through the Next Maze' (made available by



Amaze) which is usually sent to all parents of children with an SEN statement at the end of Year 8 or at the beginning of Year 9. 'Through the Next Maze' contains some information about the issues to consider in relation to health care.



Health services responsibilities in Year 12 onwards

A Transition Guide for All Services (DCSF & DoH, 2007)

'The young person should be in process of transferring from paediatric to adult health services ...'

'...set up a preparation period and education programme for the young person and the parent ...'

TRANSFER FROM PAEDIATRIC TO ADULT SERVICES

The age at which young people stop receiving specialist health services from the children and young people's trust varies. Young people may continue to receive care from their paediatrician up to the age of 19, and from CAMHS until the age of 18. For other disciplines (OT, SALT, school nursing etc) input usually stops when the young person leaves full time education, which could be as early as 16 years of age or as late as 19 years of age. (Please see table A - comparison of provision, specialist services SV to CLDT)

Table A: Current specialist health provision

Discipline	Seaside View	Community Learning Disability Team
Specialist nurses	School nurses involved until child has left full time education*	Community learning disability nurses offer service from age 18
Physiotherapy	Involved until child has left full time education*	Service offered once young person out of education (age 18 minimum)
Speech & Language Therapy	Involved until child has left full time education*	Service offered once young person out of education (age 18 minimum)
Occupational Therapy	Health OT – until child leaves school*or until 18 Social Care OT – until age of 18	From age 18
Psychiatry	Up to age 18/19	From age 18/19
Psychology	Up to age 18/19	From age 18/19
Paediatricians	Birth to 19	No equivalent for adults

*does not include further education

Potential gaps in service provision exist for those young people who may leave school at 16 years of age, when some specialist children's services may cease input, and adult provision does not usually become available until age 18. For those young people who do leave school at 16 years, the process of planned health transition becomes even less likely to occur. Health provision from some disciplines being dependent on the young person being in full time education, presents a difficulty in developing a consistent approach to health transition.



Further difficulty in health planning arises when acute health services are taken into consideration, where young people are seen in adult clinics from approximately 16 years of age.

However, there are some areas of existing good practice with regard to transfer of care for young people with a learning disability in transition:

Speech and Language Therapy (SALT):

Audiology – the paediatric audiologist contacts SALT in the Community Learning Disability Team (CLDT) to arrange a joint appointment for young people preparing to transit. This usually occurs after the person has turned 17 years of age, and before they are 18 years old.

Dysphagia – cases are handed over to CLDT SALT from children's service.

Psychiatry:

The Learning Disability Psychiatrist at the Community Learning Disability Team receives good transition reports from the Child Psychiatrist, and there will usually be a joint appointment or at least a case discussion for each young person requiring ongoing psychiatric input from adult service prior to discharge from CAMHS.

Psychology - behaviour support team:

Currently CLDT behaviour support practitioners regularly attend the clinic of the Child Psychiatrist at Downs View Link College for transition cases, in order to support planning for future placements and build relationships with the young people.

Learning Disability Liaison Team:

Whilst the team is funded to provide support for adult hospital services, the team do provide some advice and support when requested for young people with complex needs making the transfer from the children's hospital.

Most of this good practice has been initiated at practitioner or team level, rather than being led strategically or as part of a consistent approach to health transition. Establishing a similar approach across all disciplines between services at Seaside View, and the Community Learning Disability Team would be a positive way forward.

Handover to GP

In respect of the handover to GP's, feedback from GP's indicates that while they usually receive copies of clinic letters, details of outpatient appointments or copies of referrals they do not always receive a comprehensive summary of previous input and outcomes, and future needs when a young person with a learning disability is discharged from young people's services. As all adults aged 18 years of age and over are now entitled to an annual health check and health action plan from their GP practice, the first annual health check at the age of 18 could be a useful starting point for the handover of care.

PREPARATION FOR TRANSITION

With regard to preparation and education of parents and young people for transition, there does not appear to be a consistent approach to this. As mentioned previously, parents of children with special needs/disabilities receive a copy of 'Through the Next Maze' when their child begins Year 9 at school. However, there does not appear to



be any particular programme of education or information provision focussing on developing a young person's skills in managing their health or using health services, changes in autonomy & responsibility, consent/capacity, or focussing on the changing role & responsibilities of parents. Clinicians do report having discussions on an individual basis with young people and their family/carers about upcoming changes in health care, but these are all led by the circumstances of the individual.



Barriers to effective health transition

Barriers to health transition exist both locally and nationally.

1. Lack of statutory health transition

The most significant barrier is that there is no statutory obligation to provide a planned and structured health transition for any young person with a disability or complex health needs, whereas a statutory process does exist for transition with regard to education and social care. This means any proposed recommendations or pathways would be difficult to implement without direction and support at a strategic/commissioning level, and service delivery level. NHS Brighton & Hove have recently included guidelines on transitions in contracts with local health provider organisations – ‘Sussex Guidelines for Transition of Young People to Adult Services’. However, these are generic and without specific guidance on local implementation or detail on additional planning that may be required for particular care groups.

2. Lack of specific learning disability focussed good practice examples

Whilst the guidance provided in ‘A Transition Guide for All Services’ and ‘Moving on Well’ plus other guidance is good, there is very little available that is specific to the process of health transition and young people with a learning disability. The case studies and good practice examples given tend to focus on disease or condition specific pathways, or setting up condition specific adolescent health clinics. It is easier to define roles and pathways when transition is focused on one particular health condition, than it will be for a population whose health and social care needs will be complex and often require the involvement of many different professionals.

3. Lack of shared access to health, education and social care records

Another significant barrier is access to information – staff in the health section of the CYPT do not have secure access to the electronic record keeping system (specifically e-CAF documentation) that education and social care staff in CYPT do, and vice versa. This makes it more difficult for health staff to make meaningful contributions to the CAF process. In addition, staff across most teams reported poor information sharing between health, and social care and education. For example, plans for future residential or educational placements not being shared with health professionals at all or with very little notice prior to a move, making it difficult to plan for onward referrals to appropriate health services, compounded when the young person is moving out of the area.

4. Poor awareness of adult specialist health provision

There is also a lack of knowledge and information available in children & young people’s services about exactly what health service provision exists once someone is an adult. For example, very few of the young people’s services were aware of current initiatives underway in adult health services for GP practice led annual health checks and health action plans for adults with a learning disability, or the learning disability liaison service working across the local acute NHS trust. Indeed, there also seemed to be an overall lack of knowledge on what mainstream and specialist health services actually exist for adults with a learning disability and how to access them. Strategies need to be developed to address this.



5. Lack of equivalent to specialist paediatricians in adult services

Within paediatric services, concerns are consistently raised about the lack of an equivalent to the paediatrician once people reach adulthood. The lack of a specific health professional for adults with the equivalent specialist knowledge and expertise in the field of learning disability, plus the knowledge, history of individuals and continuity that paediatricians provide, is frequently cited as cause for concern. It is difficult to find a solution to this particular issue, as adult mainstream health services are simply not structured in this way.

6. Lack of information about health transitions

Currently there is no standard information available from health services themselves about the process of health transition and what can be expected. This may also be hindered by the lack of availability of information about adult health services for professionals working in children and young people's services.



Recommendations for local practice

1. HEALTH ACTION PLANNING

All of the national good practice guidance about transition promotes the use of health action plans from Year 9 onwards. In particular, 'Transition: Moving on Well' provides comprehensive guidance on the process of health transition planning – see appendix A for full detail. Implementing HAPs locally would enable the identification of health issues that need to be addressed as part of a young person's transitions, and encourage the young person to develop involvement/responsibility for their health. Whilst not providing a comprehensive medical history, a HAP could provide detail on the health needs of a young person and the actions needed to address those needs, including what specialist and mainstream services are currently involved as well as those that may need to be involved in the future.

Key themes to consider are:

- The health action planning process should begin at the start of transition planning i.e. during Year 9
- It should be offered to all young people
- It is person centred and needs focussed
- It should include all current health needs and input received
- The most appropriate professional is identified to co-ordinate HAP with young person (i.e. the professional with most on-going involvement)
- HAP is shared with relevant health & other professionals, and included in transition planning, with young person's consent
- Practicalities of moving to adult services should also be addressed, including referrals needed, who is responsible for making those referrals and when
- GP should be kept fully informed of person's current care and plans for future health service needs
- The HAP will be reviewed at regular intervals, annually at least

Examples of health action plans already exist nationally and locally. A decision would need to be made on an appropriate version to use and then ensure consistent use across services. The version currently used in adult services can be found on the Healthy Lives page of the learning disability partnership board web site. Using the same version in child and adult services would help promote consistency for young people, carers and services alike.

Information from the HAP can be used to inform the transition plan. Whether a HAP is in place for a young person or not, 'all children's practitioners should take responsibility for identifying transition needs and referring on to appropriate adult services where available' (Transition: Moving on Well – 2008). Consideration would also need to be given to how health information can be included in transition plans, without duplicating the work or significantly adding to the workload of the professionals involved.

If a decision is made not to develop a HAP for an individual, then all health practitioners involved in young person's care should take responsibility for providing written information to the annual transition reviews concerning current input,



identified health needs, and plans/timings of referral onto adult health services so that the relevant information can be recorded in the generic transition plan.

For adults with a learning disability in Brighton & Hove, Health Action Plans (HAP) are led by their GP practice, but for people under the age of 18 the GP would not lead on the development of the HAP. Health Action Planning would ideally begin at the start of transition planning, in Year 9. However, the needs of the young person should determine when it is appropriate for the HAP process to begin and for some this may be later than Year 9 if their health needs are less complex and require less planning/onward referral to adult health services. It would seem appropriate that as a minimum a multi-disciplinary HAP is developed during the final year of full time education for the young person, and considered as part of the final annual review.

Additional future action could include: guidance to be developed for staff in education settings, clinicians in young people's services, social care staff in young people's services, parents/carers, and young people to support them in HAP process; and possibly piloting the use of health action planning in local special schools.

2. HEALTH PROFESSIONAL INFORMATION EXCHANGE/AWARENESS RAISING

Clear information for Seaside View and other practitioners about current adult health care provision relevant to the adult learning disability population – both specialist and mainstream – is required. Information would need to include any eligibility criteria for services (age, level of need, diagnosis, etc), referral routes, and location & contact details as a minimum. It is expected that this would include detail of the community learning disability learning team (CLDT), learning disability liaison team (LDLT), local enhanced service in GP practices for adults with a learning disability, mental health /learning disability nurse role, Access Point for social care, and information on where to obtain details of generic health care services. This could take the form of information packs (paper and electronic) to be distributed across teams and services.

Valuing People Now (Dept of Health, 2009) makes ensuring access to appropriate mainstream health services a priority via improving access to GP practices and other primary and community health services. It would be hoped that improved responsiveness within those services would lead to the needs of adults with learning disabilities being effectively met in a more consistent way. Both improved information provision for children & young people's services about adult health care services that are available and also the training that is now provided for professionals working in those services, could alleviate some of the concerns mentioned previously in relation to the lack of an equivalent to the specialist paediatricians.

It would also be helpful to provide equivalent detail to adult specialist health services about provision for children & young people. Although they would not need to refer to CYPT as such, it could help to know what sources of information may exist about a young person's history etc.

3. BUILD ON EXISTING GOOD PRACTICE

As previously noted, some pockets of good practice already exist and a positive move would be to build on what is working now. In particular, the practice of offering a joint appointment with the young person prior to discharge from children's services



with the clinician/discipline from adult services that they are being referred to – as demonstrated by paediatric audiology & CLDT SALT, children’s psychiatrist & LD Psychiatry and children’s psychiatrist and CLDT BST. If a joint appointment is not possible a minimum requirement of a case discussion between the relevant clinicians would also promote better transition. This would require discussion at a service director/manager level between Child Disability Services and Community Learning Disability Team to agree how this might work in practice and what capacity exists to implement it.

As mentioned previously, there are issues around how health records are shared between child and adult services, and steps need to be taken to resolve this. Adult services have shared ideas about proposed content for an appropriate summary for the receiving clinician in adult services of the young person’s history, including for example:

- relevant diagnoses (inc. how reached)
- determination of eligibility for services,
- significant and enduring needs (physical and mental health etc),
- current involvement (inc. reasons for input and relevant outcomes)
- detail of involvement of other disciplines
- detail of referrals made to other adult services
- planned end date for their input
- copy of current health action plan

In addition, some work could be done to improve communication between the Brighton & Sussex University Hospitals NHS Trust working group for learning disability and the Paediatric Clinical Reference Group for Children with Complex Disabilities, and to look at clarifying roles in transition for the acute sector.

4. IMPROVING LINKS WITH GP PRACTICES

Children and young people with more complex health needs and disabilities are likely to receive most health service input from paediatricians and other specialist health services, and less so from their GP. Making the change to receiving more care from a GP practice that the young person may have had little contact with through their childhood can prove difficult. Indeed GP’s have also reported that a lack of any historic relationship with the young person can create barriers when they are expected to take a more prominent role in co-ordinating care post-discharge from children’s services.

The case summary mentioned above could also be provided to GP’s as a way to hand over key information. Indeed, a summary of any health transition needs and planned actions identified at annual transition reviews or via health action planning could be sent to GP’s from Year 9 onwards, creating regular opportunities to share with GP’s useful information to support their care for the young person at all stages of their transition and progression to adulthood.

In addition, a smoother pathway from paediatric care to accessing the local enhanced service for adults with LD within primary care would be beneficial. From the age of 18 all people with a learning disability in Brighton & Hove City are entitled to an annual health check and HAP from their GP practice, this applies whether



people are still under the care of children's services or not. Each GP practice must keep a register of people aged 18 and over with a learning disability, using this as the basis from which to invite people for a health check/HAP. At an appropriate point in the few months before a young person turns 18, their key health professional should contact the young person's GP practice (or encourage the young person/family carer to do this themselves if appropriate), identifying the upcoming increase in age, and requesting that the young person be included on the practice learning disability register and the process of a health check/HAP be instigated as soon as possible after the person turns 18. They could also include a copy of the person's HAP/summary of key health issues.

5. INFORMATION FOR YOUNG PEOPLE, PARENTS & CARERS

Young people with a learning disability and their parents/carer need to be provided with clear and appropriate information about the services they are entitled to/able to access as adults. This information should be made available in a variety of settings to ensure optimum coverage of the target population. Availability should include but is not limited to: 'Through the Next Maze' & Amaze and parent/carer forums, educational settings (e.g. Downs View Link College, Hillside School, Downs View), the health & social care team at Seaside View Child Development Centre, Connexions, Transitions Team, learning disability partnership board web site, youth advocacy services, carers centre.

Information would need to include any eligibility criteria for adult health services (age, level of need, diagnosis, etc), referral routes, and location and contact details as a minimum. It is expected that this would include detail of the community learning disability learning team (CLDT), learning disability liaison team (LDLT), local enhanced service in GP practices for adults with a learning disability, mental health /learning disability nurse role, Access Point for social care, and information on generic health care services.

Indicated in feedback as already happening, individual clinicians involved with the young person could then discuss with them the transition to adult health services, why this is happening and agree when it is expected to happen. Such detail should be included in the individual's HAP.

The 'You're Welcome' criteria (Dept of Health, 2007) would need to be considered and applied where appropriate.

6. HEALTH SKILLS DEVELOPMENT

'A Transition Guide for All Services' (DCSF & DoH, 2007) recommends that from year 12 onwards health services 'set up a preparation period and education programme for the young person and the parent ...' to facilitate health transitions.

As well as significant changes in the structure of services as people move from child to adult health services, there are also changes in culture. Once a young person is 18 years old they are viewed as an adult by the majority of health services, and able to attend appointments on their own, make decisions for themselves about their health care and the role of parents/carers changes too. A parent/carer may be used to giving consent on behalf of their child, and being fully involved in decision making



processes. Changes in the culture of health services can be as difficult to navigate as the change in actual service provision. Preparation with young people and parent/carers on topics such as autonomy/decision making, capacity/consent, information sharing, attending/co-ordinating appointments etc would be beneficial.

Further research would be needed to establish any existing good practice around the country in relation to this, and what would need to be included in any locally implemented programme of skills development.

7. HEALTH TRANSITION PATHWAY

A strategic pathway could be developed to outline the key actions needed to address health transition planning. This would need to be led at a strategic level, and implemented to correlate with the key stages of formal transition planning in education and social care. Consideration would also need to be given to current service capacity within children & young people health services and adult health services as to what can be delivered as part of the existing resources and what would require additional capacity.

As indicated already (see barrier no.2), there are very few examples of learning disability specific pathways in national guidance. However, some areas have developed the health section of their strategic transition protocol to cover all aspects of health, or specific care groups/health conditions.

A summary of the West Sussex Transition Protocol (2007) health stages relevant to young people with a learning disability are summarised here:

Age 14 to 15yrs:

Child development centre professionals, school nurses, and relevant primary/community health staff to inform the year 9 review. Looked After Children specialist nurse team to co-ordinate health assessment for 'looked after' children

Age 16 to 17yrs:

If child has unmet health needs referral to Continuing Health Care to be made. If young person identified as having severe learning disability a referral to the CLDT can be made. Where appropriate cases to be joint worked by CAMHS and WAMHS in preparation for transition & relevant professional to attend Year 11 review. Paediatricians to hand over care to appropriate adult services e.g. GP, or specialists in adult medicine. CLDT will receive and screen referrals for any young person with a learning disability from age of 16 but they will not be actioned until they reach 17 years of age. One or more members of CLDT to attend 17+ reviews, depending on which disciplines involved, to gather information, develop HAP, plus attend final appointment with paediatrician if appropriate.

Age 18 to 19yrs:

Any adults eligible for continuing care to have needs reassessed in adulthood. CAMHS/WAMHS transition protocol to be adhered to. Example such as this could provide a template for developing a local pathway.



Further Work

The following aims of the original project proposal were not achieved:

- if possible, to develop a pathway or protocol promoting good joint working
- if possible, to produce clear and accessible information about health transitions for people with a learning disability and their carers

The pathway would need to be developed at a strategic level, following further discussion with the services involved.

Information for people with a learning disability and their carers can begin to be developed as outlined in the 'recommendations for change' section above but will also depend on what is developed in terms of a pathway. Detail about any locally agreed process for health transition would need to be included in the information provided.

A workshop to look at the issues and develop an action plan would be beneficial. The workshop would require the relevant professionals to attend and provide input.

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July 2010



APPENDIX A:

A Transition Guide for All Services (DCSF & DoH, 2007)

Health Action Plans

Valuing People stresses the need for all disabled young people approaching the end of their secondary schooling to have a Health Action Plan/Health Plan. The drawing up of a Health Action Plan can make sure disabled young people continue to have access to services they need to stay healthy and not fall between services as they move from paediatric to adult health services, and move from school arranged health support. For disabled young people who do not have a statement of Special Educational Need, having a Health Action Plan can be particularly useful as they are unlikely to have health concerns and issues addressed in other forums as they may not have a standard annual review.

In some areas, Health Action Plans are developed from the Year 9 Transition Review. Like the wider transition review, the compilation of a Health Action Plan is a process rather than a one off event. It can take some months to bring together all the necessary information from a range of health professionals to ensure all aspects of young persons particular health support needs are covered. Working with other agencies in the lead up to a review and using existing appointments with the young person and their families to discuss what the plan should contain can help speed up this process.

A transition health action plan might contain the following:

- Medical management of a long term condition and how a young person might develop skills in monitoring and self management
- Access to generic health advice
- Strategies for maintaining psychological well-being, social skills and self esteem
- Support access to the educational curriculum, work experience or employment (vocational opportunities)
- Developing abilities and strategies for improving/maintaining physical skills and mobility, self-care (dressing etc) and independence (inc use of community facilities)
- Identification of specialist equipment and environmental adaptations (inc housing)

Health Action Plans need to be updated regularly for them to be useful and this can be a problem if the young person is discharged. Once again mechanisms need to be in place to make sure that a lead person is identified to keep these plans live. Drawing up a Health Action Plan can help focus all agencies on issues of importance to the young person, concerns they may have and what can be put in place to support them. This extends beyond issues relating to their impairment and could include access to personal, social and health education, including sex and relationships, and healthy eating. It is therefore essential that this is part of the wider transition planning process.



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Key documents & References

Special Education Needs Code of Practice (Dept for Skills & Education, 2001)

'.. provides practical advice to Local Education Authorities, maintained schools, early educational settings, and others on carrying out their statutory duties to identify, assess, and make provision for children's special educational needs.'

Valuing People (Department of Health 2001) and Valuing People Now (Dept of Health 2009)

Valuing People (2001) set out Government commitments to improving the life chances of people with learning disabilities, and was the first government white paper to focus on learning disability in thirty years.

Valuing People Now (2009) reinforces the principles and commitments of Valuing People, while also setting out the priorities for the provision of services focussing on personalisation, better health, what people do during the day, access to housing, and making sure that change happens.

Every Child Matters (2003, Dept for Education & Skills)

A Green Paper proposing a range of measures to reform and improve children's care, to improve outcomes for all children and young people.

National Service Framework for children, young people, and maternity services – disabled children and young people and those with complex health needs (2004, Dept of Health)

A ten year strategy aimed at improving the lives and well being of children and young people. Particularly relevant are:

- Standard 4 – Growing up into Adulthood
- Standard 8 – Disabled Children and Young People, and those with Complex Health Needs

Transition: getting it right for young people' – improving the transition of young people with long term conditions from children's to adult health services (2006, Dept of Health)

A good practice guide with the aim of improving the transition of young people with long term conditions from paediatric to adult services.

'A transition guide for all services' – key information for professionals about the transition process for disabled young people (2007, Dept for Children, Schools and Families & Dept of Health)

Good practice guidance on the roles, responsibilities and duties of all services working with disabled young people (including those with complex health needs) through their transition to adulthood.

You're Welcome Quality Criteria – making health services young people friendly (2007, Department of Health)

The document sets out principles that will help health services become young people friendly.



West Sussex Transition Protocol for Young People with Special Needs and Disabilities Who are Moving into Adulthood (2007, West Sussex County Council, NHS West Sussex, Sussex Partnership NHS Trust, Learning & Skills Council)

The aim is to improve the outcomes for young people in transition by providing a multi-agency approach to their support into adulthood.

'Transition: moving on well' – a good practice guide for health professionals and their partners on transition planning for young people with complex health needs or a disability (2008, Dept of Health & Department for Children Schools and Families)

Good practice guidance, building on existing guidance (see above) and is intended specifically for health professionals and their partners. It has a particular focus on neuro-disability but the principles can be applied for any young person with complex health needs.

Sussex Guidelines for Transition of Young People to Adult Services (2008, provided by NHS Brighton & Hove)

Designed to provide guidance to Sussex healthcare professionals for the effective transition of young people into adult services.

Aiming High for Disabled Children – delivering improved health services (2009, NHS Confederation & Every Disabled Child Matters)

Best practice examples of effective health services for disabled children.

'Healthy Lives, Brighter Futures' – the strategy for children and young people's health (2009, Dept of Health & Department for Children Schools and Families)

A long term strategy presenting the Government's vision for children and young people's health and well-being.