London Borough of Hammersmith & Fulham



HEALTH, ADULT SOCIAL CARE AND SOCIAL INCLUSION POLICY AND ACCOUNTABILITY COMMITTEE

03 June 2015

PREPARING FOR ADULTHOOD

A REPORT ABOUT YOUNG PEOPLE AGED 14-25 YEARS WITH DISABILITIES

Report of the Executive Director of Adult Social Care

Open Report

Classification - For Information

Key Decision: No

Wards Affected: All

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1. INTRODUCTION

1.1. This report highlights the challenges and opportunities for vulnerable young people in this borough regarding transition from Children's Services to Adult Social Care and provides a number of options moving forward.

Transition is an essential part of human life and experience. Here the term is used to refer to the process of change for young people, and those around them, as they progress from childhood to adulthood. This movement can be a time of celebration, change and also challenge for all young people. It is a time when young people are considering and making decisions about their continuing education, work and careers, their social life and where and how they will live.

(SCIE 2014)

1.2. Hammersmith & Fulham offers a Transition Service for disabled young people, aged between 14-25 years. However, the complex, cross sector nature of transition means that the experience of young people going through the process can be variable. Furthermore, as the needs of this group of young people become ever more complex, innovation and person centred approaches must be at the heart of our practice in order to drive improvements.

The challenge regarding transition

Supporting disabled young people in their transition to adulthood can be a challenge to service providers. This is because the process must be individual to the needs and aspirations of each young person. It is a fluid process, spread out over a number of years, and often local options for disabled young people are limited and support can be patchy and inconsistent. These challenges are compounded by young people's moves from one service to another at different ages. For example, a disabled young person may move from paediatric to adult health services at 16, then at 18 move from children's to adult social care. This is alongside the transition stages in their education. Each of these transitions is likely to occur independently of each other, which means that disabled young people and their families may repeatedly have to deal with new agencies and professionals, re-telling their story each time.

(A Transition Guide for all Services – Department of Health 2007)

- 1.3. Medical advances mean that more young people with a range of different disabilities and complex medical conditions are living into adulthood than ever before.
- 1.4. The point at which young disabled people move from children's to adult services needs to be planned for years in advance, yet planning is often poor. The reduced support which they then get from adult services compared with children's services comes as a shock to many young people and their families, who often compare this to falling off a cliff.
- 1.5. Transition is too often seen as something which need to be addressed individually by children's services or adult services, instead of both addressing it equally.
- 1.6. Young disabled people often find the adult services they need inadequate. They want services which enable them to lead ordinary lives, including a social life. They want a feeling of freedom and not being overwhelmed within adult environments and at the same time as being offered appropriate support.

The vision for the future of transition in Hammersmith and Fulham

- 1.7. Our vision is for a Hammersmith and Fulham transition service that is for all children and young people with a physical or learning disability and/or complex medical needs, and their families.
- 1.8. Our transition services will be based on listening to what young disabled people and their families want and by starting to plan well in advance, we will;
 - (a) ensure a smooth transfer for young disabled people from children's to existing adult social care, health and education services and;
 - (b) develop new adult services which respond to young disabled people's additional needs.
- 1.9. Once a young disabled person reaches the age of 14, a range of children and adult services will come together to agree a transition plan, encompassing all relevant local agencies. This plan will ideally taper services as needed to make transition less of a "cliff edge" for families.

2. EXECUTIVE SUMMARY

- 2.1. The importance of a successful transition to adulthood for young people has long been recognised in Government policy and guidance. Making a transition from one stage of our lives to another can be difficult and challenging for all of us. It can be particularly complex for disabled children and their families, particularly because of the inevitable differences in education, health and care resources available to the young person and their family as they move from children to adult services.
- 2.2. Local authority and health commissioners need to ensure that arrangements are in place for young people with complex needs to have every opportunity to lead as independent a life as possible and are not disadvantaged by the move from children's to adult services.
- 2.3. This report proposes that the key imperatives to achieve this are:
 - Review of Transition Team
 - Eligibility
 - Accessible Health services
 - Developing the range of provision
 - Sustaining a good Transition Model
 - Specific Carer Support
- 2.4. It is also stressed that any proposals for change in the approach to transition arrangements must involve young people, their parents and carers and representative organisations.

- 2.5. To implement these key imperatives will require a new culture, a more joined up and cohesive approach and the support of Elected Members to provide an agreed way forward for young people.
- 2.6. It is therefore anticipated that a project management approach may be required to drive the implementation of any service level and policy changes that are agreed. This could potentially be overseen by a newly formed, cross sector Transition Partnership Board, which may be chaired by an elected member or appropriate senior officer.
- 2.7. The number of young people with a learning disability in transition in Hammersmith and Fulham at this time is 75. To ensure that these young disabled people get all the support needed it is recommended that a review of children, adults and education services for young people is undertaken and models of provision are developed that embrace the new legislation¹, new challenges and build on the existing good practice. It is important that Health and Housing and colleagues from other Departments should also be involved in this review.
- 2.8. Young people going through transition need to be given every opportunity to maximise their potential to ensure they become adults who are valued and fulfilled. They have a vital role in planning and shaping transition, collectively and individually, including providing their views on how the process might best be managed.

3. CHALLENGES REGARDING TRANSITION

3.1. Following the implementation of the Care Act and the Children and Families Act, local authority and health services for children and adults are now working more closely together than ever before. These closer working relationships have highlighted some specific challenges and gaps in provision that hinder the ability to provide a smooth transition process for a young person with complex needs who is entering adulthood. These are listed as follows:

Differing eligibility criteria

- 3.2. Young people with autism and those who are considered vulnerable, as well as looked after children are often seen as falling through gaps when transferring to adult services, as the eligibility criteria for access to support is often different to that for children's services.
- 3.3. Furthermore, should a child have a Statement of special educational needs or an Education, Health and Care Plan, the joint assessment and planning process between social care and education at age 14 needs to be coordinated in a more efficient way. There is a need to ensure that eligibility criteria for services are aligned between Children's Social Care

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¹ The Children and Families Act 2014 and the Care Act 2015

- and Adult Social Care and that a shared language is used between the services.
- 3.4. The lead for Looked after Children, lead for Safeguarding and Assistant Director of Adult Social Care are currently working on developing joint eligibility criteria for vulnerable children transferring between their services.

Sufficiency of the local offer

- 3.5. The Children and Families Act, which was enacted in September 2014, has extended the age range of eligibility to a formal assessment and support plan for Education, Health and Care needs from 0-16 to 0-25.
- 3.6. This means that there is a requirement on local authorities to provide a seamless transition between children's and adults' local authority services and health services ensure that there is a high quality offer of specific courses and support for young people aged 16-25 with SEN and disabilities.
- 3.7. When there is a lack of specialist local provision that meets the needs of a child that is of statutory school age, the local authority often has to seek a placement with an independent provider outside of the borough. There are four overarching issues with placing a young person at such a provider:
 - The young person will generally need to travel long distances away from home each day (or in the case or residential placements, live away from home), which causes disruption to family life and does not allow for inclusion in the local community.
 - The local authority has less influence over the quality of the provider and less powers of intervention to ensure standards are consistently high.
 - Health transitions can become more complicated, as providers from other authorities become responsible for the delivery of health support.
 - Subsequent transitions to local services are challenging when a
 young person returns to the borough as he or she will have built
 up an existing network of support in a location that is a
 significant distance away from home.

Promoting independent living

- 3.8. There is a need for access to more appropriate supported housing for local residents that are transitioning to adulthood, so to support a more independent life.
- 3.9. The nature of housing in the three boroughs (i.e. tall, thin town houses) means that they are not adaptable, so innovative solutions need to be found to help address the shortfall in appropriate supply.

3.10. The Administration's Manifesto includes a commitment to 'work with providers, the NHS and other agencies to ensure that the most vulnerable in our community can live in a supportive housing environment and to consult with users and other stakeholders to ensure that we are able to put in place the most modern, appropriate supported housing for disabled people for disabled people'.

Providing pathways into employment

3.11. Employment for adults with a learning disability is nationally monitored and remains at a low level in Hammersmith & Fulham compared to the rest of the country and specifically London. Work needs to be done to improve the opportunities for education leading to meaningful work experience and employment for young people with complex needs.

Health

- 3.12. There is often a significant difference between health services for children and those for adults, and the level of support provided to a young person and their family can been seen to reduce once a young person turns 18. Communication between children's health practitioners and, for example, General Practitioners is of paramount importance to ensure a smooth transition between these services.
- 3.13. Furthermore, the recently produced Child and Adolescent Mental Health Service (CAMHS) Task & Finish Group Report recommended introducing Transition Champions into Adult Mental Health services to strengthen the pathway for young adults requiring support. This suggestion has been endorsed by Hammersmith & Fulham's Health & Well Being Boards and the Executive Director of Adult Social Care.

Projecting the needs of young people approaching transition (effective sharing of data)

- 3.14. Within the Adult Social Care client database, a new area for data collection has recently been set up to capture information on young people aged 14 and above who are in transition. This is being populated manually by transition staff from Adult Social Care based on information provided by Children's Services. This will enable Adult Social Care to plan services for young people and captures information relevant to:
 - health condition / disability
 - housing need
 - whether a wheelchair user
 - if the young person has needs resulting from challenging behaviour
- 3.15. While this new dataset is useful, it doesn't address the new requirements for the Children and Families Act in projecting demand across health and SEN needs and therefore facilitating the development of a medium-to-long-term commissioning strategy.

3.16. Active, collaboration between Public Health, CCGs, Adult and Children's Social Care is urgently required to strengthen data capture and analysis to improve planning for transitions and projected need.

4. CURRENT TRANSITION OFFER

- 4.1. Hammersmith & Fulham provides a 'Transition Service' for young people with Learning Disability. This service is made up of the following components:
 - Two Social Workers (one permanently funded by Adult Social Services and one funded by the Clinical Commissioning Group)
 - Virtual Team (this has ad-hoc membership supplied by Adult Learning Disability practitioners from Psychology, Psychiatry, Speech and Language Therapy, Nursing, Physiotherapy and Occupational Therapy)
 - Key workers for children with Special Educational Needs
 - Disabled Children's Team (Children's Social Care)
 - Children's Educational Psychology Service
- 4.2. There are additional links with other services, including Looked After Children (Children in Care), the Leaving Care service and Youth offending Team as well as the Child and Adolescent Mental Health Service (CAMHS) and the Children's Community Nursing Service.
- 4.3. There are many commissioned services for this group of young people including special schools, employment services, further education, short breaks, evening clubs, day opportunities and young carers' support groups.
- 4.4. The current practice regarding transition to adult services in Social Care, Education and Health is outlined as follows:

Social Care

4.5. In Hammersmith & Fulham the transition team work with young people with learning disabilities only. Children are assessed for eligibility for adult learning disability service as they approach the age of 18, which is generally considered to be too late to enable a well-managed transition to adult services.

Education

4.6. The Special Educational Needs Service has recently employed keyworkers who have a specific focus on young people aged 16-19 and an Assistant Head of Service who is responsible to development of the Local Offer of education provision for children aged 16-25.

- 4.7. The keyworkers are responsible for ensuring that the transition from school into post-16/19 provision is managed for a young person once they exceed statutory school age and, where appropriate, will liaise with colleagues in Social Care and Health.
- 4.8. The keyworkers are also trained in providing advice and guidance for preparing for adulthood.

Health

- 4.9. From the age of 0-18 the most significant period of coordinated Health input takes place in the first 4-5 years of a child's life and is managed by the multi-disciplinary Child Development Teams². Those young people with enduring needs will continue to receive specialised paediatric support from the service up until their 18th birthday. This can include Occupational Health input, Speech and Language and Physiotherapy, Psychology and Music therapy, in some cases specified in an Education Health and Care Plan. All other young people receive various inputs as and when they are required, and these are usually coordinated by their parents/carers via their local GP surgery.
- 4.10. At 18 years of age, those young people without complex or enduring needs will continue to access support from their local GP surgery as and when it is needed. Young people with complex needs will also transfer from their specific paediatric support to their local GP. The quality of support that these young people receive from their local GP can vary.

5. WHAT OUR CUSTOMERS SAY ABOUT OUR TRANSITION OFFER

- 5.1. Parents and carers have been provided with opportunities to feedback about services through a number of different forums and surveys, including the Children and Families Act Parents Reference Group. In addition the Customer Journey work undertaken last year by Adult Social Care highlights the frustrations expressed by some parents and outlines challenges for the future.
- 5.2. Mostly the customers who receive services are satisfied with the local offer, however it is clear that frustration is created by what can be an overly bureaucratic or unresponsive provision. This feeling is intensified when services fail to coordinate their activities.
- 5.3. The local authority has gathered feedback from parents regarding transition. Below is a summary of the key points from this:
 - It is essential to have good communication, transparency and clarity from all involved in transition.

² Chelsea & Westminster CDT operating from the hospital and Parkview Health Centre and the Imperial/CLCH CDT based St Mary's and the Woodfield road Health Centre.

- The parents commented that the experience in Hammersmith and Fulham was 'variable'. Those young people already known to Children's services moving to Adult Services had better planning.
- Parents found it hard moving from very child focussed services to adult services which had to cater for the broad spectrum of younger adults to old age.
- A number of parents still felt they had to lead and organise the future plans for their son or daughter but often did not know what was fully available.
- Parents wanted to be empowered but needed to know where to go and what was possible. An effective key worker / coordinator role, having a wide knowledge of transition was needed, guiding parents appropriately on all aspects that affect transition not just placements.
- Parents reported that there was often significant amount of time taken to resolve disputes about future funding of services and this had delayed some young people in receiving the service they needed. 'Parents should not be caught up in this wrangle'.
- Lack of suitable provision of college placements meant that some young people needed to be placed out of borough and that local colleges were only offering four days per week and this was an added pressure to cover for working parents, as well as those at home.
- It was reported that parents felt the new EHC process bringing all the agencies together was a positive development.
- 5.4. Additionally, young people have said that they wanted better housing and opportunities for employment.
- 5.5. A few parents commented on the timing of the involvement of the Transition Team and pointed out that this often occurred too close to the point of transition, creating anxiety and anger.
- 5.6. Young people have also been provided with workshops to enable them to provide views on what they may need or wish for in the design for future commissioned services. A workshop took place last year to which every young disabled person going through transition was invited. The outputs of this workshop are summarised in the report 'Children and Families Act SEN changes', available on the Hammersmith and Fulham Website.
- 5.7. At a recent Hammersmith & Fulham Mencap Transition Group, attended by families and carers of young people going through transition, concerns were raised about the limited offer of provision in borough.
- 5.8. The feedback from the recent national carers' survey has shown a slight increase in satisfaction which is higher than the London national average.

6. OPTIONS FOR CONSIDERATION

Improving the transition team model in Hammersmith and Fulham

- 6.1. A recent review of transition services in Hammersmith and Fulham has identified that parents feel the current model of transition is creating a 'cliff edge' and that there is a fear of change for young people at the age of 18.
- 6.2. Other models of provision exist and often focus upon shared staff members between Children's and Adult Social Care Teams and assessment processes initiated at an earlier stage. This would guard against rushed decision making and planning prior to a young person making the transition from Children's Services to Adult Services. It would also improve the communication and coordination between Adult Social Care and the Special Educational Needs Service, given the potential for beneficial overlap between the EHC assessment and existing Adult Social Care processes.
- 6.3. A similar model could be implemented in Hammersmith and Fulham, along with changes in practice that would make the coordination of client groups and activity more straightforward, for example undertaking the psychological learning difficulty assessments at the age of 16 rather than at 17 years 9 months as is current practice.
- 6.4. This model would require specific roles and responsibilities to be undertaken by staff. Consideration would also be needed regarding how this service might be funded and whether its activity would free up resources elsewhere in the system or the young person's pathway.

Developing the post 18 local offer for social care services

- 6.5. An issue for young people in transition is that support services and respite functions within Adult Social Care provide support for people until old-age, leading to young people having to spend time settings which are not age-appropriate.
- 6.6. Children's and Adult Social Care should also work together to understand how provision that is currently available could be used differently to better support this cohort of young people.
- 6.7. There is a risk that this work could essentially move the 'cliff edge' from 18 to 25. However, it is considered that there is much more potential and capability for a 25-year-old to transfer into adult orientated services than that of an 18 year old.

Improving the quality of the adult health offer

6.8. At 18 years of age those young people with complex needs will transfer from their specific paediatric support to their local GP. The CCG have recently undertaken an audit of young people aged 16-25 with complex needs in Kensington and Chelsea and have established that there are 24 young people using the adult GP Service. It is estimated that there are

- roughly 100 young people across Hammersmith and Fulham, Kensington and Chelsea and Westminster.
- 6.9. The overarching issue for Health is the need to increase the provision of specialist services currently on offer for young people once they become adults (for instance, Speech and Language Therapy). A coordinated approach to the strategic commissioning of such services is of paramount importance.
- 6.10. Officers in Adult Social Care have also highlighted that there needs to be an increased and increased engagement of Adult Mental Health Services in assessment and planning for young people in transition.

Improving the further education offer and pathways into employment

- 6.11. In order to address the need for more local specialist provision that helps promote independence and provides pathways into employment for young people aged 19 and above, the SEN Service have been actively working with Special Schools and Further Education Colleges in Hammersmith and Fulham, Kensington and Chelsea and Westminster. Examples of activities that are currently underway include:
 - Providing virtual local authority support teams to train FE providers as well as offering outreach support and guidance in supporting young people with SEND
 - Development of post-19 provision at Queensmill Special School specifically for young adults on the autistic spectrum, which will follow the four key pathways in the Preparing for Adulthood Framework: Employment; Independent living; Community inclusion; Health
 - Implementation of 'Project Search', which will support young people with special educational needs and disabilities into meaningful supported employment opportunities
- 6.12. The new Queensmill offer will be delivered separately from the school as a pilot from September 2015. The provision will be delivered in partnership with Adult Social Care, using some of their respite facilities, which will help to ease the transition from Children's Services and a school environment into a more adult orientated setting that promotes independence and employment.
- 6.13. A working group, led by Queensmill Governors, is working in partnership with officers from Children's Services and Adult Social Care to develop a permanent model based on the creation of a charitable incorporated organisation. This will be implemented from September 2016. Initial discussions are also taking place with Jack Tizard to develop a similar model for young people with profound and multiple learning disabilities.

Improving the planning for transition and links between health services for children and adults

- 6.14. An option to improve the quality of support that young people with special educational needs and disabilities receive from their local GP when they turn 18 is to provide specific training for GPs. However, it is not considered that this will offer good value for money as most GPs have either only one or two young people to support, or in some cases they have no young people with enduring or complex needs within their caseload.
- 6.15. The Clinical Commissioning Group is currently undertaking a review of the templates to be used for an annual health check for young people with learning difficulties. Once the templates are finalised, it is envisaged that they will be used by health professionals each year from when the child turns 14, and will ultimately inform transition needs at an early stage, enabling planning processes to be completed in good time. The CCG still need to understand how this will be planned for and implemented in the medium to long term.
- 6.16. The CCG are also developing local coordinating roles for young people with complex needs, based on the existing Primary Care Plus / Care Coordinators Roles. An option is to consider whether there is a need to increase the number of these roles for children and young adults to support effective transition. Furthermore, the 'Connecting Care for Children' initiative is aiming to provide GPs with wider support when involved in transition work. The programme is at an early stage, but its progress is being monitored.

Improving the supported housing offer for young people aged 18+

- 6.17. Housing for Disabled People forms an important element of the draft Housing Strategy 'Delivering the Change We Need in Housing' which is currently being updated following a consultation process which ended on 9 March 2015
- 6.18. Section two of the draft strategy 'Meeting Housing Needs and Aspirations' includes proposed actions for meeting the housing needs of disabled people, including those with Learning Disability'. The actions are:
 - Continue to implement the Learning Disability accommodation and support strategy and work with key stakeholder to deliver this
 - Undertake a review and reconfigure learning disabled supported housing provision
 - Map the system for updating and maintaining the accessible housing register and make recommendations for improvements
 - Review and improve the system for void notification and allocation of adapted properties
 - Review affordability of social housing and options for those on disability benefits and who are unlikely to be able to work
 - Work with stakeholders to improve access for vulnerable groups and ensure that council staff have appropriate training to enable them to identify and respond to needs

- Explore with Adult Social Care and Health initiatives to provide innovative preventative services
- Improve access to the social housing system eg staff training and changes to the registration process

7. NEXT STEPS

- 7.1. It is clear that there are many challenges ahead, but real change is achievable. The Transition framework and the joined up approach of health, social care and education should bring better outcomes for young people. Therefore, it is an absolute imperative that however we move forward we must do this together and learn together for the benefit of young people in our community.
- 7.2. Our next steps are focused upon the core themes, identified in paragraph 2.3, to improve and develop the Transition experience for young people and their family and friends, providing them with new opportunities with a local focus.
- 7.3. The table below outlines the areas that will be considered and the actions to be taken forward to realise improvements for children, young people and their families and carers.
- 7.4. To implement these next steps will require a new culture, a more joined up and cohesive approach and the support of Elected Members to provide an agreed way forward for young people.
- 7.5. It is therefore anticipated that a project management approach may be required to drive the implementation of any service level and policy changes that are agreed. This could potentially be overseen by a newly formed, cross sector Transition Partnership Board, which may be chaired an elected member or appropriate senior officer.

Closing Gaps	Actions to be considered	Timescale
Review of the Transition Team and statutory provision.	Skill Mix Review to look at a range of Transition models, including:	Review to be completed by October 2015.
•	Understand current needs, the range of provision available and the impact on commissioning strategies. Integrated with Education Health & Social Care Retain 14 – 25 with Social Care and SEN key workers. Integrated with Adults and Children to the age of 25. 7 day working for the	

	Transition Service. Join up with other boroughs to share services.	
Eligibility	To change the culture of the workforce to embrace personalisation, prevention and enhance the local offer. To include all young people with a disability. Implement Children's Mental Health 'Transitions' Champions to provide a bridge to Adult Mental Health and all other services.	Workforce model to be put in situ by March 2016.
Accessible Health	Consider extending the developing care co-ordinator roles in GP surgeries to include young people and ensure that disabled young people are accessing appropriate specialist support and link paediatric provision to the GP. Develop a LES (Local Enhanced Service, which pays GP's for health checks) for all disabled young people. Health Passports to be developed for 'frequent flyers', i.e. those young people who access hospitals regularly.	Review should take place during 2015 – 2016.
Developing the range of provision	Continue with the development of specialist short breaks. Develop further options for short breaks. Consider pooled budgets to provide greater choice. Put in place the employment pilot, already agreed and review for effectiveness.	Transition Strategy written and agreed in 2015-2016

	Improving disabled housing stock and ratify the draft housing strategy. Build on existing resources for leisure and social contact. Identifying new educational opportunities for young people. Improve data to be able to predict throughput and diagnosis to improve planning for services. Prioritising services for people with highly complex behavioural needs. (This is a direct link to Winterbourne and local demographics).	
Sustaining a good Transition Model	Create a Transition Partnership Board Create a young person's commissioning strategy. Involve young people in strategy and workforce development. Create a young person's champion role. Listen more and develop robust advice and information for young people and their carers. Particularly for those who do not meet eligibility. Embedding the EHC plan.	Commencing 2015
Specific Carer support	The culture of all staff working with parents should be that of a navigator. Offer advocacy, assessment and support to each Carer. Provide opportunities to gather carer feedback.	Commencing 2015

8. EQUALITY IMPLICATIONS

- 8.1. As this report is intended to provide an update on recent developments, there are no immediate equality implications. However any equality issues will be highlighted in any subsequent substantive reports on any of the items which are requested by the Committee.
- 8.2. Any proposals will need to be subject to an equality impact assessment, as most young people involved with have a protected characteristic (disability). The aim of any proposals will be to improve services, but the impact of any agreed changes will need to be monitored.

9. LEGAL IMPLICATIONS

9.1. As this report is intended to provide an update on recent developments, there are no immediate legal implications. However any legal issues will be highlighted in any subsequent substantive reports on any of the items which are requested by the Committee.

10. FINANCIAL AND RESOURCES IMPLICATIONS

10.1. As this report is intended to provide an update on recent developments, there are no immediate financial and resource implications. However any financial and resource issues will be highlighted in any subsequent substantive reports on any of the items which are requested by the Committee.

<u>LOCAL GOVERNMENT ACT 2000</u> LIST OF BACKGROUND PAPERS USED IN PREPARING THIS REPORT

No.	Description of Background Papers	Name/Ext of holder of file/copy	Department/ Location
1.	None		