

Committee	<b>Children's Services Scrutiny Committee</b>
Date	<b>11 March 2013</b>
Report By	<b>Assistant Chief Executive, Governance and Community Services</b>
Title of Report	<b>Supporting young people with special educational needs and disabilities (SEND) as they become adults</b>
Purpose of Report	<b>To present the initial outcomes of an introductory seminar into supporting young people with special educational needs and disabilities, particularly in the transition from children's to Adults' Social Care Services.</b>

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**RECOMMENDATION: The Scrutiny Committee is invited to consider the outcomes of the introductory seminar and consider whether, and how, to scrutinise the matter further.**

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## **1. Financial Appraisal**

1.1 There are no specific financial implications in respect of this report.

## **2 Supporting Information**

2.1 The Children's Services Scrutiny Committee on 12 November 2012 established a scrutiny review board to examine transition from children's to adult social care.

2.2 An introductory seminar was held on 4 February 2013. The attendees, notes and conclusions by the scrutiny members are outlined at Appendix 1. The presentations and discussion focussed on:

- The Transitions Service after one year of operation
- Implications of the Children and Families Bill and the East Sussex Pathfinder Project
- NHS continuing health: differences between children and adults.

## **3. Further Questions**

3.1 The Members who attended the seminar have subsequently identified a number of gaps in the discussion that may be included in any further scrutiny on this issue if required:

- The transition to adulthood experience of the much broader group of young people who have a level of need, but who are not eligible for the Transitions Service
- The experience of young adults whose parents/carers are unable to manage personal budgets or who experience a family breakup for example
- Whether we are being unrealistic with our references to "independent life" for many young people given that some Members have experienced:
  - previous independent living schemes running into apparent difficulties
  - certain individuals where the opportunity for independent living has resulted in them running into serious financial difficulties

### **3. Conclusion and reason for recommendation**

3.1 It is recommended that the Scrutiny Committee decides what further scrutiny work it wishes to undertake on this issue.

3.2 Initial indications are that Members attending the seminar do consider that some further scrutiny work is desirable to assist East Sussex County Council in balancing limited resources in Transition so as to help as many young people as possible.

3.3 A pragmatic analysis of the challenges that are being addressed currently, and the extent to which the proposed legislation will assist or exacerbate what we would all wish to do for these residents, are possible target areas for future scrutiny.

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Local Member: All

#### BACKGROUND DOCUMENTS

None

### Supporting young people with special educational needs and disabilities (SEND) as they become adults

#### Seminar report: 4 February 2013

##### *Introduction*

The Children's Services Scrutiny Committee on 12 November 2012 established a scrutiny review board to examine transition from children's to adult social care. An introductory seminar was held on 4 February 2013. This report summarises the initial findings of that investigatory discussion.

##### *Present*

###### **Scrutiny Committee members:**

- Councillor Michael Ensor (Chairman, Children's Services Scrutiny Committee)
- Councillor Kathryn Field (Vice Chairman, Children's Services Scrutiny Committee),
- Councillor Pat Ost (Member of Adult Social Care Scrutiny Committee)
- Councillor Terry Fawthrop (Member of Children's Services Scrutiny Committee)
- Councillor Rosalyn St Pierre (Member of Children's Services Scrutiny Committee)
- Councillor Trevor Webb (Member of Children's Services Scrutiny Committee)
- Councillor Francis Whetstone (Member of Children's Services Scrutiny Committee)
- Mr Jeremy Alford (Co-opted Member of Children's Services Scrutiny Committee).

**Scrutiny officers:** Paul Dean, Scrutiny Manager; Harvey Winder, Scrutiny Support Officer.

###### **Information and evidence was presented by:**

- Liz Rugg, Assistant Director (Safeguarding, LAC, and SEN), Children's Services
- Steve Hook, Head of Assessment & Care Management, Adult Social Care
- Jean Haigh, Head of SEN and Disability Services, Children's Services
- Jenny Clench, Head of Inclusion Support, Children's Services
- Alison Smith, Strategic Lead for Health for Children and Maternity, Children's Services
- Parents of young people using the Transitions Service and East Sussex Pathfinder Project: Pam Mundy and Tony Stenberg

## The Transitions Service

1. In 2007/08, an East Sussex multi-agency review of the transition provision for young people moving from children's to adults' service highlighted a number of problems. Some cases were found to have been badly managed and in particular, some young people had experienced a so-called 'cliff edge' drop in service provision as they moved from children's to adults' social care services. This difficulty arose from the different legal framework and eligibility criteria that have traditionally differentiated the two distinct areas of service.

2. The East Sussex Transition Service commenced in September 2011. It 'straddles' both children's and adults' services and aims to support young people from the age of 16 to 25 with the most complex special educational needs and disabilities, and their families, in creating a seamless transition from childhood to adulthood.

3. The service coordinates assessment and support between Education, Health and Social Care services through a single point of contact. The approach is termed 'person-centred' and 'self directed' and provides young people and families with control over personal budgets. Personal budgets are the key to providing greater choice and control over the kind of support a family receives and can be used much more creatively than before. Traditionally, the approach would have been to attempt to 'shoehorn' young people and families into a standard set of 'provided' services without stopping to explore fully whether there were better possibilities.

4. The result is an individually tailored support plan for each young person. Indications are that the approach provides an improved experience with, for example, some young people being successfully diverted away from life-long residential care towards supported, independent living arrangements.

5. The two family members who provided evidence said:

- *"Our case worker plays an extremely important role as a friend, advocate and holder of the purse. This balance of roles is very important."*
- *"The Transitions Service has helped us broaden our minds and has brought us to the attention of experts who can tell us what is available. Together with our case worker, we are starting to put things together slowly. However, there was no blueprint for how to do this. Hopefully, our experience will be scalable to a greater number of people in the future."*

6. During the first year of operation, 112 young people have been supported by the Transitions Service. Outcomes have been:

- 8 young people have been placed into residential care
- 55 have a direct payment/personal budget
- 5 are also participating in the Pathfinder Project (see below).

7. A further group of some 1,500 young people aged 14 – 25 have statements of special educational need but do not receive social care support. Five SEN personal advisers, employed by the Transitions Service, are the allocated workers for this group.

8. Based on the positive results so far, future developments and aspirations for the Transitions Service include:

- more creative use of direct payments, especially supporting pooled budgets to form small scale 'commissioning units';
- developing social enterprise and supported employment schemes for younger people;
- developing a 'shared lives' respite provision (in a carer's home for example) rather than residential care respite;

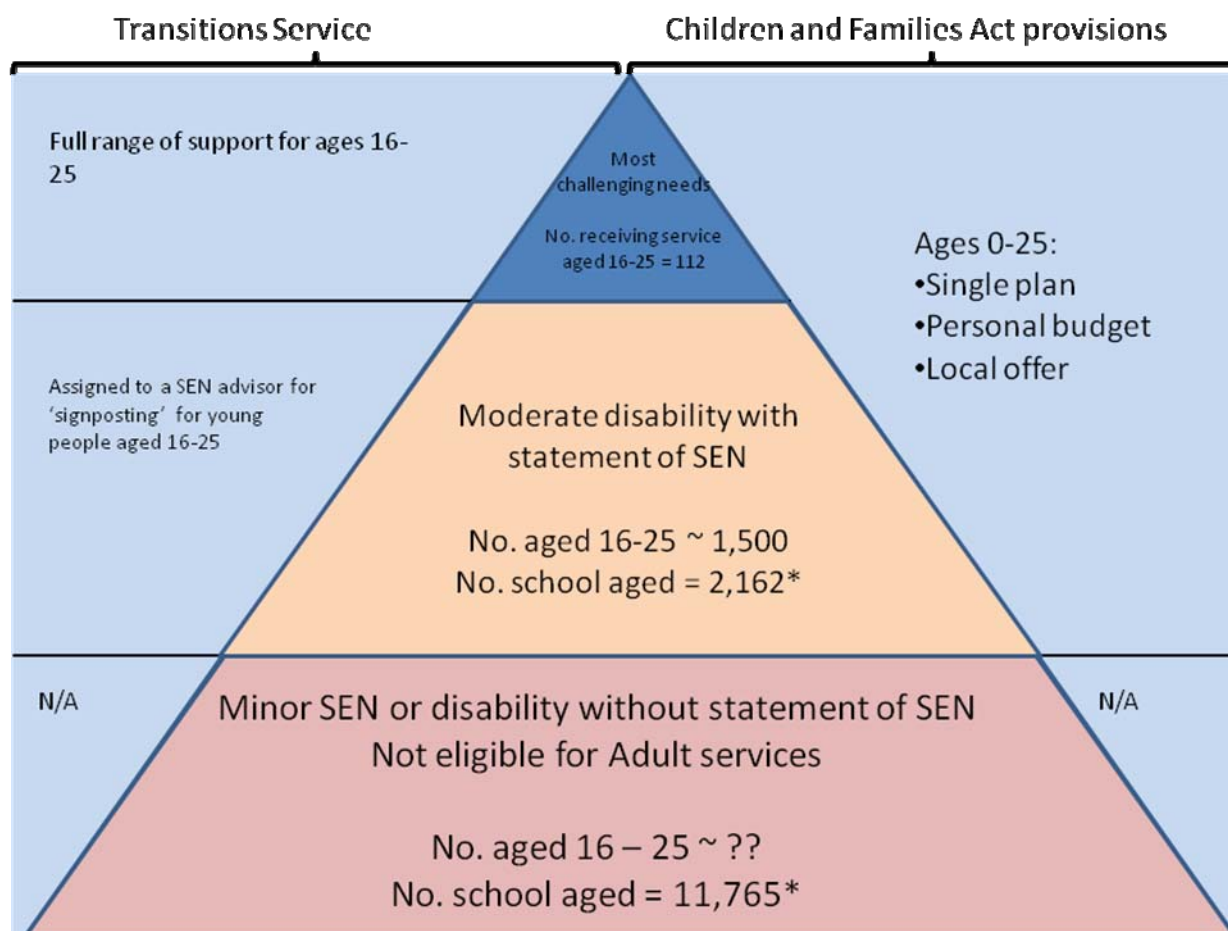
- Commissioning supported living schemes for working-aged adults with disabilities. (These schemes are being jointly commissioned by Adult Social Care and housing associations. Of the 30 new units being developed, around one third will be for under 25's).

## Conclusions

1) The Transitions Service appears to provide an excellent, 'full' service to the relatively small group of those young people with the most complex needs.

2) We are unclear about the transition to adulthood experienced by the thousands of young people with less complex needs. If we envisage a tiered 'triangle of need' with the small number of young people with the most complex needs at the apex, then we need to understand better the provision for the rest of the 'tiers' in the triangle (see figure 1 below).

3) Finding sufficient housing that is suitable for supported living arrangements is going to be increasingly difficult; demand for such accommodation is likely to outstrip supply. The Council will need to work pragmatically on various levels and especially with districts and boroughs to ensure that disability remains high on the housing 'agenda'.



\* Source East Sussex in Figures

**Figure 1: Tiers of eligibility: Members wish to develop a better understanding of the transition experience and provision for young people with moderate or minor SEND.**

## The Children and Families Bill and the Pathfinder Project

9. Reforms that will give families greater control and choice over the care their children receive, are set out in the wide-ranging Children and Families Bill, introduced by the Government on 4 February 2013. Once enacted, probably by April 2014, this legislation will make considerable changes to the way that services are delivered to children and young people with moderate or complex special educational needs from birth to age 25.

10. Provisions featured in the Bill include:

- replacing the current requirement for multiple assessments with a **single plan** developed between families and professionals called the '**birth-to-25 Education, Health and Care Plan**'. It will provide statutory protections similar to those of the SEN statements for young people **up to the age of 25 (provided they are still in education)**, thus extending the period of guaranteed support;
- a guaranteed **personal budget** for all young people and their families who have developed a single plan, giving them greater choice and control over their support;
- local authorities to publish a clear, transparent '**local offer**' of services, so that parents and young people can understand what support is available;
- **local authorities and health and care services to commission services jointly.**

11. The Government has established pathfinder projects in several local authority areas, including East Sussex. These projects are testing out the main provisions of the proposed legislation before it becomes law with a particular focus on finding the best ways to improve young peoples' transition from childhood to adult life.

12. A national development support team called *Preparing for Adulthood* has been established to advise pathfinder authorities on best practice. It has produced a poster that sets out the aspirations that all young people should expect to achieve in the form of ten challenges for local authorities, their partners and wider communities. These challenges can be used to identify the elements of the 'local offer', and ultimately could be used to judge the success of our service.

<b>Challenge</b>	<b>The 'local offer' / measure of success</b>
<b>Better co-ordination of care between different agencies</b>	
Develop a shared vision across all partners, with families and young people at its heart and focus on improving life chances	
Raise aspirations for a fulfilling adult life, by sharing clear information about what has already worked for others	Publishing advice leaflets that are co-written with parents
Ensure that the experience of young people and their families inform strategic planning and commissioning by using approaches such as Working Together for Change	
<b>More control for the young person and their family over the kind of service they receive</b>	
Develop information with families and young people themselves	Co-developing the Birth-25 Education, Health and Care Plan with families and young people

<b>Challenge</b>	<b>The 'local offer' / measure of success</b>
Develop personalised curriculums so that children learn what they need for adulthood	
Use person-centred planning and reviews to inform support planning and ensure individual budgets lead to life outcomes for young people	Offering personal budgets to parents that are using the Transitions Service and the Pathfinder
Invest in family and young people leadership	
<b>A greater focus on preparing for adulthood</b>	
Stimulate the post-16 market so that young people get a job and get a full life	Working with post-16 education providers to support educational outcomes identified in plans that also support greater independence and meaningful engagement and occupation.
Think inclusion and keep focused on life outcomes	
Set an example by employing young disabled people.	

13. Under the East Sussex Pathfinder, 50 young people now have a birth-to-25 Education, Health and Care Plan and a personal budget. The family members that provided evidence said:

- *“The single plan ensures that we are all singing from the same sheet. It is a fluid document addressing all our needs”*
- *“Co-production of the plan empowers parents”*
- *“Our son had a strong circle of support but was actually quite isolated. The single plan helped him to better shape his own future and has broadened the circle of people he comes into contact with. It is a great start and I wish it had been available years ago”.*

14. The Government considers that continuing the work of the Pathfinders is essential to help ensure that the regulations are right. Funding has therefore been extended until September 2014 which will mean that the single plan can now be promoted to more families.

15. Personal budgets are clearly beneficial for many families. However, some families may struggle to manage them effectively and others may be unable to realise any benefit from them at all. The parent network groups, established as part of the Pathfinder, have begun to discuss solutions to this problem. One approach being tested so far is the engagement of an independent advocacy service to help families manage their personal budgets.

## Conclusions

**4) Whilst the *Preparing for Adulthood* messages are aspirational, it is important that the 'local offer' is factual, realistic and expressed in plain English. The fact that Pathfinder materials in East Sussex have been co-written with parents is very welcome.**

**5) Independent advocacy is being trialled for families who may, for example, have difficulties managing a personal budget. However, it is uncertain as to whether this is sufficient or whether alternative approaches are also needed.**

**6) The Bill as drafted provides statutory protections for young people up to the age of 25 only if they are receiving formal education. Young people with SEN aged 16-18 are more likely not to be in education or employment (NEET) compared to their peers. This is a significant weakness of the proposed legislation which ought to provide protection to all young people regardless of education status.**

## **NHS Continuing Health Care (CHC)**

16. NHS continuing healthcare is an NHS-funded package of continuing care for people with ongoing healthcare needs that is provided outside hospital. Those eligible have complex medical conditions that require significant levels of care and support, or need highly specialised nursing support. These care packages, and the processes governing access to them, operate alongside the social care services provided or coordinated by the local authority. There is high demand for these services and some families have experienced difficulties in accessing advice about what CHC services and alternatives are available.

17. Several connected issues impinge on attempts to create a coordinated, single-plan approach that underpins the Transitions Service, the Pathfinder and the vision behind the proposed children and families legislation. Separate national frameworks govern the commissioning of NHS continuing care for children and adults. This creates the potential problem of transition in NHS provided continuing health care that mirrors that being tackled in local authority provided social care provision.

18. The Children's Health Commissioner works across the local authority on areas of joint commissioning agreement, such as SEN and Disability (SEND). For adults there is a joint local authority/NHS process. There is some discussion around including SEND for children and young people in the joint commissioning framework. This would include continuing health care as well as the local authority processes and budgets.

19. A pilot scheme is being trialled in East and West Sussex around personal health budgets. Network parent groups, established as part of the Pathfinder, are coordinating experiences to find common solutions to help speed up the process.

## **Conclusions**

**7) There has been a sizable, temporary upsurge in demand for continuing health care because a number of older cases have been brought forward over a relatively short period of time.**