

**Improving the Outcomes for
Young Disabled People and
their Families going through
Transition**

Briefing Paper

March 2009

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1 INTRODUCTION

Despite the consensus on the importance of good transition planning, research shows that young disabled people are not getting the help they need. They experience particular difficulties in making changes in education, employment, housing, family life, leisure opportunities and social networks. Support during the transition tends to come from segregated services with disparate funding streams.

A London Borough commissioned the Institute of Public Care (IPC) to work with stakeholders to develop proposals to make a practical difference in improving the outcomes for disabled children and their families.

This report aims to outline the current outcomes for young people and their families based on previous research and information collected during the course of this work. Secondly the report summarises some of the issues and barriers to achieving good outcomes. It details suggested practical proposals aimed at improving outcomes and provides case study examples. Questions for further thought and clarification are raised.

2 OUTCOMES FOR YOUNG PEOPLE AND THEIR FAMILIES

The outcomes for many young people and their families in the borough match the picture found in national research. There are limited further education and employment opportunities, limited access to leisure activities and a lack of local opportunities for more independent living. The following section describes the findings from previous research in relation to outcomes for young disabled people in general before summarising the evidence from the borough.

2.1 Previous Research

The Norah Fry Research Centre (2004) found that young people wanted:¹

- A job
- To go to college
- More independent living – house, shopping, cooking, transport etc.
- To learning to manage money, pay bills etc.
- To make friends through normal channels such as going to clubs, the pub etc.
- A boyfriend / girlfriend
- To be safe
- To be in control
- Emotional support

¹ Beth Tarleton Norah Fry Research Centre (2004) *The Road Ahead? Information for young people with learning difficulties, their families and supporters at transition*. University of Bristol

Indeed, taking up employment, moving to independent living arrangements, economic self-sufficiency, social participation and adult role-taking are factors generally thought to mark the successful transition of young people to adulthood.²

Parents of young disabled people measured a good outcome to be one in which their son or daughter was happy and content, was able to pursue existing interests, had a social life, and had the opportunity to engage with a range of activities. Some also considered a successful transition to be one where the young person was able to communicate their wishes and needs freely, and had the confidence and self-esteem to do what they wanted to do, rather than what might be offered or expected of them. A few considered a good transition to be one in which the young people would be supported to make further transitions in their lives e.g. to some form of employment, more independent living arrangements.³

Yet the reality is that young disabled people face multiple barriers, which make it more difficult for them to achieve their potential, to achieve the outcomes their peers expect and to succeed in education and further life.⁴ At age 16, young people with disabilities have aspirational levels similar to their non-disabled peers, yet these diverge significantly in early adulthood.⁵ Research shows that young people with a disability between the ages of 16 and 26 are less satisfied with their lives and have lower subjective well-being than people without any disabilities of the same age.⁶

A report for the Joseph Rowntree Foundation goes some way to explaining the reasons for this. The report highlighted that few young people with a disability are employed, many use day centres, college is often the expected route of progression from school regardless of desire, and little emphasis is placed on leisure, friendship and emotional support.⁷ In addition, young disabled people often find that the only option for leaving their parents home is not a move into a home of their own, but instead into a housing scheme or group home.⁸ The decision about where to live is more often determined by what vacancies are available, than by a young person's choice about where and who they want to live with.

A study conducted by the Norah Fry Research Centre found that out of the 15 young people they followed through transition 4 left school or college not knowing where they were going and so had to return to the family home. Another 2 returned home because

² Heslop, P. and Abbott, D. (2007) School's Out: Pathway for young people with intellectual disabilities from out-of-area residential schools or colleges. *Journal of Intellectual Disability Research*

³ Heslop, P. and Abbott, D. (2007) School's Out: Pathway for young people with intellectual disabilities from out-of-area residential schools or colleges. *Journal of Intellectual Disability Research*

⁴ Everitt, G. (2007) *Transition? How to find your way through. An overview of recent transitions research for parents and practitioners*, Dimensions (UK) Ltd.p12

⁵ Burchardt T (2005) *The education and employment of disabled young people: Frustrated ambition*. York: Joseph Rowntree Foundation, Policy Press

⁶ Everitt, G. (2007) *Transition? How to find your way through. An overview of recent transitions research for parents and practitioners*, Dimensions (UK) Ltd.p20

⁷ Morris, J. (1999) *Hurtling into a Void: Transition to adulthood for young disabled people with complex health and support needs*, Joseph Rowntree Foundation.

⁸ Everitt, G. (2007) *Transition? How to find your way through. An overview of recent transitions research for parents and practitioners*, Dimensions (UK) Ltd.p61

of the breakdown of existing arrangements. None had moved into supported living or any other accommodation other than the family home or residential accommodation. In terms of daytime activities, none of the young people had moved into work, or supported work.⁹

Such poor outcomes were further evidenced by CSCI (2007) which reported that:¹⁰

- Councils stated that most young people with complex needs lived with their parents after transition.
- According to residential school staff the worst outcomes were when young people were forced to return home because alternative arrangements had not been put in place.
- There was a tendency for people with complex needs to be placed out of area.
- There was a lack of further education provision for people over the age of 19.

The difficulties of achieving positive outcomes in terms of transition from child to adult services and to 'coming of age' are acknowledged in government policy and associated guidance documents with an increasing emphasis on a multi-agency approach and specific and specialist support to ensure the best possible outcomes for young people.¹¹

It seems that whilst the expectations of young people with a disability are very similar to their peers; they expect to go to work or college, have a social life, continue their hobbies, make friends and have relationships.¹² It is rare for the outcome of transition services to be a young disabled person achieving 'adult status' in terms of work/financial independence, living away from home, social/sexual relationships¹³ and understanding their rights and responsibilities.

The evidence implies that young disabled people do not, on the whole, achieve good outcomes and their aspirations are seldom met.

2.2 Evidence from the London Borough

The following analysis is based upon information collected via interviewing a variety of staff from both Children's and Adult services, reviewing reports provided by the borough and reviewing 11 case files of young disabled people aged 16 to 25 years old. (See Appendix One for Case File Summaries)

The case files and interviews indicated that whilst many young people going through transition did access further education for anything from 1 year to 3 years, there was a lack of opportunities after this.

⁹ Heslop, P., Abbott, D., Johnson, L., and Mallett, R. Norah Fry Research Centre (2007) *Help to Move On*. York Publishing Services Ltd.

¹⁰ CSCI (2007)

¹¹ Beresford (2004) On the road to nowhere? Young disabled people and transition *Child: Care, Health & Development Vol 30(6)* p.581-587.

¹² Everitt, G. (2007) *Transition? How to find your way through. An overview of recent transitions research for parents and practitioners*, Dimensions (UK) Ltd.p8

¹³ Beresford (2004) On the road to nowhere? Young disabled people and transition *Child: Care, Health & Development Vol 30(6)* p.581-587.

'The normal route for people is that they leave school and go to college for a couple of years. There aren't many other options. This results in there being two phases to transition: the first when they leave school, the second when they leave college.'

The case files indicated that only 2 out of the 11 young people had the opportunity to participate in work experience or supported employment schemes. The 2 that did were those with less complex needs.

The evidence suggests that many young people with complex needs were placed out of area due to very limited local provision.

'Of the 313 people with a learning disability known to health and social care in 2007-2008, 128 live out of area (120 in residential care and 8 in supported living services)'.

'There are no special schools in the borough so kids are often placed in special schools out of area. It is fairly unusual for kids to be in mainstream school. Mainstream schools are usually unable to meet their needs'.

Analysing the information on the care packages for those with Learning Disabilities going through transition indicated that once the young person left school they either lived at home with their family, went to a residential college, moved to a residential home or in one case moved into an adult placement. Whilst several people did eventually move into a supported living environment or their own flat, no one did this immediately after leaving school. Furthermore, those who lived at home before moving into their own accommodation tended to remain at home until the situation broke down and became untenable.

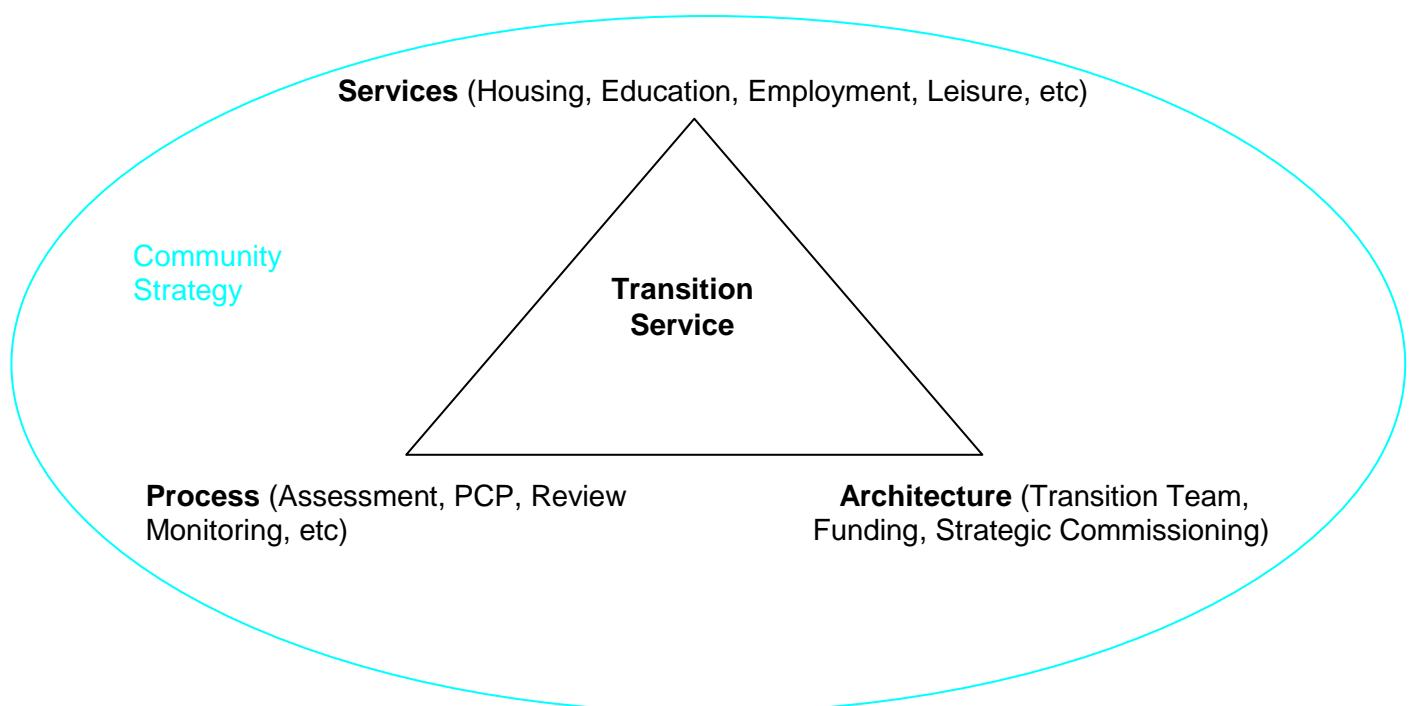
In summary it seems that the outcomes for young disabled people in the borough are not dissimilar from those described in previous research.

3 BARRIERS TO GOOD OUTCOMES IN THE BOROUGH AND POTENTIAL SOLUTIONS

The data collection and subsequent analysis highlighted nine main barriers to achieving good outcomes for young disabled people and their families:

1. Delays due to limited capacity of transition workers, delayed allocation to teams and need for greater access to health services
2. Limited monitoring and tracking
3. Insufficient strategic planning
4. Parents feeling they had little information about transition
5. A need for all transition reviews / plans to be person centred
6. Out of area placements (schools, colleges, housing)
7. Lack of supported employment services
8. Difficulties accessing activities
9. Difficulties around funding

The overall need is to develop a transition service in the borough. This is much more than just having transition workers or even a transition team, it is about creating a holistic service that enables and supports young disabled people to move towards and onto a new life stage.



This type of holistic transition service can only be accomplished via consultation with all stakeholders and it must sit within the wider circle of the borough's Community Strategy that places responsibility with other council departments to take young disabled people into account in plans.

The following section aims to describe each barrier in more detail, provide the evidence that suggests it is a barrier and outline some practical proposals for ways forward that would help to create the type of holistic transition service identified above. Attention will be drawn to questions surrounding the proposals.

3.1 Delays due to limited capacity of Transition Workers, delayed allocation to teams and need for greater access to health services

Transition workers are located in both the Children's and Adult teams. However, transition workers have a normal case load and so are unable to dedicate sufficient time to supporting young people and their families through this difficult time.

There are often delays whilst decisions are made about which adult team a person should be allocated to.

3.1.1 The Evidence

Interviews with a range of staff from both the Children's and Adult teams indicated that whilst there was a good protocol and care pathways in place it was not always followed due to limited resources. Staff felt that having more transition workers or ensuring that those in the Children's team involved in transition only worked on transition cases, would enable the protocol to work more effectively and hence would improve the outcomes for young people and their families.

'There are simply not enough transition workers. It is a resource issue.'

'We only have two transition workers which is not a big enough resource. As a result they get involved too late'.

'Those involved in transition [in the Children's team] have a normal caseload so they often have to prioritise other cases and transition ends up being pushed down the priority list'.

It is also interesting to note that the borough spends only half the amount of Tameside and Oldham on Assessment and Care Management for the adult learning disability team. Tameside & Oldham have similar populations and overall LD spend. They also have good person centred planning and transition protocols. This perhaps indicates a need to invest more heavily in this area.

Table 1 : LD Net Current Expenditure (without SP) 2006/07

	London Borough £7.388m	Tameside £10.777m	Oldham £9.929m
Assessment and care management	9%	20%	18%
Nursing care placements	0%	1%	2%
Residential care placements	39%	19%	9%
Supported and other accommodation	18%	20%	35%
Direct payments	1%	1%	3%
Home care	7%	8%	2%
Day care	24%	28%	8%
Equipment and adaptations	0%	0%	0%
Meals	0%	0%	0%
Other services to adults with learning disabilities	2%	3%	23%

Further interviews with staff identified that the delays caused by the need to do IQ tests were problematic. In some cases the delays resulted in high anxiety for the young person and their family and a few services whilst decisions were made. Clearly this resulted in poor outcomes for all concerned.

'Educational psychology does not use IQ so none of the kids have an IQ assessment. But adults need to know IQ to know which team they fit in e.g. IQ < 70 = LD. For people on the borderline IQ assessments have to be done before a decision can be

made about which team they will be allocated to. This slows things down. This can result in their being a gap where they do not receive a service at all. For some parents they have been treating YP as though they have an LD all through childhood and then at 18 they are told the YP doesn't and is not eligible for services. This can have a major impact because LD are joint services so if they have the LD label they get physio etc. If they lose the LD label they lose these health services'.

'If the young person has a disability the year 9 paper work gets sent from Education to the adult LD team. LD team confirm whether the young person has a LD or not. If not but clear PD then sent onto PD team. Problem is often the paperwork isn't clear about disability level or type'.

Currently there are people who are involved in transition work in each team and whilst there are good working relationships between teams the current arrangements are not conducive to ensuring good communication and joint working.

For young people with complex continuing health needs successful transition from childhood to adulthood demands the engagement of both children's and adult health services and the GP. Satisfaction with many aspects of transition in relation to good health outcomes can be improved through implementation of a structured, coordinated health transition / action plan¹⁴. It is a personal plan that describes what a young person can do to be healthy, to reduce the impact of health needs on future choices and maximise opportunities for independence. It should be offered to all young people but the experience in the borough has shown that not all young people wish to have one.

Furthermore anecdotal evidence suggests that even for those young people who do want a health transition / action plan, and have been supported to develop one, it does not always guarantee access to good health services and hence the achievement of good health outcomes.

A number of models for health transition exist, and it is clear that different models are effective in different settings and conditions. Models include the transfer from paediatric sub-specialist to adult sub-specialist; a primary-care-based model coordinated by the GP; the development of generic adolescent health services; and the development of a community-based young adult team, which might be coordinated by a consultant in rehabilitation medicine. Whichever model is used, a key feature is the presence of a skilled multidisciplinary team able to take responsibility for both long-term health needs and disability management. Other models include learning disability teams, community matrons and district nursing teams.

3.1.2 Proposal

A multidisciplinary transition team consisting of transition workers from both Children and Adult services. The transition team would work with young people from at least the age of 16 and up to 25. The transition team would have access to input from care managers / social workers, community nurses, OT, physio, psychology etc to enable multidisciplinary assessments to be completed. Care managers / social workers on the team would only work on transition cases. The transition team would embrace the culture of transition as moving on to a new life stage rather than a transfer between services. The process of developing and implementing transition plans would take a holistic approach and be modelled on person centred planning.

¹⁴ DH (2009) *Transition: Moving on Well* p5

The transition protocol that the team would work to would be flexible enough to allow for different levels of service response and monitoring to different levels of need.

The team would be managed by a Team Manager.

Benefits:

- The transition team would provide a single point of access for referrals and enquiries for young people, families, internal and external stakeholders.
- Every young disabled person could have a person centred plan and a health action plan by the time they left school.
- Young people and families could still have some consistency in relation to a point of contact even if there are delays in relation to IQ tests.
- The transition team could facilitate person centred planning and provide signposting and monitoring for those who will not be eligible for services.
- The transition team could collate information from person centred plans and other monitoring to feed into the strategic commissioning of services.

Case Study Example – Walsall

Walsall's transition team is part of an integrated team located in adult services. The transition team has a network meeting once a month which is attended by representatives from children's services and adult services. The full range of services are represented including looked after children and physical disabilities.

The nature of the integrated team in Walsall is such that all assessments undertaken by the team are completed jointly by community nurses and social workers. This is seen to be crucial due to the complex nature of the young people who are coming into the system. This effective joint working results in all young people having health action plans and person centred plans by the time they leave school.

Case Study Example – Surrey

Surrey have a County Lead for Transition based in the Children's Service working across both children's and adult social care service. The Lead is also the Transition Champion on the Learning Disability Partnership Board.

Surrey implement transition as follows:

Lead for Transition

Multi agency Transition Steering Group

Transition Strategy

Transition Protocol

Virtual Team

Specialist Post

Communication Strategy

All are co-ordinated and managed by the Lead for Transition.

The Virtual Team is a number of key professionals in transition who work in partnership to ensure a smooth transition, e.g. children's and adult social care services, education, Connexions, LSC, Health.

Dedicated specialist posts have been established to work with children/young people in transition, e.g. employability officer, mobility officer for the blind, specialist transition care managers, Project Manager for Autism and country transition adviser.

Case Study Example – Lewisham

Lewisham's Inter Agency Transition Team (IATT) was set up to work with Children and Young People aged 13-25 years, who have the most severe and complex needs within the borough. The role of the team is to co-ordinate and oversee the transition process from Childhood to Adulthood, ensuring that effective and efficient planning is undertaken within acceptable timescales; therefore seeking to deliver a quality assured service. The approach is a holistic one, as it is recognised that the young people with extreme disabilities/difficulties often have a combination of needs varying between their physical, mental, emotional, social or educational welfare. Success is therefore dependant on multi-agency work, with a commitment to promoting the welfare of SEN children and young people, equally keeping in line with the 5 priority outcomes "Every Child Matters"

Case Study Example – Nottingham

'Positive Futures' is Nottingham's joint strategy for people with learning disabilities. It has a 'Staying Healthy' group whose members offer training to Primary Care and Accident and Emergency staff, with the aim of improving access for people with learning disabilities. The group has also developed a basic health record, co-ordinated by a health promotion specialist. Forty-four specially recruited and trained Practice Nurses see people with learning disabilities at their practice, using their health record. Resources are provided for each nurse. The links and information sharing from both these initiatives should provide a good basis for the development of Health Action Plans.

Case Study Example – Tower Hamlets

'Healthy Partners' is a joint initiative by the Tower Hamlets Primary Care Trust, the Community Learning Disability Team and 'One to One', a local self-advocacy organisation. The project was funded in part by the City and East London Education Consortium (CELEC). Individuals with learning disabilities involved in the project have given a lot of thought to meeting their health needs. They are involved in training local General Practitioners, nurses and practice staff. The project has taken a lead in developing client-held health plans.

Questions

- To what extent are care pathways followed? Do current care pathways result in improved outcomes?
- Should the transition team be a real team that is co-located or a virtual team?
- Should the transition team's primary function be one of providing or commissioning?
- Should the transition team stop working with people after a certain age e.g. 25 or once there is a stable package of support in place?

- Should the transition team have responsibility for cases or should cases still be held by either the Children or Adult teams?
- Are there mechanisms other than IQ tests for deciding which team should take responsibility for a given service user?

3.2 Limited monitoring and tracking

There is limited information about young disabled people in the borough that is centrally held and useful for strategic commissioning. The need for such information is not only recognised in good practice models of commissioning but has also been highlighted in various policy and guidance documents e.g. Putting People First.

3.2.1 The Evidence

313 residents with learning disabilities are known to social services. This is only one tenth of the predicted learning disability population in the borough.

Table 2 : People aged 18-64 predicted to have a learning disability in 2008

	Learning Disability	Moderate or Severe LD
18-24	466	106
25-34	989	212
35-44	805	202
45-54	506	114
55-64	419	91
Total Pop 18-64	3185	725

Currently there are predicted to be approximately 725 people aged 18-64 with a moderate or severe learning disability in the borough. We must be careful about applying national prevalence rates to this borough, because it is a mix of the very rich and those who qualify for social housing. This means that the population does not match the average population profile.

This aside, research indicates that the majority of people with moderate or severe learning disabilities do need at least some support with daily living. The fact that only 313 people are known to social services indicates that there is likely to be at least some unmet need in the borough. Further evidence of unmet need comes from Education who divide SEN into moderate and severe. The majority of those with moderate SEN do not meet the criteria for adult services and yet do need some support.

'Many of our kids have multiple disabilities. Each one is not severe so they don't meet the criteria for any team. However, when all these 'mild' disabilities are put together in one person it results in severe difficulties for that person and a need for support which they don't get'.

There are currently 52 young people known to the adult learning disability team who are aged 19-25. Population estimates indicate that in the borough there are predicted to be approximately 106 people with a moderate or severe learning disability aged 18-24.

This may indicate that approximately half of this population are either not meeting the eligibility criteria or are slipping through the net altogether, the consequence being high levels of unmet need.

Unmet needs often result in people coming into services when they are in crisis. This often results in costly services that may have been avoided if the person had been in receipt of low cost services earlier¹⁵.

Case Study

We (Mum, Dad and I) all used to live at home. Then Dad got ill and had to live at the hospital. Mum goes to see Dad for a couple of days most weeks but says I am not allowed to go. I can't be trusted in the house on my own so I sleep outdoors those nights.

James, a 22 year old man with mild learning disabilities

James has always been different. There were always problems at school and he has never had a job. My husband is waiting for a transplant so when I visit him in London I have to leave James on his own. I can't trust him in the house since the fire so I have to lock him out. I did go to the social once but they said James was not disabled enough so they couldn't help. They suggested he goes to stay with family when I am away, but there isn't anyone else, only us.

James's Parent

(Shadow Lands (2008) IPC)

There is a corporate responsibility for those who may not meet criteria for adult services but yet do not easily fit into society.

It is predicted that there are likely to be increased survival rates among young people with severe and complex disabilities.¹⁶ Anecdotal evidence suggests noticeable increases in the rates of survival into adulthood of children with severe and complex disabilities. The effects are likely to result in increased demand for high cost support for children and young adults with severe disabilities in the future. Currently the borough does not have comprehensive information on these children.

'We have a health led Children's Disability Register managed by Westminster PCT. However you can't track children and it is a voluntary register so is likely to under estimate prevalence'.

'The information that is held does not give you all the business information you need about the cost of packages'.

Table 3 : People aged 18-24, 25-34, 35-44, 45-54 and 55-64 predicted to have autistic spectrum disorders, projected to 2025

	2008	2010	2015	2020	2025
18-24	172	178	184	187	191

¹⁵ Mansell, J. (2007) *Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs. Revised Edition*. London : DH Publications.

¹⁶ CSED PANSI Tool

	2008	2010	2015	2020	2025
25-34	397	409	432	440	437
35-44	329	337	347	360	379
45-54	219	239	277	297	303
55-64	185	186	190	222	255
Total Pop 18-64	1302	1349	1430	1506	1565

Many people on the autistic spectrum do not meet eligibility criteria and fall in the gap between services. As a result many do not receive services after the age of 18. For a significant proportion of people on the autistic spectrum this results in crisis and the need for costly emergency services¹⁷.

The population estimate above, and information from interviews highlight that the needs of people on the autistic spectrum are not being met and the number of people in the borough on the autistic spectrum is set to rise.

'We are currently picking up lots of people with Asperger's Syndrome who don't meet the eligibility for the Children with Disabilities Team and certainly won't meet the criteria for adult services. The problem is they need support'.

'There has been a rise in the number of kids on the autistic spectrum. 50% of the current youngsters coming through are on the autistic spectrum. Many of them do not get a service because their IQ is above 70. Many of the parents who have a perception that there are no services out there are parents of kids with ASD'.

Research indicates that up to 40% of people with a learning disability will also have an associated mental health problem.¹⁸

Table 4 : People aged 18-24, 25-34, 35-44, 45-54 and 55-64 predicted to have a learning disability and associated mental health problem, projected to 2025

	2008	2010	2015	2020	2025
18-24	186	193	199	202	206
25-34	396	407	430	438	435
35-44	322	330	341	355	374
45-54	202	222	258	279	286
55-64	168	168	173	202	232
Total Pop 18-64	1274	1320	1401	1476	1534

The numbers above indicate that there is going to be an increasing need for significant input from mental health services and specifically the challenging needs service.

¹⁷ IPC (2008) *Shadow Lands. Application and Impact of eligibility Criteria on Young People with Disabilities.*

¹⁸ CSED PANSI Tool

Research indicates that where this support is not given, placements breakdown resulting in more costly and even secure placements¹⁹.

The percentage of young people with learning disabilities from black and minority ethnic groups in transition from children's services is increasing indicating a need for culturally appropriate services.

The latest RAP reports published by CSCI/DH show that there were 2453 clients (18+) with a physical or sensory disability known to social services in 2008. The prevalence of a personal care disability is 5% nationally²⁰. Applying known prevalence rates to Census based projections, there are a projected 5,295 with a moderate or serious disability requiring personal care. Once again this may indicate a significant level of unmet need in the borough.

3.2.2 Proposal

A central Disability Register that collects information on Children and Adults with Disabilities and can be easily accessed by all commissioners. The register would need to identify the type and level of disability and cost of current support packages.

Benefits:

- Commissioners would be able to predict the number of people, level of need and cost of services.
- Commissioners would be better informed about the need for services and therefore better able to commission appropriate, cost-effective services.

¹⁹ Broadhurst, S. and Mansell, J. (2007) Organizational and individual factors associated with breakdown of residential placements for people with intellectual disabilities. *Journal of Intellectual Disability Research Vol 51(4) p293-301*

²⁰ Bajekal M, Primatesta P & Prior G (2001), Health Survey for England, ONS

Case Study Example – Sheffield LD Register

The Sheffield Learning Disability Case Register was established in 1974. It aims to gather information on people with a learning disability by interview and visits. For children these visits are every two years and for adults every five years. The register includes information about people's ages, the nature and severity of their disabilities, their use of services, and the age of their parents or other caring relatives. As most people with a learning disability are referred to the register as children and young people, data is increasingly robust over the age of 10 to 15 years. People are often referred to the register because they have come into contact with a health or social care service. Furthermore, people / families can self refer and the register is notified of children whose families consider them to have learning disabilities by the Child Disability Index. Once a person has been referred, an interview is arranged to gather the detailed information held on the register.

Questions:

- Should the register be a register for all disabilities or should there be one for LD and one for PSD?
- Could the register track people who are not eligible for services?

3.3 Insufficient Strategic Planning

In the borough there is an operational group that has been set up to track all children and make sure no one falls through the net. However, it does not address strategic issues hence there is insufficient strategic planning in relation to transition.

3.3.1 The Evidence

Developing a clear, multi-agency, agreed, strategic transition plan on how local services will work to meet the needs of disabled young people in their transition to adulthood can transform the effectiveness of local support.²¹ The strategic planning group responsible for developing such a document needs, at a minimum, to include:

- local disabled young people and their families
- children's services
- adult social services
- health services
- local colleges
- connexions services.

The strategic plan should:²²

- Set out the statutory framework
- Set out the roles and responsibilities of all agencies.
- Set out how agencies can work together at strategic and practitioner level to implement their responsibilities.
- Set out what is involved in the process, such as Person-Centred Planning, Year 9 Annual Review, and 'Section 140 Assessments' of the Learning and Skills Act 2000 relating to learning difficulties/disabilities.

²¹ Wheatley et al (2007) *A Transition Guide for all Services. Key information for professionals about the transition process for disabled young people*. Nottingham : DCFS Publications p.4

²² *Parliamentary Hearings on services for disabled children* (2006) p.2

- Be agreed by the local authority Multi-Agency Transition Groups.
- Include suggested good practice for all organisations and agencies involved.
- Include procedures for notifications, which will ensure that all agencies necessary are involved in the process from the beginning.
- Include details of how the Transition Plan will be implemented and how it will be reviewed.

For the effective commissioning of services the Strategic Transition Planning Group needs to be linked into the children and young people strategic partnership board and the learning disability partnership board in adult services.

Currently the borough has an operational transition group that meets regularly to discuss individual people but there is not a strategic group responsible for the strategic planning of transition services.

Interviews with staff and feedback from previous consultation with parents identified the need for a joined up, strategic approach to planning transition services.

'Each department tends to sort things out for now rather than there being a longer term view'.

'There isn't a cohesive philosophy in the council. We need better links between children (16/17) and adult commissioning'.

'We have a transition operational group but we need a strategic commissioning one too. It would need to include health, housing, education etc'.

'Full of Life have been quite proactive and are doing their own thing, but it isn't a strategic approach'.

'There may be a need for cross borough planning as well as longer-term planning'.

Achieving individual and strategic outcomes is dependent upon the necessary information from person centred plans feeding into the commissioning strategy. Systems must be in place to ensure that the information collected through developing person centred plans is captured and analysed at a strategic level as well as an individual level.²³

3.3.2 Proposal

A Multi-agency Strategic Planning Group that links into other boards such as the children and young people strategic partnership board and the learning disability partnership board in adult services. The planning group would base decisions on a range of information including data collected via person centred plans. The Strategic Plan and associated monitoring would be outcome focused.

Benefits:

- Commissioners would be better informed about the need for services.
- There would be a joined up approach to the commissioning of transition services.
- Resources could be more wisely and effectively invested resulting in long-term savings.

²³ IDeA (2008) *Person Centred Commissioning – Now* KLM Press

Case Study Example – North East Lincolnshire

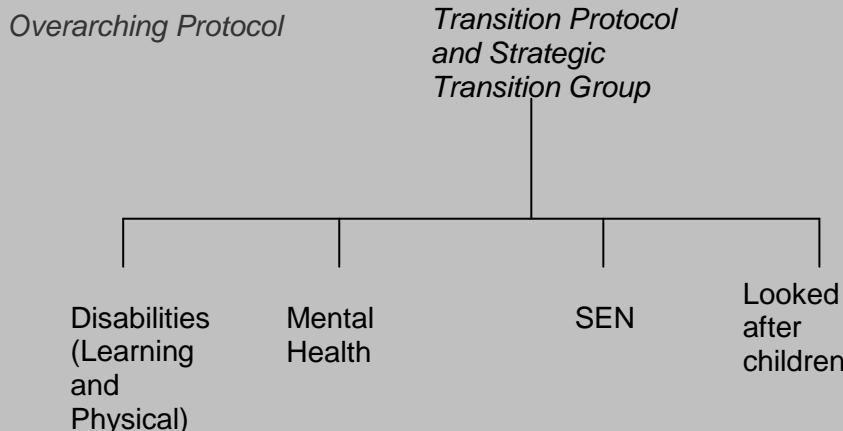
In North East Lincolnshire people with learning disabilities are supported to develop person centred plans. The plans belong to the people themselves, however to ensure the outcomes that people are planning for, are linked with strategic development within the area, the following key themes are forwarded to the relevant personnel to include in

their strategic development. Housing requests are sent to the housing learning disability data base; this informs immediate, intermediate and long term planning / commissioning of housing. Health action plan requests are sent to the health and wellbeing team. Leisure requests for activities are sent to the leisure coordinator (fulfilling lives team) and day opportunities to impact on day opportunities and local leisure services development/provision. Employment requests are forwarded to the supported employment team; this enables people to access local employment and joint working between Employment Services and PCP.

Person Centred Commissioning Now (2008) p9

Case Study Example – Shropshire

The overarching Transition Protocol provides the framework for transition of services for young people as they become adults in need of ongoing Health, Education and/or Social Care Support. For each Service User group a specific detailed Transition Agreement will be developed. Each agreement will specify the exact arrangements for staff from all agencies to follow so there is clarity for every young person.



Strategic Transition meetings are held at 6 monthly intervals in March and include;

- Children's and Adult Joint Commissioners
- PCT Director of C&YP Services
- Assistant Director Social Care & Safeguards
- Assistant Director Adult Social Care Service
- Assistant Director Youth Support
- Assistant Director Raising Achievement and Inclusion Services
- Housing representative
- Parent representative

The meeting is chaired by the Director of Commissioning. The panel receives reports from:

- The operational transition group for disabilities
- The operational transition group for mental health services
- The operational group for SEN
- The looked after children and leaving care service

The reports identify:

- Numbers of young people in transition
- Needs
- Service gaps
- Exceptions (where difficulties have arisen in planning)

Questions:

- Would the Strategic Group be responsible for actually commissioning services or for simply feeding the relevant information into other commissioning bodies?

3.4 Parents feeling they had little information about transition

Care managers find that parents often comment that they do not feel they have been given enough information about transition or services. It can also be difficult to engage parents in the holistic transition planning necessary for good outcomes as there tends to be a focus on education.

3.4.1 The Evidence

The issue was identified in a number of interviews with staff and previous consultation with parents.

'Parents say they don't get enough information. We think may be they do but not in the format they find useful. Accessing parents is difficult because they don't attend drop in sessions. Our young people are really spread out so we can't access parents through the schools'.

'In children's services it's quite a medical model and it is all about supporting the child through the parents. This all changes in adult services. It is a complete culture shift that happens quite abruptly leaving parents feeling devalued'.

'Some parents have a perception that there is nothing out there. It is mainly the parents with kids who have high functioning autism who are most worried. Parents of kids with severe LD do have some fears about the lack of local provision. Some of these fears could be alleviated if they had more information about what is available'.

'We need to be better at ensuring that families know early on what the process involves. They tend to think it is just about school but it is much more than that'.

'The information we have on transition is not that accessible to families'

'We would like to start doing home visits (and then have someone available for follow-up questions) with the child and parent to explain the whole transition stuff and get them thinking about it earlier. Get them to think holistically. But it is not easy to fit in. Resources don't really allow for it. Transition workers (we have 3) only get to do the transition stuff if they have time on top of their normal case load'

3.4.2 Proposal

- The transition team mentioned in section 4.1.2 to do an initial home visit to talk both the parents and young person through the transition process. This visit would be done when the person is first referred to the transition team.
- Develop or adopt a tool to help structure the information gathered.
- Develop a web-based transition resource that can be accessed by everyone involved in transition and provides information on the process and services. The resource could also have a restricted area where those going through transition could social network.

Benefits:

- Parents would have a single point of contact.
- Parents and young people would have the opportunity to talk through their individual situation helping them to feel valued and informed.
- A web-based resource would enable all those involved in transition to access the same information.

- Sharing experiences via social networking would help young people and their families to feel less isolated.

Case Study Example – No Limits (Suffolk)

No Limits have developed a website for disabled young people in Suffolk. Young people helped to put it together and it aims to:

- Give people up-to-date information about services and opportunities.
- Help people find out things for themselves to plan for their future.

There are various communication aspects to the website. People can change the font, background etc. They can opt for information to be read out to them or for it to be signed to them via the computer.

Case Study Example – Swansea Social Networking Site

Swansea People and Places is a Facebook / Bebo-style site offering a safe and secure online social environment for people with a learning disability and members of their planning and support circles. It provides the opportunity for adults with a learning disability to talk and message and to access message boards, activity planners and online diaries. They can use it either as an individual or part of a group and there are currently 196 registered users. The site grew out of the successful Swansea Lives website which was the first website for people with a learning disability in Wales providing access for users and carers to get quality and easily understood information on services. Swansea Council provided funding for the initial development of the website. Cathy Murray, Principal Officer in Mental Health and Learning Disability Services at Swansea Council, said: "It's still early days in using this tool in Swansea but already we are seeing the benefits of individuals expressing their views and wishes and sharing their experiences with friends, family and staff within services. The Instant Messenger facility that has just been developed can provide users of the site with immediate feedback to questions and queries and can offer information or just general chat to support the development of social networking in a safe environment."

Questions:

- Would the web-based resource be maintained and updated by the borough or would this be contracted out to either the third sector or a private organisation?

3.5 A need for all transition reviews / plans to be person centred

Some schools have embraced person centred planning and are very good at supporting the young person to contribute to person centred transition reviews which result in a holistic person centred transition plan. However, other schools have not developed this approach leaving some young people without a clear idea of the outcomes they wish to achieve.

3.5.1 The Evidence

The National Service Framework (NSF) for Children expects that Transition Plans be written in a person centred way, focusing on the needs and views of the young person. A successful transition programme needs to cover information and guidance about leisure and social opportunities, benefits, future housing options, the transfer to adult health and social services, opportunities for further college education, independent living skills and how to plan future goals.

Hudson states:

'It is through the person centred planning process that localities can build up accurate profiles of individual and local need; to fail to undertake such mapping exercises would be to plan in ignorance of what young people need and want'.²⁴

3.5.2 The case file review highlighted that some young people in the borough had been supported to develop a person centred transition plan in their school setting whilst others had not. Interviews with a variety of staff identified that not all schools had embraced person centred planning.

'We tried to introduce doing person centred plans at the year 9 review. In one school it has worked but for others it is adhoc'.

'There is a lack of PCP culture partly because there isn't any funding attached to it. May be if there was funding attached we could commission Circles Network (who are a national body) to do the PCP stuff'.

'We were involved with a PCP pilot about 3 or 4 years ago through valuing people. They provided us with specialist training around a person centred approach to reviews in year 9. One school really liked the approach so invested in further training. Other schools weren't so keen'.

3.5.3 Proposal

- The transition team mentioned in section 4.1.2 to facilitate person centred reviews in schools.
- To start a mentoring program between schools that involves those who have embraced the approach, mentoring those who need further support.
- Ensure that all young people have access to an advocate to help in the development of their PCP.

Benefits:

- Understanding the young person, what's important to them and what they require from their support in order to live their chosen lifestyle (via their person centred plan) is the essential starting point for designing, developing and purchasing support and services.
- It is not always easy for schools to implement PCP. A mentoring programme would help those schools that are struggling gain advice and support from schools that have faced and overcome similar problems.
- Ensuring access to advocacy for all young people would help to guarantee that the content of the person centred plan was representative of the young person's wishes.

Case Study Example – London Borough of Barking and Dagenham

In 2008 The London Borough of Barking and Dagenham are planning to implement a person centred planning approach to reviews in educational settings. The person centred plan will be completed over time in two parts. The first part aims to produce a profile of the young person. Work on the second part will begin in year 8 / 9 and focuses on discerning the aspirations for their adult life.

²⁴ Hudson,B. (2003) *From Adolescence to Young Adulthood: the partnership challenge for learning disability services in England*. Disability & Society Vol 18(3) p.259-276

Case Study Example – Oxfordshire

Oxfordshire recognised that the voice of the young person was not always being heard in their review, especially for those young people who had severe communication difficulties. The decision was therefore made to involve the local advocacy service. This empowered those who are able, with the appropriate support, to voice their opinion. The service has also ensured that the rights of those who are unable to say what they want or instruct an advocate are upheld. This is achieved through the use of non-instructed advocacy which is a form of advocacy that sets out to ensure that:

- All options are considered
- The person's preferences and personal tastes are taken into account
- Their rights are respected
- No particular agenda is being followed

For further information www.oadg.org.uk

Questions:

- Could all person centred plans for those going through transition be facilitated by the transition team in partnership with schools or would there be a need to commission an outside agency to do this?

3.6 Education and Skills and Accommodation

There are no special schools in the borough so Children with disabilities whose needs cannot be met by mainstream schools are placed out of area.

There are few options for further education for those with complex needs. Consequently a significant proportion of young people with complex needs attend out of area residential colleges.

There are limited local housing options for all young people with disabilities. Once again this results in people being placed out of area.

3.6.1 The Evidence

'It is fairly unusual for our young disabled people to be in mainstream schools. This is because either the parents, the school or the statement indicate that a mainstream school would not meet the needs of the young person. As there are no special schools in the borough most of the kids attend out of area special schools.'

'When young people have been attending an out of area school or college for sometime they build up links there which can make it difficult to bring them back to the borough'.

'Learning is limited in terms of there being a rich menu of options'.

Service mapping (see appendix two) and case file reviews indicated that there was only one college in the borough that could support young people with disabilities. It was also clear that even colleges in neighbouring boroughs were only able to offer limited options for further education and that young disabled people were only able to attend college for up to 3 years. In the main this was because colleges had a limited range of courses that were deemed suitable for young disabled people.

However, there is potential to do more. Nationally, a new Foundation Learning Tier is being introduced for entry level and level 1. The concept is to put in place progression pathways in which students can gain accreditation for completed units at their own pace. This means that they do not have to repeat units if they need to have a break eg for physical health reasons, but can progress to other units. There are four pathways. There is one pathway for the 14-16 age group for leading to a Foundation Diploma, GCSE or other appropriate destination. There are currently three post-16 Progression Pathways undergoing phased implementation, leading to one of the following:

- a first Full Level 2 in the QCF
- skilled work or an Apprenticeship
- supported employment or independent living.

Each of these Progression Pathways includes three components:

- vocational or subject knowledge, skills and understanding
- functional skills
- personal and social development.

However, it is clear that more emphasis needs to be given to providing space and facilities to support those with more complex needs during the design of new build or adaptations. It may be possible for the Learning and Skills sub-region to be encouraged to develop a more consistent and coherent approach to providing enriched opportunities in the 12 colleges in the 7 central London boroughs. An example would be to provide more courses to continue learning during the long summer break; often young people with learning difficulties require a more continuous style of learning. The LSC would encourage local authorities to provide as much information as possible about the numbers of likely students and their needs as early as possible in order for them to plan the support required.

There is an opportunity to pursue this agenda when the budget for funding further education for young disabled people (i.e those statemented under Sn 139) aged 16-25 is transferred from the Learning and Skills Council to local authorities in 2010-11.

A further possibility is to introduce Individual Learning Accounts or Skills Accounts to run in parallel to personalised budgets for those aged over 18 (see below). We understand that this approach has been piloted in Cambridgeshire. At first, this would most likely be restricted to the additional learning support element of the budget: the principle would be for the funding to follow the student rather than go directly to the colleges as happens at the moment. It would be unlikely to cover the programme element as well, at least initially.

We understand that the borough is in the early stages of a proposal to develop a site in-borough to host a number of young people with complex needs in a learning facility with accommodation attached. The concept is that the main staff would be teachers, but that support staff would visit to provide support for independent living. LSC would be approached to assist with capital funding and Adult Learning and Adult Social Care would look to pool revenue funding, but with clarity on which funding stream supports what. The local parents' group has expressed interest in being involved in developing this proposal.

The table below illustrates that almost half of the people with LD known to services live out of area.

Table 5 : Services and accommodation for people with learning disabilities in 2007-2008

	In borough	Out of borough
Accommodation		
- Hospital		3
- Residential care	19	120
- Supported housing	60	8
- Live independently or with parents	73	
Total	152	131

More detailed information on the 52 young people with LD in transition indicated that no one had moved into their own home or a supported living environment once leaving school. The options seemed to be remaining at home with parents or moving into a residential home.

3.6.2 Proposal

- Further work to identify if more young disabled people could be supported in local mainstream schools if further support was provided to the schools.
- Further work to ascertain whether schools could increase provision to young disabled people over the age of 19.
- Work with a provider(s) to develop living and educational services for people with complex needs in borough.
- Work with the Learning and Skills Council to encourage local colleges to develop their provision for young disabled people. Encourage provision and take-up of the new Foundation Learning tier.

Benefits:

- Developing local services will help young disabled people to maintain their links with family, friends and the local community. This will help to enhance their quality of life.
- Developing local services could be cost-effective in the long-term.

Case Study Example – MacIntyre

Throughout the wide range of services we provide, Learners are given the opportunity to work towards nationally recognised qualifications, these include National Vocational Qualifications (NVQ's) and Open College Network (OCN) Qualifications. Partnership working is an essential part of our approach to Lifelong Learning, we have several partnerships with local Adult & Community Education teams and General FE Colleges. Some of our partnership work involves external tutors delivering learning to individuals or groups within our services.

Case Study Example – Challenging Behaviour Foundation (CBF)

The CBF have embarked on a project designed to enable young people with severe learning disabilities and challenging behaviour to be part of the community and included in the local further education college. The project offers young people a coherent package of support and encouragement for their behavioural needs. The service is provided in a small residential home in the community linked to a dedicated college course. The young people have support to access the range of social opportunities available in the college and the community.

Case Study Example – Care UK

Care UK learning disability services division was awarded a contract from Staffordshire County Council to provide a service for four young adults in transition from residential college. Following the award of the contract Care UK set up a project team headed by the Service Development Manager and including the Regional Manager, Service Manager, Human Resources Administrator, Quality Assurance Manager and Training Manager from Care UK. The project team met with staff from the service users' previous college placements and carried out a thorough holistic assessment to enable the transfer team to set up support plans, risk assessments and behavioural management strategies so they would be in place prior to the move and would form part of the new staff members' induction program. Care UK advertised for suitably experienced staff, led by a House Manager, and devised a program of induction and training to be undertaken before the team member's commenced working with the service users. Care UK staggered the staff start dates to reduce the set up costs and to facilitate the introduction of new staff to the service users at a pace that would not cause anxiety. Care UK supported each service user to spend time in their new home, visits ranged from a few minutes to an overnight stay once they had gained enough confidence to do so. Care UK supported them to choose the décor and purchase new furniture and fittings for their own bedrooms and communal areas. Each person had a dedicated key worker who worked with them through the transfer stage and thereafter. The key workers supported them to initiate the person centred planning process, to send invitations to those in their circle of support and to hold a meeting. This process enabled the service users to set goals and provided a forum to ensure that those involved were committed to playing their part in making things happen.

Questions:

- Are there any organisations who currently provide services in the borough who might have the potential to develop these kind of local services?

3.7 Lack of supported employment services

There is some provision for work and volunteer experience in the borough and one recruitment organisation do provide support to find a job. However, there needs to be more focussed supported employment opportunities for young disabled people in the borough.

3.7.1 The Evidence

The case file review (see appendix one) and service mapping (see appendix two) identified that there were few employment options for young people once they had

finished full time education. In the published literature 'getting a job' is an outcome young disabled people identify as something they aspire to doing.²⁵

The borough is re-tendering the current employment service and is looking for broader supported employment provision. The borough has also engaged a consultancy organisation to assess the opportunities for social enterprise from a business perspective i.e. enterprises that can make money. The idea is to identify ten to eleven options, and then work up two to three of them into business cases.

3.7.2 The Proposal

- Work with a provider(s) to develop a supported employment service.
- Work with businesses / providers to set up social enterprises.

Benefits:

- Achieving good outcomes for young disabled people is about helping them to achieve 'adult status'. Part of this is having a job.
- Getting people into employment could ensure long-term savings for social care.

Case Study Example – Employability

Stirling Council's supported employment project aims to support people across the spectrum of disabilities into or back into employment. The project is part funded by EQUAL and has been operating since October 2003 working in partnership with various agencies ranging from Health services to education institutions. The project uses a person-centred approach where the pace of progression is very much based upon the needs and aspirations of the individual. An open referral system exists where clients can refer themselves and the partner agencies can also act as a referring agency. Clients then go through a period of assessment which involves goal setting and establishing the stages that will enable them to achieve their goal. Once in work clients receive in-work support and an aftercare programme exists where regular reviews take place after three weeks, six weeks, three months, at six months and then annually to help clients sustain employment. However, if a client requires more support then contact can be made more regularly. Aftercare can take the form of practical as well as emotional support.

A 29 year old male who had never been in paid employment before due to his learning disability is now in full time employment and has been able to turn his life round full circle. The client received in-depth support to find a job in his area of interest. He said "before I went into work I got about 50 hours of care support from Social Services. Now I only get 6 hours a week. I don't need any more." His employer, who was facing difficulty recruiting manual labourers, was persuaded by Employability Stirling of the business case to recruit someone with additional support needs. The employer was worried that such a client may experience difficulties adjusting to their line of work but decided to give the client a chance. They were impressed with the client and said that "on reflection we may not have given this opportunity to R, due to our ignorance, but we would have missed a great opportunity. R is now on a 39hr a week contract and is an integral part of our workforce"

²⁵ Beth Tarleton Norah Fry Research Centre (2004) *The Road Ahead? Information for young people with learning difficulties, their families and supporters at transition*. University of Bristol

Case Study Example – United Response

We run a number of social enterprises. These provide employment opportunities for people with learning disabilities in a setting that suits them. They include a cleaning business run under the banner of UR in Business, a disability consultancy, UR Consultants, and UR Sorted, a mailing and fulfillment service staffed by people with learning disabilities.

UR Consultants is a unique service providing bespoke disability awareness training and consultancy at realistic rates. The service was set up to provide a range of practical solutions for businesses, companies and organisations to help them communicate better with people with learning disabilities. In doing so, the service is making sure that people with learning disabilities are more included in society. UR Consultants can provide accessible versions of information and carries out mystery shopping, audits and disability awareness training.

UR Sorted is a professional mail out service in Greater Manchester and Norfolk. It is staffed mainly by people with learning disabilities and offers a range of professional and cost-effective services.

Questions:

- Are there any organisations who currently provide services in the borough who might have the potential to develop these kind of local services?

3.8 Difficulties accessing activities

The issue around accessing activities is less about appropriate activities being available and more about a limited access to transport and 1:1 support to enable the person to participate in their chosen activity.

3.8.1 The Evidence

The case file review identified that there are a number of young disabled people for whom accessing public transport is not possible due to the way in which their disability impacts upon their health or behaviour. On many occasions their families are also unable to transport them as either they do not have access to a car or the young person needs an escort as well as a driver. These young people can therefore only access activities if transport is provided.

Similarly, the complex nature of some people's difficulties means that they need 1:1 support to access mainstream leisure activities. This is often due to the risk assessment completed by the organisation providing the activity who feels that 1:1 support is necessary for insurance purposes.

'One example is a young person who wanted to go swimming. We found a suitable pool and swimming club and managed to organise transport. We then found that the swimming club insisted he needed to have 1:1 support in the pool by someone who was trained to work with people with disabilities. We couldn't arrange this so the young person was unable to do the activity'.

3.8.2 Proposal

- The transport budget would be part of the budget available for funding Individual Budgets.
- Work with services to increase awareness and understanding of disability issues. The aim being to develop a culture and policy of risk enablement rather than risk assessment.

Questions:

- Would it be possible to incorporate the transport budget into the funding available for IBs?
- Which services would it be best to begin work on risk enablement with?

3.9 Difficulties around funding

The issue is twofold. Firstly, there are often delays in the transition process whilst applications for funding are made. This causes high anxiety for young people and their families. Secondly, there is a disparity in funding and eligibility for services between children's services and adult services, such that often young people experience a drop in the level of services they can access when they make the transition to adult life.

3.9.1 The Evidence

Information from interviews and case file reviews highlighted that planning packages of support are often delayed whilst decisions are made about funding.

There is a range of funding streams which could possibly be better used and integrated for young disabled people and young people with learning difficulties making the transition. At the national level, within the DH's Individual Budgets pilot, sites were encouraged to develop processes for the alignment and/or integration of a number of funding streams in order to maximise flexible use of resources for people when purchasing their support²⁶. The funding streams identified as part of the pilot were:

- Adult Social Care
- Independent Living Fund (ILF)
- Supporting People
- Integrated Community Equipment Services (ICES)
- Disabled Facilities Grant (DFG)
- Access to Work (AtW)

As each income stream works in a different way, with different legal rules and policy guidance, it was acknowledged that bringing them together would not be a simple task.

Overall, the study concluded that: "What is not yet clear is whether this continued development of personalised support for individuals will

²⁶ DH, "Funding Streams: Examples of alignment and integration within the Individual Budgets pilot", Putting People First, Oct 2008

include funding streams other than social care." In particular, DWP Ministers decided not to continue to include Access to Work within Individual Budgets for customers of social care.

There have also been some discussions about aligning health funding. For example, the report notes that in Barnsley the local authority and PCT agreed a protocol which aligns the application process for Continuing Healthcare funding with the resource allocation system. This enables a streamlined process for the individual. The local authority offer an indicative allocation and any Continuing Healthcare funding is identified after planning and reclaimed by the local authority from the PCT. And as part of the Next Stage Review, the Department of Health gave a commitment to pilot different models for personal health budgets across a range of health services. It is expected this pilot will commence in Spring 2009. We understand that there are discussions at the local level about piloting provisional individual health budgets: if these pilots go well, the concept could be transferred to young people in transition.

3.9.2 Possible ways forward for using funding more flexibly

- Using a self-directed support (SDS) model under Putting People First. We understand that Adult Social Care has just begun to implement SDS and a Resource Allocation System (RAS) for adults over 18. The approach here would be to undertake an assessment of needs earlier in the transition process (say at age 16) and use a RAS to reach an indicative level of funding to meet those needs. The transition worker would then work with the young people and family to explore options for services to develop a plan within this budget, and then broker the services. The mechanism could be either Direct Payments, or an Individual Budget managed in trust.
- This would require pooling some Family Services' budgets relating to young people with disabilities and some Adult Social Care budgets relating to services for people with disabilities and learning difficulties, including transport, respite, home care etc.
- Examining third-party top-ups. Some families might consider topping up the funding to increase the range of options for services to the young person, in a similar way to third party funding for residential and nursing care for older people. Transition workers could also suggest parents think about provision in their wills.
- Working with Learning and Skills Council to develop individual additional learning support budgets as part of the young person's Individual Budget. These would be in parallel to the personalised budget. This would also require the LSC to work with local colleges to develop more opportunities (see above).
- Exploring the possibility of individual health budgets, again to run in parallel to personalised budgets.
- Exploring housing possibilities early. This could include working with Housing Options for private tenancies with additional support from Supporting People (which could itself be included in the RAS allocation). Other options could include shared ownership with Registered Social Landlords (RSLs).
- Accessing Disabled Facilities Grant (DFG) and Integrated Community Equipment Services (ICES). Transition workers could help access these funds early to enable more young people in transition to live independently.
- Helping more disabled young people to access the Independent Living Fund (ILF), which is a national resource dedicated to the financial support of severely disabled people to enable them to choose to live independent lives in the

community rather than in residential care. Transition workers could work on helping to make applications to this fund.

- Using the experience gained in exploring these options to inform the Commissioning Strategy for young disabled people and young people with learning difficulties.

3.9.3 Proposal

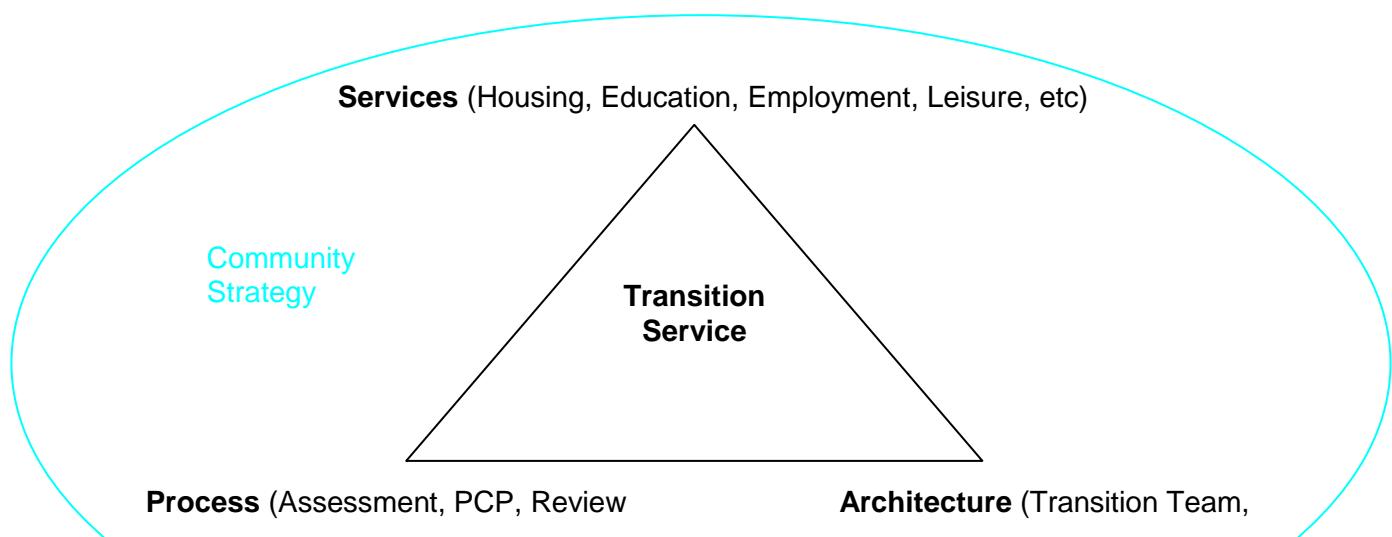
- Set up a working group to examine these options in more detail in order to develop a flexible funding plan, including the concept of parallel personalised budgets, health budgets and skills budgets.
- Develop a mechanism for pooling some funding from Adult Social Care, Children's Services, Adult Learning and Transport to support young disabled people and young people with learning difficulties in transition. There would need to be a mechanism to demonstrate that the funding streams were contribute to the objectives for which they are designated.
- Consider using part of the Social Care Reform Grant to fund a pilot with a few young people to assess how well the proposals work in practice.
- Analyse the funding of individuals in year cohorts to gain a better understanding of where money is spent and how well services purchased match identified needs.

4 SUMMARY

This report has outlined the current outcomes for young people and their families based on previous research and information collected during the course of this work.

The report has summarised some of the issues and barriers to achieving good outcomes. It has detailed suggested practical proposals aimed at improving outcomes and provided case study examples. Questions for further thought and clarification have been raised.

The data collection and subsequent analysis identified the need to develop a transition service in the borough. This has been defined as much more than just having transition workers or even a transition team, it is about creating a holistic service that enables and supports young disabled people to move towards and onto a new life stage.



Monitoring, etc)

Funding, Strategic Commissioning)

This type of holistic transition service can only be accomplished via consultation with all stakeholders and it must sit within the wider circle of the borough's Community Strategy that places responsibility with other council departments to take young disabled people into account in plans.

Appendix One : Case File Summaries

Case Study 1

Referred to adult services aged 16. N attended a local special needs school, lived at home with Mum, had transport to school and received 62 hours of home care/ week. Had initial assessment aged 16 that identified 2 female carers were needed for personal care tasks, 1:1 support required in the community, female escort required to use minibus or taxi. Mum requested information on local options that would enable N to stay at home. Also requested re-housing as current flat was not suitable.

Age 17 second assessment completed. The assessment did not identify any changes. Mum was still requesting the same information.

1 month before 18th birthday agreed that N would continue at the School for another 18 months. 43.5 hours of home care was agreed. CHC funding applied for.

Just after 18th birthday family moved into new accommodation.

1 year left until N leaves the School and there does not appear to be anything else in place yet.

Case Study 2

Referred to adult services 1 month before 17th birthday. P lived at home with Mum, attends a local special needs School, receives 3 evenings / week at an after school special needs club, attends the school holiday scheme and has 48 days 1:1 support at a special needs playgroup.

Initial assessment completed just before 17th birthday stated that Mum would like to explore options for residential college as she would like to return to work.

Last entry states that P will be offered a full assessment at 18 by adult services.

Case Study 3

Referral to adult services aged 16. Lived at home with parents. Attends a local special needs School. Goes to special needs after school club 3 evenings a week, attends kidsactive on Saturdays and in the holidays. Needs 1:1 support for personal care and when in the community/using public transport.

Initial needs assessment aged 16 stated Mum wanted to continue to care for J at home but would need similar hours of activities for J to attend.

At 18 individual budget agreed and temporary use of after school club and kidsactive for a couple of weeks.

At 19 started college with funding for 1:1 support. Partly funded by education and funding agreed on a termly basis. Plan to attend college for 2 years.

Plans to visit day centres when age 20. Would like to continue with further education.

Case Study 4

Initially referred by children's team aged 16. Not allocated a worker so no needs assessment completed. Statement to say M will need an assessment aged 17. Case closed. Referred to adult services again aged 17 this time by the Challenging Behaviour service. Referral indicated that M was attending local special needs School, lived at home with parents, attends after school club 3 evenings/week.

Initial assessment aged 17 identified M can use public transport independently once taught the route, wants to work with children or in Tesco, wants to go to college, would like to move into own flat.

Needs assessment aged 18 identified M had left school and was going to attend

college 5 days/week on a 2 year course with an option for a 3rd year. Would like to move into a shared flat before moving into own flat. Couple of months later moved into a flat but placement broke down and M chose to move back to the family home. Aged 20 moved into supported living. Started working in a supported employment environment.

Case Study 5

Referred aged 17 by family behaviour support services. Lived at home until he was 9 and attended a school for people with moderate LD. School and Mum struggling so specialist education placement for autism found. They too struggled but managed until T was 16. However, school felt their follow on college was not suitable so T moved to another residential school. Expelled from the school so lived at home with Mum and support from 2 staff taking him out to local activities. Aggression to Mum increased so emergency placement found. Placement broke down so went back home to live with Mum. Aggression towards Mum increased again so she asked for residential placement. Placed in temporary residential placement where his behaviour was putting the placement at risk.

Age 18 funding was secured and 1 year on T remains in an out of area residential placement.

Case Study 6

Referral to adult services age 17. Referral stated the need for an IQ assessment. Initial assessment aged 17 identified that H was living at home with Mum, attending college 3 days/week. Travels to college independently, can become physically aggressive. Would like to go to University once college course finishes. Would like some part-time employment for the 2 days she is not at college. Has 1:1 classroom support at college. Care plan suggests referral to Specialist Recruitment Agency at age 18.

Case Study 7

Referral to adult services age 15. Work not allocated so initial assessment not completed until age 17. Initial assessment identified that A was currently at a local special needs School, received 4 hours support from a Domiciliary Care organisation on Sundays, 1 night a week and 1 weekend a month at a residential respite service. Mother wishes to continue caring for A at home or for A to move into a flat with her sister. A would like to access further education, needs female only carers and transport to activities.

A left school at 18 and attended a local college 5 days a week. College will finish in July 2009. Transport to and from college is provided by education services. Continues to live at home and receives 4 hours support on Sundays and a further 7 hours support / week. Goes to a youth club and is on the waiting list for outreach from local respite service.

So far no plans in place for when A leaves college in July. Local advocacy group are going to work with A to create a PCP.

Case Study 8

Referred to adult services aged 16. Case not allocated so initial needs assessment not completed until age 17. Initial assessment identified that L attended a local special needs school and would be going to a local college aged 18 for 3 years (due to leave college July 2009). Due to age there was a need to change respite services

for evenings and holidays.

Age 18 began to access 2 evenings a week at a local special needs club during term time and 4 sessions a week at a holiday scheme during the holidays. However, the club did not always have space for L so started to receive IB that allowed for a more flexible approach to respite.

Care Plan Review dated March 2008 states that Mum is concerned what L will do when he leaves college and that this will be discussed after September 2008.

Case Study 9

Referred to Physical Disability Team age 17. Initial assessment completed and identified that K wished to go to college and to continue living at home with her parents.

Care Plan review age 19 stated that K was:

- Attending college
- Travelling to college independently on the bus
- Attending a singing course
- Going to yoga classes
- Had made friends
- Had done work experience in a jewellery shop

Case Study 10

Referred to Physical Disability Team age 18. Outcomes age 25:

- Passed driving test and has her own car
- Moved out of the family home and living in a 1 bed flat. This is temporary accommodation but permanent accommodation has been found and a moving date confirmed.
- Health has improved.
- In receipt of cognitive behaviour therapy for depression.
- Not attending college.
- Does not have a job or work experience placement.
- Small circle of friends who visit her although she tends not to go out with them due to a lack of energy.

Case Study 11

Referred to Physical Disability Team age 18. Initial assessment identified that M was living at home with his Mother and attending college. M wanted a job in the travel industry so had completed a 1 year course in Leisure and tourism but his grades were not good enough to go on to do a GNVQ. M then completed an evening course for 3 months in Airline Ticketing and did a work experience placement in a travel agents.

M would like to do a modern apprenticeship. He would eventually like to live more independently but needs to develop his self care skills. In receipt of 5 hours support on Saturdays. Only regular leisure activity was Friday night swimming club.

Outcomes aged 21:

- Passed driving test and has own car
- Attending assertiveness training, photography course and cookery course
- Full qualification in ticketing from virgin atlantic

- *No further work experience placements*
- *Still living at home with his Mother*

Appendix Two – Service Mapping

The service map has been removed from this copy of the report for reasons of confidentiality.