Guide to Services for Young People with Learning Difficulties/Disabilities and Mental Health Problems/ Challenging Behaviour:

Technical Document -

Chapter 5.2 Findings from Fieldwork – Telephone Interviews

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Guide to Services for Young People with Learning Difficulties / Disabilities and Mental Health Problems / Challenging Behaviour – Chapter 5-2 Findings from Fieldwork – Telephone Interviews with professionals engaged in transition planning and support to young people with learning disability in transition

This part of the fieldwork programme extends the short programme of focus group interviews completed in 2004. In this stage a wide a range of professions with a variety of associations with transition have been consulted, and their views elicited on what makes for effective transition planning at a strategic level and for individuals with learning disability and mental health problems.

41 people have been interviewed to date. Interviews were undertaken between April and December 2005.

Respondents were recruited from the following fields, on the basis of their known involvement in transition, and by recommendation (snowballing). Recruitment continued until a point of saturation was reached, where no new information was being given:

Joint commissioning	(n = 2)
Social services	(n = 4)
Primary care (OT; GP; SALT; Nurse, School nurse)	(n = 6)
Connexions	(n = 5)
Education policy	(n = 4)
Health Policy	(n = 3)
Voluntary sector (Carers support; MENCAP)	(n = 3)
Advocacy	(n = 1)
Valuing People Support Team	(n = 1)
Academic Research	(n = 3)
Psychiatrist for LD	(n = 5)
Teacher	(n = 2)
Clinical Psychologist	(n = 1)
Parent and author on transition	(n = 1)
Total	**(n = 41)**

Semi-structured interviews were conducted using a topic guide consisting of a series of issues that have emerged in the course of focus group interviews and data obtained in GDG meetings. The function of the topic guide is to prompt discussion rather than to obtain specific data - to discuss freely their experience and points of view, and to offer their opinions on a variety of issues, rather than give factual information or corporate data.

The initial questionnaire consisted of a number of primary topics or themes, and a series of subsidiary ones under each heading. This quickly proved too complex and inhibiting to the natural flow of the interview, and was dropped in favour of a few broad and open themes that allowed people to respond freely.

These covered:
1) The respondent's own involvement in transition planning
2) Their views on what constitutes and is necessary for good transition planning at the strategic level (if appropriate) and when working with individuals
3) Examples of good practice.

Responses were recorded by handwritten notes. As far as possible verbatim statements were recorded, though the majority of data consists of summary notes by the researcher. These were written up as Word files, and transferred to NVivo for thematic analysis.

The codes used to identify themes were derived from the topic guide and expanded as themes as emerged in the course of analysis. The 'code tree' as this structure is known is presented in Appendix A. Data under each code were read and key themes summarised.

Results of analyses

Results of analyses of notes taken in interviews are presented below under various themes. To a large extent, the distinction employed between strategic and individual planning problems is an arbitrary one, issues of significance in one often being of relevance in the other. The very nature of the group of people with which we are concerned implies a significant and continuous need for support, potentially at considerable cost to the public purse. At the same time, this group of people are least likely to benefit from 'generic' services that attempt to provide common forms of service to all such people at a similar time and in a similar place. Such service types, while arguably providing benefits of economies of scale, are not only inappropriate to meet the needs of this group of people, they are out of step with the prevailing ethos of service delivery for people with learning disability in the UK, which emphasises the rhetoric of personal choice and of equal access to mainstream services. Such rhetoric is unfortunately often not matched by the resources needed to fulfil it, leaving a significant shortfall in the options open to service users, their families and carers, and practitioners and managers alike.

Strategic planning problems

> *"In theory it sounds simple and therefore easy, but in practice it is complex and difficult. There are many different systems, lots of different types of information, various divisions between services within and out with sectors; different policies and working practices."*

Joint planning
As the quotation above indicates, one of the main problems in strategic planning for this client group would seem to be the lack of a common framework in which to conceive joint plans. This problem exists at the level of individual planning as well as strategic planning. In spite of many forms of local mechanisms and initiatives and various examples of joint planning forums, strategic planning remains generally a

haphazard affair. Various factors were cited to account for this, including what a number of respondents described as a 'silo mentality' on the part of various service providers and commissioners. Various factors contributed to this phenomenon – a lack of leadership in strategic planning, no mechanisms or precepts existing to determine which agency should take the lead in seeking information and in organising forward planning for this group; conflicting thresholds and definitions of eligibility; non-coterminous geographical and political boundaries; a wide range of often incomplete and incompatible data sets; and unequal levels of representation in planning processes. As another respondent put it:

> *"Too much planning goes on without sufficient knowledge of the needs of this group of young people, and of the local population. Frequently the only grounds for decisions are internal to the service itself, often without the basis of research."*

One respondent, a consultant psychiatrist for people with learning disability, summed up the views of many. The points made in the quote below regarding diagnosis and medication were reflected in other arenas, such as education and personal and social development:

> *"The main problem with the 'system' is that there are so many different services and so many local variations. There is often no continuity of diagnosis between children's and adults' services – for example ASD, ADHD, and certain developmental disorders may be recognised in childhood, but 'disappear' in adulthood, where services tend to work mainly on the basis of traditional diagnoses (schizophrenia, depression, psychosis etc.) so what happens is that the 'need' is determined by the way services function, rather than services developed to meet need. To give a more specific example, children may receive medication under the direction of a paediatrician or child psychiatrist, but may lose that guidance when they become adults and must rely on their GP or a non-specialist psychiatrist to prescribe. Both may be reluctant to take on responsibilities they do not feel trained to deal with. Yet the need remains the same throughout life. For this reason a lifespan model is best for people with learning disabilities."*

Priority

The number of cases of complex needs that might be expected to cross the threshold from children's services to adults' services in a year is small: about 12 cases on average. Though this might in itself seem cause enough to wonder why so many of these young people experience poor transition, it may in fact be a contributing factor. This client group, though often requiring individual packages of care amounting to tens or even hundreds of thousand of pounds per year, is small in number, and thus has a low priority. It is also diverse in the range of service responses needed to meet its needs.

Resources

As might be expected, some respondents cited a lack of resources as a key factor affecting the quality of provision at transition. It wasn't just that there was not enough money, staff or other resources to provide for increasing levels of need, but that the funding system itself allowed for conflict rather than coordination. Certainly there is no 'standard' or universal system by which joint funding is agreed. Rather, the levels of funding available for this client group vary from place to place and from time to time. Pooled budgets were cited as a useful mechanism to facilitate the funding of packages requiring on-going input from health and social services, but even these could not in themselves provide for effective transition without strong and reliable financial commitment and good communication between all parties. There were some who felt that the move away from institutionalised care had not been complemented by an increase in opportunities in a community setting, and that the rhetoric of 'individualised care' was a mask for a transfer of responsibility away from the state as a source of support to the individual and the market, where only the strong were able to prosper and thrive.

Duties of care

At the heart of most conflicts over transition from children's to adults' services, and between health services and social services, is the question of clinical and service responsibilities for young people with learning disabilities and mental health problems/challenging behaviours. Who should take responsibility for these young people is often a contested issue, made more complicated by difficulties in establishing the factors contributing to many of the behaviours that present as 'challenging' to services. Examples were cited of people who had been 'pushed from pillar to post' because their needs could not be reconciled with the policies of different agencies. As one respondent put it:

> *"People with learning disability and mental health problems*
> *may be too vulnerable for mental health services, and too*
> *aggressive for learning disability* [health] *services."*

The problem was particularly acute when people needed to transfer from one service to another. The upper age limit for eligibility for paediatric services for example is usually 16, whereas the lower limit for adult mental health services is 18, leaving those in between potentially unsupported. The matter could be further complicated for those young people at mainstream schools, for whom full-time education under the aegis of the school and the LEA could continue to age 19, though they might transfer to 'adult' health and social care services some time before this. Definitions of learning disability are at variance, too, health services using the threshold IQ X and Social Services IQ Y. [give some examples of what this might mean for individuals]

Specialist services

Access to specialist psychiatric and other services for people with LD was considered important for some individuals, if often unavailable, by many respondents, on the basis that their needs could not be properly addressed within the constraints of mainstream services. Thus while accepting the principle of equal access to mainstream services (such as general psychiatry or mainstream schools and colleges, and so on) many respondents were concerned that in practice these facilities were often ill-equipped to respond to the particular demands presented by some people with

complex learning disabilities and mental health problems or challenging behaviours. The training of many doctors did not include to any significant degree the needs of people with learning disability. It was claimed, for example, that in many places, community paediatricians are the only consultants available to children with learning disabilities, though their knowledge and experience may extend only to the minor psychiatric disorders of children with normal intelligence. Likewise, there were concerns that the needs of children with complex emotional, behavioural and other health needs were not well catered for in mainstream education. One respondent, a consultant Speech and Language Therapist who works extensively with children with ASD and ADHD, was concerned at the low levels of diagnosis of these conditions, and at the fact that many such children were labelled simply as 'disruptive' and excluded from school. Young people with ASD may have particular difficulties in adapting to the more complex and less stable regimes implemented within further education colleges.

Guides
Guides to transition were seen by some as having only limited influence on the formation of policy, though such guides were often hoped to have a 'bottom up' effect. Guides to practice, however well conceived, were not seen to address problems of conflicting policies in the health and social services sectors. There is a need for a 'top down' approach as well if policy and practice are to meet successfully and to produce positive outcomes for all young people with learning disabilities and mental health problems.

<u>Strategic Planning – Solutions</u>

A number of recommendations were made about what was required for improved strategic planning. These included:

➢ Clear lead and commitment from the most senior management forums within and across agencies.

➢ Visible and transparent structures that facilitate joint working and that promote early intervention, particularly the involvement of adult services with young people who are known to need life-long support, so that transition management does not turn into crisis management.

➢ Policy frameworks that allow the exploration of alternatives.

➢ Clear and jointly recognised definitions of need, based on a holistic conceptualisation of physical, mental and social well-being, that recognise that some of the disorders that afflict people with learning disabilities are life-long.

➢ Distinctions between childhood / adolescence / adulthood imposed by service structures should always reflect the needs of individuals.

➢ Good quality and accessible epidemiological information.

➢ A common understanding of the planning processes among staff from different agencies.

➢ Champions to foreground the needs of this group of people.

➢ Budgets attached to individuals e.g. *In Control* (identified at year 9?).

➢ Development of staff roles and relationships to facilitate joint working (A good example of which is the role of Transition Personal Advisors (TPAs , implemented jointly by Somerset Social Services ands Somerset Connexions – see page 12)

➢ Specialist multi-disciplinary teams for 'vulnerable adults' to overcome service barriers.

➢ More services to choose from.

➢ Retention of specialist learning disability services, including special schools and psychiatry of learning disability services.

At a more abstract level, qualities of flexibility, trust, imagination and a willingness to seek solutions rather than deflect problems were widely cited.

Implications for research

The items above, while representing various perceptions of how problems in strategic planning for this group of young people should be addressed, read rather as a 'wish list.' There is a need to formulate key principles that may guide agencies in the development of better joint working 'in real time.'

Individual planning problems

Eligibility: Needs and demands
Many of the comments made about individual planning problems mirrored those concerning strategic planning problems. Those cited often concerned the contested nature of learning disability and mental health, and whether the needs of this group should be seen as the responsibility of health providers (i.e. a medical model) or social care providers (i.e. a social model). This group of young people are often poorly served by the policies of major service providers. For example, many students with learning disabilities – particularly ASD - do not have Statements of Special Educational Needs (SSEN), and examples were cited of the obstacles parents have to overcome for one to be granted (one respondent had recently published a book on her experiences of getting SSENs for each of her four adopted children with ASD / Asperger's syndrome. Her account describes a programme of almost systematic obstruction on the part of the LEA).

It was a source of frustration to some that the only specialist psychiatric service for young people (Child and Adolescent Mental Health Services - CAMHS) often lacked expertise in working with children with learning disabilities. Training in the mental health of young people with learning disability was not widespread amongst staffs

working in paediatric services, and so access to specialist help was often hard to achieve.

For the group of young people with which this guide is concerned, diagnosis of mental illness is often difficult, and the distinction between learning disability and mental illness or emotional disorder is sometimes hard to determine. To a degree such distinctions are irrelevant, at least in so far as the nature of the person and their overall quality of life are concerned. Yet such distinctions are of crucial importance when decisions over clinical and other service responsibilities have to be made. Where this cannot be agreed the young person and their family can be 'stranded' between services, much sympathy being directed at them but little action.

The process of determining eligibility would seem to be a dynamic one, and the relationship between need and demand somewhat fluid. If a need is to be met it must first be translated into demand. This may involve certain key staffs, such as commissioners, presenting the young person's case so that it fits current service priorities.

Lead role

There was widespread agreement that a single lead agency, represented by a named and trusted individual, was of practical help in supporting the young person and their carers through transition. In practice the process of determining who that should be is a matter of chance, depending on the availability and willingness of the parties involved. Though Connexions have a formal duty to take on the lead role, their powers are often limited, and their main influence is on the transition from school to further education and / or employment. The issue of transition is often an afterthought in the young person's annual review, and in a large school many transition reviews may be held at the same time, so that key staffs – such as Connexions Personal Advisors - are unable to attend them all. This relatively simple administrative factor was seen as illustrative of the status of transition in the minds of many schools. It was noted that a number of local authority social service departments had developed new Transitions Social Worker roles dedicated to supporting young people age 14-25 through transition; though it was also noted that these roles brought no new resources with them.

Dominance of the Education Sector in Transition Planning

For many young people with severe/profound learning disabilities, the option of further education is not always appropriate: yet it is only within the education system that there is a prescribed and 'universal' process of transition planning at all. This process, which is prescribed by the SEN Code of Practice a transition plan for people with disabilities is only available for those children with Statements of Special Educational Need while they are in full time education. Initiatives in the transition planning process seemed to some of our respondents to be driven almost entirely by children's / education services: adults' services (health and social care) are perceived to be somewhat reluctant to engage in planning for care in advance of presentation.

Mainstream schools were perceived often to have a poor understanding of behaviour problems and limited resources to deal with it. Once again, this was particularly acute in cases where the child has ASD:

> *"There is a certain culture of denial in many schools. Kids with ASD will often behave well in school, though mainly through sheer effort of will and a desire to conform, and then they'll 'let rip' when at home. Parents know this all too well, but schools often believe only what they see, and don't want to recognise things that are not actually their problem…Teachers don't have much time to devote to problem kids…and they often don't have training in working with kids with ASD."*

> *"Schools don't recognise the value of specialist services…and there's an unfair distribution of responsibility. It's one thing to get a diagnosis of autism or special needs, but while the kid is at school it's the LEA that has to fund any extra support, not the NHS or the social services department."*

The net result is that problems often go unrecognised or ignored within schools for want of understanding and commitment.

A service driven process
Often the process of deciding the level and form of support for these young people is conducted without reference to principles of rights (other than the right under certain circumstances to an assessment). Care packages are in practice likely to be determined (at least to an extent) on the basis of the degree to which an individual 'challenges' existing service provisions. Thus, aggression (to others or towards him / herself) is more likely to attract attention than more passive expressions of illness or distress.

Lack of information, and misused information
The whole transition process is extremely complex, even for those experienced in the field. Frequently professionals do not know who to refer to or how to get advice, information or help, even within their own service sectors. Such information as there is may be hard to access, incomplete or inaccurate. It is not unknown, it seems, for an adult service provider to reject information provided by a children's service in favour of its own assessment. This is done on the misconceived notion that information about a young person, as a child, is not relevant or appropriate to them as an adult. Similarly, while there are a number of standardised assessment tools available, these often require application and interpretation by specially trained staffs and present results that are not compatible with or transferable to other forms of assessment.

Parents are devalued
Parents often feel their knowledge and skills are taken away from them once their son or daughter crosses the administrative threshold of adulthood and he or she 'becomes an adult' and thus acquires a notional degree of autonomy that they did not have even so much as a day before they crossed the threshold, and which they are often quite unable to exercise. Yet it often falls to the parent to act as champion to the child's best interests, at times in the face of considerable opposition from statutory agencies. One parent, who has written a book on her experiences of supporting her four children through the special education needs system, described the difficulties she had encountered in persuading her own local Education Authority and Special Education

Needs Tribunals to grant Statements of Special Educational Needs for each of her four children with ASD / Asperger's Syndrome. Without enormous persistence, skill and courage on her part, and in the face of direct opposition from 'the system', she argued, none of her children would have received the help they needed.

Hard to place groups
There are a number of significant groups of people with learning disability that do not fall within the principal domains of eligibility for many services, including those with ASD / Asperger's syndrome, and those with unspecified mental illness, and those with mild learning disability and mental illness or behaviour problems. The latter group are particularly likely to 'fall between two stools', being seen as neither learning disabled nor mentally ill. For them, diagnostic overshadow, in which the mental health needs of a person are not identified because of assumptions that the presenting problems are caused by the learning disability, is a real risk.

For those with ASD or Asperger's syndrome, specialised, individually tailored forms of help are often a necessity, not a luxury. Yet that help is increasingly difficult to find. The key to special education, for example, is a Statement of Special Educational Needs, which is awarded by the Local Education Authority. The award of such Statements, however, is discretionary on the part of the LEA, and often hard to obtain, even in the face of clear and overwhelming evidence from medical and educational expert assessments. A number of respondents claimed that the likelihood of obtaining such a Statement had diminished in recent years, and that the mantra of mainstream provision was wholly inappropriate and even damaging in many cases.

Invisibility
Many young people with learning disability remain invisible to service providers, even though their needs may have been present from a very young age. If such a young person is not in receipt of a service of some kind from social services before transition, it seems they are much less likely to receive one after transition. Thus, it is essential to be 'in the system' if one's needs are to be recognised. Many young people, while they are in school and fully cared for by their parents, are not in receipt of social services. Some parents tend to assume that the level of support provided by the education system will automatically continue once their son or daughter leaves school. This is not often the case.

Person Centred Planning (PCP)
There was general agreement that Person Centred Planning is a good framework in which to foreground the wishes and needs of an individual and to allow a more imaginative approach to the provision of services. Though some people expressed concerns at its cost and complexity, a number of others were confident that person centred planning, if it is well done, could promote communication between agencies and staffs and carers, and thus facilitate better access to services and improved solutions to problems.
However, PCP was seen by some as expensive to administer due to the level of contact required and the skills needed to do it well. Also, no amount of person-centred planning can be effective if there are insufficient resources available or the mechanisms to access them are inadequate. If PCP is implemented extensively within a locality, it is important that the information that is gathered in the process is recorded and translated so that it may help to inform strategic planning. Such a

translation will require appropriate mechanisms and political will to ensure its usefulness.

Expectations

Far from wanting the moon, young people and their parents are generally realistic about their aspirations and their understanding of what is possible – provided they are given good information and are fully involved in an on-going dialogue with service providers from the start.

> *"Most people realise that expectations often fall foul of reality. What they find hard to tolerate is false promises, dishonesty, and inconsistency."*

Individual Planning – Solutions

A number of suggestions were put forward to improve transition planning for and with individuals. These include:

- ➢ A commitment to ensure that interventions are timely. Start early and review plans regularly. Avoid delaying important decisions as far as possible.
- ➢ Routine screening for ASD amongst children who present with behaviour problems would help to identify problems early and avoid a 'culture of denial.'
- ➢ Person Centred Planning is a good framework in which to foreground the wishes and needs of an individual and to allow a more imaginative approach to the provision of services.
- ➢ A commitment to involve the family as fully as possible.
- ➢ A commitment to be realistic about what is possible.
- ➢ A commitment to engage adults services as soon as possible prior to the young person leaving school / children's services.
- ➢ Provide a 'trusted navigator' who can help guide and support the young person and their family through the transition process.
- ➢ A commitment to ensure a young person has a document that they own and that records their wishes, likes and aspirations as well as their needs.
- ➢ A commitment to transfer power as far as possible to the individual or their representative. This may be by means of an allocated budget or by a Direct Payments scheme. Such budgets may be held by the person, or more likely on their behalf by a third party. It can also be fulfilled through the quality of transition planning and the support given to individuals and their families.
- ➢ Plans should be able to show they have balanced the need for security and support with the need for opportunity and for experience. The range of information provided to parents as well as young people should go beyond the provision of services to include information on housing and leisure opportunities, friendships, and include such issues as providing for a beneficiary who is disabled in a will.

Examples of good practice

Respondents were asked to give examples of what they considered to be good practice. Suggestions ranged from particular tools for use in personal transition planning to examples of service partnerships. No information was available on their effectiveness. They are presented under various types below:

Service partnerships
➢ Walsall Transition Team (based on the Team Around the Child model) consists of a social worker, a community health worker and a manager. They only work with young people with SLD & CB, not those with ASD.

➢ Sandwell m/d Transition Team. Three Connexions workers will be seconded. In principle there is agreement for a youth coordinator, a LD nurse, a social worker for children with disabilities, a care coordinator, a social worker for adults with LD, and access to physical and sensory support staff. All of these are seconded. The transition team is one of a number of different teams for various age ranges: pre-school 0-5; school age 6 13; Transitions 14 - 25 (those with more complex difficulties may be supported through to 25, otherwise 19). It will comprise: Pre-school education team; Child Development Centre Team (used to be in Sandwell Hospital; Children with Disabilities Social work Team; Education services support team; Transition Team (14-25) (including 4 Connexions staffs); CAMHS; Therapists; Youth & community worker with a brief to facilitate leisure needs;

➢ Transition sub-group, Stoke on Trent Partnership Board, which includes and works with Education, Connexions, and so on. They seek and share information, and this forum was said to have facilitated better inter-agency working.

➢ A Connexions PA has been linked to the Early Detection and Intervention Team in Aston, a mental health service for young people. The team only works through GP referrals.

➢ There are discussions in Birmingham to set up a Transition Team for people with LD aged 13 - 25. The team may be multi-disciplinary, but will focus on assessment only, not provision. The advantage is that only one transition age would present, instead of three (16 and 18 and 19).

➢ LD services in Somerset have a Transition service that involves Transition Personal Advisors seconded from Connexions employed to act as specialist coordinators for young people with LD. Clients must be people who are eligible for a service from the Adults Services at the local authority.

New Posts within existing services
➢ The Adults CLDT in Dudley is creating 2 new Transition posts to work with children aged 16+. These will be social workers, for whom part of their responsibilities will be informing and involving parents and service users.

Provider Services
➢ KeyRing is an organisation that aims to provide flexible forms of support to people with LD, including those with MH problems. Active in about 20 Local

Authorities, it seeks to support groups of about 10 individuals living within a fairly close geographical area in individual supported living units, with staff available to help if needed. Their way of working can be good for those whose needs are likely to change or fluctuate. At the moment they are involved mostly with adults, but they could work with young people moving into independent living. The local Housing authority provides the accommodation, and KeyRing the staff. Each individual is a tenant. Their way of working is more risky and demanding for staff and commissioners. But it also allows the uptake of opportunities.

➢ Red Roofs Surgery, Nuneaton, has been doing regular health checks for its adult patients with learning disabilities for many years. They have developed a good database.

➢ PAMIS (Promoting a More Inclusive Society) is a voluntary organisation for families of and people with PMLD in Glasgow. They employ a community worker with funds from the Community Fund

➢ YouthPass – enables young people to buy help for community activities for up to 12 hours a month. The service is run by people with disabilities, and aims to help people define their needs themselves. It is a preparation for people about to receive direct payments. As yet, it is not used by people with PMLD (who are even less likely to take up Direct Payments). Such people could if supported appropriately, for example by an Independent Living Trust and suitably trained staff, sympathetic managers and family, and so on. So far it is used primarily by people with a physical disability.

➢ A new day service for people in Stoke who need intensive support. This has a base, but undertakes most of its activities away from this.

➢ Liaison workers, Bradford - can be instrumental in facilitating a plan, in driving it, and in involving YP and families. The liaison role is often better if it is non-professional. The people who really need a liaison worker are those with problems accessing even basic services; or with little awareness of those services. In Glasgow there has been a project to create liaison workers for asylum seekers entailing virtually the same job description. This could suggest a useful model.

Financial initiatives
➢ The In Control Project is funded by the VP team and involves 6 Local Authorities. It represents a way of building upon PCP by granting an individual a sum of money to spend on LA services. The sum is based on an assessment by the local authority.

Tools / policies
➢ Transitions Pathway. Excellent practical guide to transition for all young people with disabilities.

➢ A pilot Regional Transition Strategy is currently being developed in the West Midlands and led by Connexions. The aim of this is to support collaborative

working and to speed up the process of identifying needs and sharing information. It is intended to extend further than some of the 'basic' needs provisions, such as residential care, and to embrace employment, further education, direct payments and so on.

➢ The SEN Regional Partnership Boards have each addressed the theme of transition to one degree or another. For example, The Eastern Region has developed a protocol on placing people out of county, to which a number of Local Authorities have signed up. They also have a parents' guide, called Thinking about the Future. The south west has developed a short guide to transition planning. The North East developed a CD ROM called Transplan. The National office has a document called Future Positive, to which over one hundred LAs gave evidence of out of county school placement. The East Midlands have a document giving an audit of 'Low Incidence' (sic) i.e. kids with high support needs (low incidence means, 'not many of them.').

➢ Communication passport (MENCAP), which involved 'buddying' a person from a special school with one with disabilities from a mainstream school. The pair would choose each other from a portfolio consisting of photos, diaries, pictures & words. This is a national project, part of Multimedia profiling: http://www.askmencap.info/IFM/GenInfo.nsf/0/B9B55AB13E07497D80256E 920042B324?OpenDocument.

➢ MENCAP has recently developed a Transition Pack for use by schools and young people, that includes training items for teachers and a lot of web-based resources for students.

➢ Decision to promote PCP by the Learning Disability Partnership Board in Stoke-on-Trent. A local agreement has been made between members of the Partnership Board to focus on PCP in the transition years. Such an agreement may serve to foreground PCP as the primary framework in which needs and services should be conceived, and to emphasis that Valuing People provides a moral and policy framework for all services, not just SS & Health.

Information
➢ Stoke on Trent. An 'approved' list of providers who are able to develop individualised packages of care for people has been developed. Most of these come from the Not For Profit sector in the county

➢ SEN Regional Partnerships Board has developed a Transition Information Network (TIN), which is a source of information on matters relating to all children with disabilities. The TIN includes the council for disabled children, the National children's bureau. http://www.patient.co.uk/showdoc/26739256/ TIN produce a guide to sources of information on transition. See http://www.myfuturechoices.org.uk/downloads.php

<u>Conclusions</u>

Interviews to date have helped to highlight some of the many presenting problems of transition at both a strategic and an individual planning level, and to indicate a range of solutions that are being practiced in various parts of the country.

In spite of many positive efforts and much hard work on the part of many people and organisations, it seems that transition planning generally is a haphazard affair. There is also very little good evidence on what works; and if our project is to have any effect it may be to take steps towards identifying some of the key factors that contribute to successful transition planning for this group of young people.

From what we know so far there are few common standards to guide the practice of transition planning for practitioners, commissioners or parents. Those that do exist, such as those contained within the SEN Code of Practice and various National Service Frameworks apply only to certain young people with learning disabilities (i.e. only those with statements of special educational needs) or to people with certain kinds of health conditions for which treatment or care is provided under the NHS (e.g. those with mental health problems or mental illness, or with chronic health problems). Even where these frameworks are appropriate there may be a wide variation from place to place in how they are implemented and the way services work together.

Successful transition would appear to depend on a combination of a number of factors, not the least of which is a champion – often a parent – who is able and willing to challenge the barriers that exist between services and to promote an individual young person's needs in the face of hostility and indifference. The problems seem not to lie with individual professionals or agencies but with a system that is designed to prevent rather than facilitate support. Without a definition of rights applicable across both health and social care sectors, a common set of standards and procedures, and the resources to provide them, it is hard to see how access to the kinds of services these individuals need can be assured in all locations.

Part of the problem lies in questions of identity: are these young people primarily 'learning disabled' or are they 'mentally ill'? Are they children, or are they adults? From these follow questions of recognition – whose responsibility are these young people, for what and when? The fact that that they are a 'small volume / high cost' group of people, who may each present a range of needs related to all of these areas at the same time does not help to clarify their position under present regimes; and there is little sign of any generalisable mechanism to do so.

Strategically the problems of this group of people may be said to boil down in many cases to problems of recognition. Their transition to adulthood is often not well recognised by services that will take up responsibility for them once they reach a certain age; and their mental health needs are not well recognised in an education system that prioritises education development within an academic curriculum. Likewise, their mental health needs are not well recognised within schools. Service user's views and parents' views are not well recognised in a system that marginalizes them in favour of professionals' views and service requirements. And so on.

If better strategic planning can be achieved through improved and more sophisticated recognition of needs, improvement in individual planning will follow from enhanced levels of commitment to broadly 'person centred' principles. Such commitment is manifest in the behaviours of key individuals who represent certain organisations, and who thus embody their organisations' moral as well as structural codes. There are many such individuals working hard to overcome problems imposed by inadequate systems and processes. These barriers are fundamentally political – i.e. they stem from policies and the philosophies and power relationships that drive them - rather than clinical or educational factors inherent in any individual.

Many examples of good practice cited by respondents in the course of interviews involved new and largely untested multi-disciplinary teams, the belief seeming to be that simply putting professionals together and calling them a team would overcome problems of poor communication. Some respondents expressed scepticism towards this belief, arguing that such initiatives did nothing to enable service users directly to influence the way support was organised, and that only by transferring power would equality of access be achieved. Power is best manifest in funds to purchase services and in the role of the service user as a consumer.

A number of questions remain: how far are services prepared to change to recognise the particular problems of this group of young people and to see them in their own terms; how willing are they to see beyond their own boundaries and understand the nature of other organisations and the contexts in which they function; and how committed are they to relinquish power so that individuals have more choice and control over their own lives. These are fundamentally moral issues, from which questions of resources and techniques of planning and 'joint working' stem.