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

Technical Document -

Chapter 5.1 Findings from Fieldwork – Focus Groups

Nick LeMesurier; Research Fellow,
Niyati Bathia; Research Associate,
Shoumitro Deb; Clinical Professor of Neuropsychiatry and Intellectual Disabilities, and
Gemma L. Unwin; Research Associate

Correspondance to:
Shoumitro Deb, MBBS, FRCPsych, MD,
University of Birmingham,
Division of Neuroscience,
Department of Psychiatry, UK.
Email: S.Deb@bham.ac.uk

www.ldtransitionguide.bham.ac.uk

May 2007

Guide to Services for Young People with Learning Difficulties/Disabilities and Mental Health Problems/Challenging Behaviour – Chapter 5-1 Findings From Fieldwork – Focus Groups

The Practitioners Group

This group focussed much of their discussion on the presenting problems suggested by the vignettes, their possible treatments, interventions and support strategies; and the obstacles before them in securing a smooth and stress free transition, many of which were widely recognised by participants but which often seemed to them inexplicable, or at least unjustifiable. Their approach tended to focus on the needs of individuals as exemplified in the vignettes,

Peter was regarded as a good example of a complex case, presenting significant health needs and likely to encounter problems at transition. His needs were easy to summarise:

> *"Peter needs a highly specialised service to do at least three things. One is to alleviate his self-injury. One is to minimise his aggressive behaviour. And a third is to enable him to develop better ways to help him to interact socially."*

While needs may be relatively easy to identify, arranging for them to be met was seen on the whole as a process characterised by conflict:

> *"I think there is a sense its almost like playing chicken. There's a sort of stand off between the services."*
>
> *"You mean; it's all down to who blinks first?"*
>
> *"Yeah. Exactly, and let's wait a bit longer to see whether we can force health to step in or we can force social services to step in. The stand off continues until the eleventh hour, and they both come together and say, well we must do something jointly. But then of course, they're lacking the time and where do these solutions come from?"*

…………

> *"At the eleventh hour what will probably happen is that social services will come in and they will ring up and say, please take this person; they've got to move. Then perhaps the person will be moved somewhere that is totally unsuitable because it's the only place that's got a vacancy, which will very rapidly break down because of an escalation of behaviour, and then they'll be admitted* (to hospital)."

The process of developing services for individuals who require high levels of support was acknowledged to be complex. But there was a sense of frustration that it often did not happened till it was too late, at which time there was no option but to admit the person to an acute service:

> *" Where we have a problem is when a young person…needs to have something created for them, and there really isn't a mechanism for the joint commissioners to get together and to agree (*a transition plan). (At that point) *we need to find start up costs, we need somebody to build this, and we need somebody to design it. That sort of commissioning doesn't seem to be happening very effectively. That's not to say it never happens. It does – sometimes. Where it tends to work is where somebody has been in hospital. This is why I end up with people in my* (assessment) *unit who have been admitted to me at 14, or 15, or 16, who are with me for three years…It sometimes takes that long for the whole process to start and for them to be discharged to something that has been designed around them.*

The sense was thus of a process in which too little was done too late, in spite of the fact that throughout childhood a person with multiple disabilities would attract many assessments and interventions from a wide variety of services. It was therefore not in the collection of information, but in its transfer.

The issue of choice for people with complex needs was a strong theme in the interview; but it was not without its difficulties:

> *"I think that* (offering meaningful choice) *is incredibly problematic, because how can you work with somebody with severe learning disabilities to get them to understand their theoretical choices about the future? With somebody with his level of problems, it's only going to work if you've got two or three clear options that you can show him, and say which one do you like? You can't talk to him about theoretical possibilities of somebody developing something for him in the community; it'll have no meaning for him. The only information that will make sense…is concrete information and things that he sees."*

Some felt that meaningful expressions of choice could be recognised if staff and services are attuned to recognise it:

> *"But some of the choices and preferences are to do with much more immediate things, like preferred activities and preferred lifestyles, you know. We always make life difficult for us by saying, well, have you given him choice? But actually I would think that most of our clients, no matter how disturbed they can be, prefer doing some things rather than other things. You know, there are some things they just don't like, end of story. What we are*

> *relatively poor at doing is regarding that as a choice, and then respecting that. And then saying, what can we do to maximise the things that he likes to do, and maximise those. I think the challenge for us is not to say, well he's SLD – no choice! But to say that he's expressing certain, manifesting certain behaviours which are obviously positive. Because some people obviously don't like, say loud noise, say rapid change. And how do we then support that, when he's saying, I don't want have an abrupt change; he's saying that in his actions. We need to be sophisticated enough to understand. So I feel that we make this issue of first preferences rather black and white, and rather simple, when actually it isn't."*

Naomi's case threw up a number of issues that participants recognised as problematic. The first was diagnosis, and the implications this had for eligibility. Whereas Peter's needs had been identified quite succinctly at the start of the interview, it was clear Naomi fell between a number of stools. The following dialogue illustrates the difficulty of 'placing' her needs with any particular agency. Whose responsibility is she?

> *"Initially, we* (social services) *would say we couldn't work with her. It has to be moderate to severe learning disability or else we don't touch it."*
>
> *"That's a policy decision?"*
>
> *"Yes. Up till now, disability assessment officers, who before us did all disability, learning disability as well as physical, well now we don't. Transition social workers do learning disability only, and then it has to be moderate to severe."*
>
> *"Can I check your definitions as well?"*
>
> *"We* (community nursing) *have got very brief eligibility criteria that's come out this year that we've still not come to grips with, to be honest."*
>
> *"We* (mental health services for children) *have this problem all the time with people who have a mild learning disability but are described in educational terms as having a moderate or severe learning difficulty."*
>
> *"Social services don't use disability. We use difficulties and statements."*
>
> *"So we are talking IQ levels?"*
>
> *"That's part of it. Social services have got a procedure that goes through a number of criteria to determine whether someone has got a moderate or a mild LD…Also our health colleagues do work with people with a mild learning disability and will often refer to us, but we have to say, I'm sorry we can't work with this person, which causes a lot of unrest between us."*

This health worker was more succinct. Her use of language is illustrative of a sense of frustration:

> *"I can guarantee that if it went to mental health services, in our district, they'd see learning disability and hand it straight back. They won't touch anything they think has a whiff of learning disability."*

The problem can be compounded if a young person has ASD in addition to other disorders. Though ASD can present problems in learning, communication and social functioning, it may not be recognised as a significant disorder. This comment was from a health practitioner

> *"So we have a young person who may have autism, who certainly has epilepsy, who has very complex needs, which functionally may well be functioning at a level that is far below a mild LD. And if you have somebody with a mild learning disability or even borderline learning disability who has severe enough autism they will function as if they have a severe LD. They need the appropriate support, as if they had a severe LD."*

The view of this social worker was somewhat different:

> *"I think it is important as well not to label this girl. If she is presenting as having a mild learning disability regardless of whatever reasons, if we try and push her down the road of going with our services in SSD, which are for people with moderate to severe learning disability, then there is nothing we could offer her that would in any way enhance her skills. We would be looking toward Connexions to offer other alternatives, rather than put her in a service with people who have less ability."*

Managers and commissioners group

The managers and commissioners group focussed largely on general issues and principles, particularly the rights of individual service users and the difficulties they (commissioners) had in securing funds from many disparate sources to provide the kind of multi-disciplinary care that is needed for people with complex needs.

There was widespread agreement that early planning was important if transition was to happen smoothly. However, participants seemed to acknowledge that in reality much was done for individuals at the last minute, and there was little in the way of forward planning at a district or regional level for those people with complex needs:

> *"There needs to be some kind of agreement in place, or some kind of system set up that those kind of things are resolved very early. Because frankly Peter is not going to be, for want of a better word, cheap to look after. He's probably going to need some kind*

> *of individualised placement, he's probably going to need some kind of physical interventions, and he has needs that indicate that being with other people is probably not the best way of managing things. And I think that the general approach to this is: hope it doesn't come back; hope we don't get anybody like this. And of course the statistics tell us that somebody somewhere will, and increasingly we will find people like this…"*

A defining characteristic of the system in which transition is undertaken would therefore seem to be fragmentation. For example, different areas seem to offer different mechanisms and options, and there appeared to be little concurrence between Local Authorities and the Health services as to how their separate responsibilities should coincide:

> *"Looking at the circumstances, having a policy which suggests that people should be accommodated in their own area when you don't actually have the resources to do that is a difficult one, but I'm sure not unfamiliar to us…There are different guidelines for local authorities and the health service about what is and isn't out of area anyway…"*

The portrait of the commissioning process that emerged from this interview is of one that is rarely functionalised, and is thus dependent to a large extent on the particular skills and ingenuity of the local commissioner for a successful outcome.

> *"The…issue… is to define a... need, because health is free at the point of contact, whereas social care is not. It's discretionary; so as a commissioner you are working with two different legal frameworks, that you have to try and bring together. You've got Fair Access To Care in social services adults services; and you've got Continuing Care in health…So what you have got is two agencies arguing over what is going to be picked up and what is not. And in both cases, as a commissioner, you have to be able to demonstrate health and social care needs, both to accountants and to solicitors if ever you are challenged."*

Part of the art of the commissioner is therefore to create a profile of their client's needs to funders so that they may be recognised by them as eligible for services. This may nevertheless involve a 'trade-off' between an ideal service and one that can be afforded:

> *"I think we are all grown up on this though. I mean people don't live at home forever if you can avoid it. You know, I think we'd like to give people the opportunity not to live at home if that's possible. It's just that with pressures on resources, pressures on actual places, places on skills, people and all those things, you end up*

> *taking options that you might not necessarily think are the normal ones"*

How a person's needs are presented may have a crucial effect on what happens to them as they pass through transition. Appropriate use of language and subtle interpretation of the various legal and policy frameworks are important aspects of this largely obscure art:

> *"I think it goes right the way back to practitioners who are assessing need, and the language they use. I think one of the issues we've got, someone who worked on the Disability Discrimination Act and social model of disability in health terms; it's a medical model, and in social terms; it's a social model. And so the language people use: if someone quotes someone as having complex needs, then that will not get to any health fund. The kid doesn't have a condition attached to it. In legal terms, I am talking about now. You've got to overcome that sort of language barrier, where you are actually sitting down and saying, what are the presenting behaviours, what are the diagnoses, what are the needs, what are the recommendations? And it's really the trust between the two organisations – and it usually is two organisations, that's been my experience, or a voluntary provider. And looking and saying, in the service specification, you are going to buy, are you going to ensure that the social needs of that individual are flagged up with equal value to a health need."*

It follows that those young people who do not have very clearly defined problems, or who do not obviously 'challenge services' may be harder to define in these terms, and are thus less likely to attract attention when it comes to seeking funding for services.

> *"The beauty…for us would be to be able to say, he's got a severe learning disability. We know that our process could follow this route. But it's when we start to find someone with a moderate or mild learning disability, then that's when the funding gets difficult. As you say, if you don't get a direct key worker that follows it through and gets the funding then nobody wants to take the responsibility for the funding."*

Some people felt that so-called 'pooled budgets' should offer a useful mechanism in cases like these that required a high level of multi-disciplinary involvement. However, pooled budgets did not provide extra funds and were still subject to definitions of responsibility:

> *"…you can't have health providing social care, nor social care providing health. You have your section 31 Agreement, which is your pooled budget; but my argument, my experience, is that the amount of money is no different. The process is different, but the amount of money is no different, because it is still the same two*

> *amounts of budgets that they are pooling together. What you've got to do is strategically flag up; these are individuals that we have a duty of care to, which you have not strategically planned for in your local delivery plan, or your committees within social services. We need to get learning disability on the agenda. And without doing that at a strategic level you really are struggling."*

The market for services for people with highly specialised needs includes many independent and voluntary sector providers operating under license from local authorities, who are able to seek funds independently to meet the needs of a particular client group. There is thus competition between providers, with individual agencies seeking to attract clients in search of services tailored to their needs, with varying degrees of quality and effectiveness.

Not everything was chaos and despair, however. One participant described a recent attempt by her PCT to develop a more systematic approach to commissioning, involving a seven stage process that is initiated by the commissioner. This is based on a tendering process in which selected providers are invited to submit proposals to meet a person's needs, along with a breakdown of costs. It is unclear, however, to what extent the individual's wishes are included in the process, and it still requires the commissioner to have a sophisticated knowledge of the funding system and to know how to exploit it by emphasising the person's deficiencies in terms that suit particular funders. It is thus arguably not as person centred as might be claimed.

Parent carers group

There was an overwhelming sense in this group that services are not responsive to the needs of young people with complex needs, particularly autism or their families. They often felt marginalized in the process of transition by staff in adults' services. By contrast, they felt that staff in children's services generally recognised their contribution. In their view, their offspring did not so much grow into adulthood, but pass from the responsibility of one sector to that of another. They felt that their efforts and their knowledge were often disregarded, especially by social workers, who saw parents as a barrier to their offspring's autonomy and growth. Yet, ultimately, they argued they are the ones who provide consistency of care and know their son / daughter better than anyone else.

> *"This whole normalisation thing, the idea that they have choice and they have rights, and that's fine. The problem with* (our children) *is that it doesn't quite fit…because they don't understand the consequences. And they say it's the parent trying to be controlling!"*
>
> *"Yeah, professional services don't actually have that inbuilt feeling that comes with knowing that emotional drive you have as well."*
>
> *"Absolutely! I'm classed as a carer, but at the end of the day, I'm his Mum!"*

> *"Parents don't see themselves as carers, not at all, not until they get to an adults' service."*

One of the general themes to emerge in parents' discourse on the subject of transition was the conflictual nature of the process. They often expressed a sense of powerlessness, particularly in the difficulty they experienced of accessing information. They felt isolated, excluded by a system that is complex and largely out of their control, and even pitched against them.

> *"You know, they don't give you information about direct payments, they don't give you any information about person centred planning... It is there, it is about, and people do get packages together which include social care, housing care, education...but you have to find out for yourself".*

One parent complained that one local authority was deliberately obstructive in the way it informed parents of their rights.

> *"The other issue is that X social services are actually saying that nobody is entitled to a community care assessment until they are 18, which is blatantly not true... So not only are they not giving any information, they are giving mis-information!... When an individual challenges them, with a lawyer or whatever they give in and they do it...They settle literally on the court steps, so there is never a court judgement. And that's how they work, because it is all about crisis management. It saddens me to this day that this is how it works."*

Parents, of course, maintain life-long relationships with - and often responsibilities for - their offspring. This may be one factor behind the call made by this parent, widely supported by others in the group, for a single, continuous source of information and support:

> *" If under one roof they provided the information through the education set-up, primary and secondary, and straight into social services set up, and that the people that were operating this system within it were able to be fairly regular and not have a change of personnel every few weeks and months,...If all these things were available from one central source, whether it was in the form of packs or, you know, what's available to you, or personnel that were actually doing the help, the whole lot was in one centralised source, you would feel that you were able to walk in and walk away feeling that you had probably got a deal. But you can't at the moment because everybody's all spread out all over the county. When you go back the next time, it's a different set of people, and they don't know anything about you!"*

Contrary to the policies of many local authorities to resist out of area placements wherever possible, parents in this group were prepared to accept them, if that meant their son or daughter received the best care:

> *"I think fundamentally it would be nice to accommodate them within the area that you live. But you can't. You've got to look outside"*
>
> *" I have concerns when they are withdrawing out of county, because they want to bring everybody back, simply to save money."*
>
> *"Its not about the most difficult people, its also about choice...If you want to, say, access further education for your child with learning difficulties...you may have to go out of county. It isn't about the fact that they are difficult...It's about sending your child to the best university if they can get there. You don't hear anything about your other kids going off to Edinburgh or wherever. As a parent you'd be saying, well actually I found a great place in Doncaster that I want my child to go to."*
>
> *"Yeah, but social services especially, they say, you've got to get everybody back in. You are throwing the baby out with the bathwater."*

'Mixed' Group

This group, consisting of people drawn from the previous three focus groups, specifically considered solutions to the problems of transition for this group of young people.

All members agreed that there was not enough accessible information available to describe the profile of young people with complex needs. The irony of this statement, given the amount of information that is recorded about these people by various agencies, was not lost on the group.

> *"You need to know your client group. Who's out there, who they are? That's what you need in order to do your strategic planning, to know who's going to be coming through, who's going to need your services. And I don't think that's always as well done as it could be."*
>
> *" Which is odd really, seeing as all these people go through schools. So what better way of getting hold of that information than using the whole of the school system to deliver that to your door stop? But we still don't seem to do that, somehow."*
>
> *"There are so many other agencies involved with children at school now."*

This group shared the view, held more or less consistently throughout the whole programme, that the problem is not lack of information, but its effective transfer.

> *" I think it is clear that children's services, regardless of who they are, they know what children they are working with, they know their problems, they know the issues they are going to face. And lots of times, if you talk to people like education psychologists, when they go round in schools, they can pinpoint people that they know, when they become 15, 16, or 17, they'll be out of county, because they will be so challenging or so difficult or complex that local services can't provide it. So they know that. So it's about transferral of information, it's about key people taking that role on, its about joint working. Its actually not rocket science."*

Rocket science it may not be, but there are still considerable barriers to overcome in a system that is unnecessarily complex and often dysfunctional. The tone of this interview, as with the others, was often one of frustration, due in part to awareness that the welfare of individuals with disabilities was largely a matter of chance, that they commanded few rights and little status:

> *"I think there's a step that we need to acknowledge, and that is that most of the large agencies don't do things unless they have to. It's really important for the legislation, the policies and the guidelines, that they say they have to have the knowledge of the children coming through. So that's the first lever of strategic planning, to be saying, there's no question, you've got to do it."*

Allowing for the fact that there was little hope that the broader legislature could be influenced, the discussion turned to more immediate steps that could be taken to help bridge some of the gaps. The basis of these was agreement on the underlying philosophy and how a person with disabilities was recognised and construed by the system. This health worker argued for a process of definition based on severity of diagnosed need:

> *"There are two dimensions; one is a clinical dimension which is to do with labels (such as 'children', 'adults', 'learning disability') and all that brings with it. But the flip side of that is the need, something that needs some action, something that is not right …One of the ways in which to try and reduce the delays is to try and highlight the need…The second thing is, we are talking complex health and social care needs. So we need trigger points in the system to make more and more things happen, depending on the severity of the problem…There has to be some kind of discrimination which allows us to pick out the more needy from the less needy, and that way reduce the size of the problem."*

The answer, from this point of view, is to functionalise the whole system, so that specific responses are formally designated to specific agencies to address specific needs, and to define this process according to a pathway with clearly defined stages and gateways along predetermined routes. Such a pathway is already under development within the West Midlands for all children with disabilities at transition.

Central to the pathway process is the influence of a 'Transition Coordinator':

> *"Now the transition worker is in a sense not disability specific. But they are transition specific…Somehow this transition worker has got to be linked in either structurally or through management with adults' services, so that cases are handed over through the transition worker."*

An emphasis on a single transition worker was seen as somewhat idealistic by some members, who expressed doubts that any one individual could command such authority:

> *"I have some difficulties with that. What I have a problem with is the expertise of the transition worker…It demands a lot of someone's knowledge and expertise to do that".*
>
> *"…It can't be in the ownership of one of the agencies because the stakes are too high and it's too complicated. We do need to know about the health issues. But equally from a social care point of view, social services need to be involved. And then there are things like lifelong learning and education.* [They all] *need to be included.*

One solution is a pathway to help people negotiate the system. This could be used to support a transition worker, or stand alone as a reference for all parties involved in transition. Such a tool is under development in the West Midlands for all children with disabilities. The advantage of a pathway is that it can provide an external referent, independent of any particular agency:

> *"I've done a care pathway; I think they're really good because it gives you a model to work from that people can actually use... Changes to the whole transition thing will need to come from the top, like the vulnerable adults, where if you don't act you're in serious trouble. But for now, something like this I think is the key to a lot of things."*

On its own, a pathway is not enough, however. For strategic planning to be effective the pathway has to be rooted in good epidemiological data:

> *If you can get the transitions right for that person you'll save millions of pounds at a later date. We won't*

> *have to waste our time looking at all these out of county placements, because we will have commissioned in an informed way for future generations, because we will know these people are coming up.*

Summary

The overwhelming message to emerge from these focus groups and interviews is that there is a need for better coordination of information and of responsibility for young people with learning disabilities and mental health problems at transition. There is much good work going on, and a great deal of information recorded about a relatively small population of people whose needs, while often complex and difficult to meet, do not change significantly and are usually well recognised. These people are likely to need high levels of service from an early age, and as such are well known and thoroughly assessed!

Beyond the call for someone to take charge, there was little agreement who should do this or on what basis. The needs of such people are likely to remain a mixture of health, social care and education needs, and as such cut across a number of service boundaries and legal definitions of responsibility.

While major changes to the system are likely to come about through policy decisions made ‘at the top’, there were a number of local strategies that it was felt could help ease the problem. Central to these is the form of some kind of unifying authority, either in the form of an agency or role that cuts across all agencies; or in the form of a pathway or guide that is recognised by all agencies and is seen to provide at least a blueprint for how transition should work.

Whether the authority is in the form of a person or agency; or a written guide, it should be accessible, comprehensive, authoritative, and flexible enough to allow for inevitable variations in needs and preferences, as well as being sensitive to local circumstances. It should be politically neutral, in that it should not reflect the interests of one group or agency over another, and it should function on the basis a clear and explicit definition of the individual and their rights. Such a demand, taken to the limit, is unlikely to be met. Indeed, it may express more clearly the extent of the problem than a practical response to it.

As a step towards this the process needs to be defined and functionalised, probably on the basis of a pathway or plan in which key stages, ‘triggers’ and accountable parties are clearly identified and their responsibilities defined. The pathway should be constructed so that individual service users and parents have some degree of choice in the services that are constructed for them. And though there is no National Service Framework for people with learning disability, standards in other NSFs are appropriate to this group and can be used to provide benchmarks and emphasise the importance of equity of care.