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

# Technical Document -

# Chapter 4.4 Literature Review – Summary of Papers on Joint Working

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 4.4: A summary of the papers discussing the impact of Joint Working for young people and adults with Learning Disabilities and Additional Mental Health Needs

**Case, S (2001). Learning to Partner, Disabling Conflict: early indications of an improving relationship between parents and professionals with regard to service provision for children with learning disabilities. *Disability and society*, 16 (6), 837-854.**

## Background

The literature that discusses the experience of parents who look after learning disabled children has, more often than not, reflected parental dissatisfaction with the professional world owing to a lack of shared perspective for the child's future. Many studies seeking the parent's perspective on their experience with professionals (mostly medical), has concentrated on their reports of feeling marginalised and disempowered, resulting in an unequal relationship.

This study seeks to discuss in further depth the issues and concerns raised from an initial interview of parents, conducted by Brown (1998) and Case (2000). In these initial CATCH interviews, parents could freely discuss a number of issues that were deemed of most concern and importance. Inevitably, parents discussed their relationships with professionals and most pertinently, the failure of professionals to understand their needs as well as those of the child.

## Aims and Methods

The present study aims at elaborating on the issues expressed by parents in the initial studies by Brown (1998) and Case (2000). Parents of 84 children with learning disabilities and communicative impairments were sent CATCH questionnaires that consisted of 51 questions. Parents were already members of the CATCH! advocacy organisation for parents with children who have a variety of learning and communicative impairments. The children within this study included those with cerebral palsy (37), autism (13), Downs's syndrome (4), epilepsy (2) and 11 with no formal diagnosis.

Parents were asked questions that were based around the 6 themes identified in the earlier interviews:

1. Diagnosis
2. Professionals
3. Therapy
4. Advice
5. Temporal Concerns.
6. Social Support.

Questions assessed parental satisfaction/dissatisfaction, service preferences and the salience of services (i.e. Do you think your involvement is important?). Single (yes or no) and multiple responses (positive/negative/uncertain) were presented**.**

## Results and Conclusions

The results of the questionnaire were analysed using the non-parametric Chi-square 'goodness of fit' test and are presented according to the 6 separate themes:

1. **Diagnosis**. Parents were neither satisfied nor dissatisfied with the information given to them at diagnosis.
2. **Professionals**. Parents reported that whilst they felt that professionals were approachable and non-judgemental, they were dissatisfied with the level of information they were provided. They were particularity dissatisfied with the work of social workers.
3. **Therapy**. Parents preferred therapy to be offered rather than requesting it themselves.
4. **Advice**. A significant proportion of parents found professional advice useful and easy to understand. However, parents were more likely to request for advice as opposed to it being offered by professionals.
5. **Temporal concerns**. Parents were significantly worried about the future when their care giving capabilities would be limited and their child would be left to cope alone.
6. **Social Support**. The introduction of a disabled child significantly affects the sociability of the parents and therefore both child and parent become isolated from any informal sources of support.

The results of the CATCH questionnaire reflect a developing parent-professional relationship. Parents appear more assertive in terms of service provision and are beginning to shift away from the passive consumer of services, that accepts the expertise of professionals. Professionals are increasingly acknowledging parental expertise. However, professionals continue to dominate service delivery and fail to offer counselling and advice. Nonetheless, when advice and information was sought after, parents found its content useful and easy to understand.

## Implications for Our guide

The results from the CATCH parent sample cannot be generalised to all parents of children with learning disabilities as they arise from a group of parents with considerable negative early experiences with professionals. The results indicate the possibility of a parent-professional partnership emerging. Although professionals still dominate service delivery there is growing evidence professionals are addressing parental and child needs in order to improve existing services. This growing partnership can have a significant impact on accessing primary, secondary and tertiary health care.

**Geenen, S. J., Powers, L. E., Sells, W. (2003) Understanding the role of health care providers during the transition of adolescents with disabilities and special health care needs.** *Journal of Adolescent Health*, **32(3), 225-233.**

## Background

Transition is multidimensional and involves health, education, employment and accommodation. Health care professionals need to understand that thoughtful and co-ordinated health care transition facilitates transition in other areas as well. For example, health care transition can help to identify the appropriate types of accommodation and employment. It is essential for a smooth transition from paediatric to adult health care, and that health care professionals adopt a meaningful working partnership with parents and young people.

## Aims and Methods

### Aims
The study sought the perspectives of families and health care providers on 3 main issues:
- The exact role of health care providers during transition.
- The current role of health care providers in transition
- Factors that significantly impeded transition for adolescents with special health care needs and disabilities.

### Sample
753 parents of adolescents aged between 13-21 years returned postal questionnaires. Parents classified their child as having a mild disability (23%), a moderate disability (42%), a severe disability (27%), or a very severe disability (8%). The disabilities they reported ranged between:
- Developmental (22%)
- Physical (17%)
- Learning (15%)
- Emotional (10%)
- Health impairments (6%)
- And multiple disabilities (18%).

In the parent sample, 78% reported that their child's primary health care provider was a paediatrician, with the remainder of the sample reporting that a general practitioner or other family practitioner assessed their child's health needs.

141 health care providers also responded to questionnaires. Respondents were primarily paediatricians (76%) with other specialists (14%), family physicians (2%) or 'other health care professionals (8%) forming the remainder of responses. The majority of doctors reported that 25% or less of their patients were adolescents (21 years of age or below) and had special health care needs or disability.

### Instrument
Transition activities were identified from a literature review, input from families and healthcare professionals and also a pilot test on 6 families and 4 paediatricians. The13

transition activities identified that health care professionals may engage in to help young people prepare for adulthood include:

1. 'Taking care of a youth's disability
2. Taking care of a youths general health
3. Talking to the youth about sexual issues
4. Talking to the youth about drugs and alcohol
5. Screening youth for mental health problems
6. Coordinating the health care of youth with other health care providers.
7. Working with the school to coordinate care for youth with disabilities or health conditions.
8. Connecting youth to other services in the community
9. Helping youth to apply for or keep Social security income.
10. Helping youth get health insurance when they become an adult
11. Finding health care providers who will care for youth when they become an adult
12. Discussing with the youth how to take care of their health to be successful at work or college.
13. Teaching the youth to manage health conditions by themselves.

In the parents' questionnaire, parents were asked to rate the 13 transition activities on a Likert scale of 1 to 5 (1 representing 'not at all' and 5 representing 'very much') according to the following:

- How important the area is for their child in general
- How much their primary health care provider has helped in this area
- The extent to which it is the primary health care providers job to help in this area.

In the provider's questionnaire, health care providers were asked to rate the 13 transition activities according to the following:

- The level of their own involvement in transition activities.
- The extent at which they feel it is their responsibility to assist youth and families with the transition process.

## Results and Conclusions

Analysis of the questionnaires was carried out using two sets of Students t-tests to compare the parents and provider's answers. ANOVA's were also calculated to investigate whether parental ratings of the importance of transition activities varied by type of disability of the child.

**Parent's Questionnaire Results**

**Transition areas important to all parents**
The activities identified as having the greatest importance were those that had a mean rating of 4.0 on the Likert scale. These included:
'Taking care of the child's general health
Taking care of the child's disability

> Coordinating the child's health with other health professionals
> Helping the child to get health insurance
> Helping to find a health care provider when the child becomes an adult.
> Teaching the child to manage its own health
> Working with the school to coordinate care'.

**Differences among parent groups**

A significant difference was found between parents of children with developmental disabilities and the other parents, on the importance of certain transition activities. Parents of people with a developmental disability rated the following activities with less importance than other parents:

> 'Talking about sexual issues
> Talking about drugs and alcohol
> Screening for mental health problems
> Discussing with their child how to take care of their health at work or college
> Teaching their child to manage his/her health'.

These parents also reported less involvement of providers in assisting in these same transition activities. However, in line with the responses from other parents, parents of children with developmental disabilities believed it was within the health care providers role to assist in these activities.

**Comparisons between Parents and Provider**

The results of two sets of Student's t-tests revealed many differences between providers and parents perceptions of the level of primary care involvement, and also the extent to which the transition activities were considered as part of the role of primary health care professionals.

**Role of Health care Professionals**

Compared with parents view, health providers reported a significantly greater role to assist in 11 of the 13 transition activities. Providers reported a significantly greater premise in talking to the youth about drugs and alcohol, talking to the child about sexual issues and teaching the youth how to manage their own health.

**Involvement of Health Care Professionals**

Providers reported a greater involvement in 11 out of the 13 activities, compared to parent's account of the level of health care involvement. Providers again reported a significantly greater involvement in the same three areas they identified as core to their role in providing health care for young people with special health care needs or disabilities.

**Barriers to Provider involvement**

The majority of providers (63%) reported time as a significant barrier to the level of their involvement in transition planning. 43% indicated that they required further training

**<u>Conclusions</u>**

Parents seemed to have a more restricted view of the provider's role than the providers themselves. Parents' responses indicated that the provider's major role was

to take care of their child's health or coordinate their child's health care with other providers and were less certain as to their role in talking about drug, alcohol or sexual issues. The results indicate a need for health care providers to clarify with parents, their roles in assisting in the transition process. It may also be beneficial for parents and providers to identify between each other the transition activities that are of most importance for the young person.

## Implications for Our guide

The results of this study can be generalised to all professionals, not just healthcare professionals. Given that the transition process involves a number of multi-agency professionals, it would be good practice for professionals and parents to discuss the extent of that professional's involvement during transition. This method of working would allow parents and the young person to identify a central individual responsible for a certain transition area and would allow greater communication between families (including the young person) and providers. Having a single person with which to discuss areas of transition would also allow families, and professional to work together to identify a shared perspective that fully takes into consideration the views of the young person.

**Simons, K. & Russell, O. (2003)** *Lines in the Sand: A summary of findings from "Crossing the Line": a research project on the interface between mental health and learning disability services,* **Bristol, Norah Fry Research Centre**

## Background

Simons and Russell (2003) set to address existing problems of the interface between learning disability and mental health services. It was identified that in the south-west region there were particular problems with:

- ➢ Identifying specific roles and responsibilities of mental health and learning disability services.
- ➢ Continuance of expensive out of area placements, due to a lack of local area provision.
- ➢ 'Bed-blocking of in-patient assessment and treatment resources caused by lack of social care facilities with the appropriate expertise.'
- ➢ 'Unpredictable demands from individuals originating outside the region.'

Recent policy changes surrounding services for adults with learning disabilities and mental health problems (National service framework for mental health and Valuing people) are also discussed in order to help address some of these concerns.

## Aims and Methods

The research aimed to describe patterns of service use and identify 'pressure points' within services for people with learning disabilities and mental health problems in the south-west region. This was achieved through three distinct stages:

1. A retrospective two-year census of case records for 348 adults (over the age of 19) with a dual diagnosis of learning disability and mental health. who met the following criteria:
   - ➢ Referred from learning disability to mental health services or vice versa.
   - ➢ Placed 'out of area' by specialist services or referred 'into area'.
   - ➢ Admitted as an in-patient of either mental health or learning disability services.
2. A series of in-depth interviews of 30 key professionals involved with local services (i.e. psychiatrists, psychologists and community learning disability nurses).
3. Telephone interviews with a total of 19 commissioners - 10 from learning disability partnership boards and 9 from local mental health national services.

## Results and Conclusions

Following analysis of the audit and interviews, five separate themes were identified and discussed:

- Interchanges between learning disability and mental health services.

It was identified from the case notes that the majority of referrals were from mental health services to learning disability services (approximately 85 of the 348 case notes). Although most referrals were accepted, disputes continued to feature among mental health and learning disability services regarding their respective roles and responsibilities. Finally, the audit revealed few examples of joint working (15%), with the majority of individuals being delegated to services through 'straightforward transfer of clinical responsibility.'

Analysis of the provider's accounts reiterated the results from the case notes. Providers identified that learning disability services continue to accept a large number of individuals that 'do not fit the remit of other services'.

Although providers of both services could point to instances of joint working, it was admitted that developing joint service initiates did not feature high on the agenda in their collaborative meetings. A number of other factors complicated joint working.
Firstly, mental health and learning disability services appear to operate according to different cultures. It was identified that the former approach care through intensive short-term intervention whereas the latter are dedicated to long-term support. In their experience this difference significantly impeded joint working initiatives. Secondly, the existing pressures on both services have led to the unfortunate situation of crisis led 'batting of individuals backwards and forwards'. In the absence of protocol that addresses these individuals' needs it was feared that this might continue. Many providers felt that the NSF for mental health was not at all relevant for people with learning disabilities.
Finally, many providers had come across individuals that fell to the edge of both services. These individuals are primary candidates for joint working initiatives, and are likely to incur huge cost implications on the service responsible for their care.

- **'Out of area' and 'into area' placements**

The audit of case notes found that referrals out of area and into area were surrounded with much controversy. Over the two-year period, 20 individuals were referred to out of area placements due to an inappropriate current placement or owing to the complex needs of the individual. Two-thirds of referrals to specialist learning disability services were on behalf of those placed into area. Of particular interest was the evidence of policy confusion surrounding commissioning responsibility of health and social services for individuals placed into area. There was also considerable doubt as to whether statutory health assessments had taken place or were taken into consideration when placement arrangements were finalised.

The interviews of providers regarding 'out of area' moves shared similar concerns. The suitability and quality of these placements given their high cost was questioned. Many individuals believed that the resources spent on out of area placements would be better spent on improving local specialist provision.

'In contrast, discussion of 'into area' placements raised a very different set of concerns'. The differences between social services and health commissioning were highlighted with one provider quoted as saying that 'local health and social services are planning for quite different populations'. In particular local social services seemed to lack involvement and awareness of the scale of into area placements, and this is reflected in their commissioning.

- **In-patient admissions**

During the study period, 171 individuals were considered for in-patient assessment and treatment. Data from the case notes revealed the majority of admissions were to specialist learning disability services, with only 11% admitted to a generic service. In some cases length of stay in an in-patient facility was at least two years, due to difficulties in finding appropriate alternative placements. Length of stay was the topic of many disputes between health and social services

Views from providers revealed an overall concern regarding 'bed blocking' of in-patient resources. It was believed that these issues stemmed from the relatively low priority social services departments assigned to people with learning disabilities in inpatient units compared to people in need in the community. Many interviewees reported that local social services were slow in picking up in-patient cases in order to coerce health services to take more responsibility of these individuals (referred to as 'perverse incentives').

Concerns also existed of the capacity of local residential facilities to maintain care in the community. It was also acknowledged that there is limited capacity to develop specialised housing for people with complex needs.

- **The commissioning context**

The audit and interviews with providers and commissioners identified an overall need for significant development of learning disability and mental health services in order to meet the standards set in Valuing People and the NSF for Mental Health.

Commissioners acknowledged significant boundary disputes between mental health and learning disability providers (14/19), with 79% rating commissioning of the local learning disability service as needing significant improvement.

The progress that has been made is in its early stages of development (i.e. developing housing strategies and protocols agreeing relative responsibility between learning disability and mental health services).

- **Implications for health and social care**

These results are grouped into two broad themes:
1) **'Managing the links between learning disability and mental health services'**
It is suggested that extensive development of relationships between Partnership Boards and Mental Health Implementation teams may facilitate improved links between learning disability and mental health services. Development of a 'joint local strategy for promoting and supporting joint working' may improve a number of the issues raised in the report mainly facilitating the development of agreed protocols, informed by the experience of local providers. The core value of these joint local strategies is joint working and will allow the development of better links between services through joint training, research and service development programmes.
    These initiatives appear crucial for those who do not meet the eligibility criteria for either service
2) **'Developing comprehensive housing and support strategies'.**
This will require development of local options (for 'out of area' placements) and consideration at a national level for 'into area' placements.

At the local level, developing comprehensive housing options will require a review and further development of local options. Consideration will have to be taken into devolving money spent on resources for out of area placements into a budget to improve local area specialist options. The possibilities of developing intensive individualised options for those individuals, who fall on the edge of services, needs additional consideration. The providers expressed particular concern regarding 'bed-blocking' thus requiring effective strategies to be in place to prevent such occurrences. The report suggests resources be flexible to allow additional support for those in independent sector housing and support services, without needing to be admitted for assessment and treatment**.**

This paper discusses the need for updating the 1999 draft *Establishing Responsible Commissioner Guidance* in light of *Valuing People*. At a national level clearer guideline regarding health assessments and adequate care plans prior to the move need to be addressed.

**Implications for our Guide**

This comprehensive document exploring the interchanges between learning disability and mental health services has influential implications on the types of individuals who form the focus for our guide.

Firstly, the overriding theme of the need extensively to develop local joint working initiatives has major implications for individuals with learning disabilities and mental

health problems and/or challenging behaviour. These individuals notoriously find it difficult to meet the criteria for learning disability or mental health services, as their needs are vast and complex in nature. In order to provide a needs-led service for these individuals, detailed input from specialists representing both services is required through joint meetings and commissioning opportunities. Many of the providers of services interviewed in this report feared that unless clear protocols are developed these individuals needs will be continue to remain difficult to place within existing service infrastructures. In order to solve the problems associated with lengthy in-patient stay, it was also suggested that the capacity for specialised housing options be reviewed thus preventing lengthy 'bed-blocking' and providing individuals with complex needs a suitable environment in which to transfer.

Simons & Russell (2003) additionally report evidence of the confusion surrounding health and social services commissioning responsibility for individuals placed out of area, into area or admitted for in-patient assessment and treatment. It was suggested that the resources spent on expensive out of area placements be pooled into a budget for higher quality within area placements. This would allow individuals to remain in areas they are familiar with and reduces unnecessary tension caused by radical out of area placements. Individuals also benefit from being closer to their family members, whilst retaining their independence associated with adulthood.

Though this report does not incorporate transition from children to adult services, the findings and recommendations have significant implications for learning disabled individuals with additional mental health and/or challenging behaviour problems. The development of joint working initiatives that may be put in practice during the transition process could significantly affect where a young person may be placed to live, work or access day care.

**Townsley, R., Abbott, D., Watson, D. (2004)** *Making a difference? Exploring the impact of multi-agency working on disabled children with complex health care needs, their families and the professionals who support them'*, **Bristol, The Policy Press**.

## Background and Aims

The research project set to explore the experience and consequences of multi-agency working on the lives of disabled children with complex needs, their families and the professionals who support them. The study was funded by the Community Fund and conducted by the Norah Fry Research team and the Family Fund between 2000 and 2003.

## Methods

Methods of data collection were divided into three stages:
- 'An exploratory phase to determine the extent of multi-agency working for disabled children with complex health care needs in the UK.'
- Data collection from 26 services regarding multi-agency working.
- 'Case study visits involving six of the services across the UK (3 in England; 1 in Wales; 1 in Scotland and 1 in Northern Ireland). At each service interviews were conducted with professionals (115), families (25) and children/young people (18) involved in the multi-agency service.'

## Results and Conclusions

An overarching finding from the six services that were studied was that there was no defined model of multi-agency working. Each service had organised and arranged the resources needed to work together in different ways. Of the six services, only one service established a 'truly multi-agency approach' through resource sharing at both an operational and strategic level.

The remaining findings of the study are divided according to the experience of families, professionals and the young people with complex health care needs.

**The impact of multi-agency working on professionals and agencies.**

- Overall professionals reported that multi-agency working benefited their working lives. They reported improved understanding of and effective working with families, agencies and other professionals.
- It was also felt that having the support of a multi-agency service or a key worker particularly had a positive impact on families.
- Problems that continued to influence joint working arose due to 'different statutory frameworks, incompatible IT systems, and a lack of commitment from some agencies and individuals.'

**The impact of multi-agency working on families.**

- Of the 25 families interviewed, two-thirds felt that the multi-agency service had a positive impact on their lives.
- Many families continued to experience difficulties with finding appropriate social activities for their child and reported little input from multi-agency services regarding practical, emotional and financial advice.
- Although over half of the families had access to a key-worker, only 6 of these families understood the role of the key worker as co-ordinating services for them. Many families experienced a lack of co-ordinated input from services resulting in multiple assessments and reviews.

**The views of disabled children and young people with complex health care needs**

- The benefits of multi-agency services seemed to bypass individuals with complex health care needs. Many of these children continued to experience barriers in accessing suitable activities, forming friends and making relationships.
- It appears that a lack of effective communication between the multi-agency service or key worker and the young person was responsible for many of the barriers in these individuals' lives.

Although, multi-agency working appears to have many benefits for key individuals in need of this type of service (particularly the families), what is clearly missing is effective multi-agency input for young individuals in all aspects of their life. The project highlighted that whilst young people benefited from improved access to

education, other aspects of their social and emotional lives had not benefited from the input of a multi-agency service.

## Implications for Our Guide

Effective multi-agency working is a crucial element to the successful transition of a young person from childhood to adulthood. It is also important for members of a multi-agency team to understand each other's professional fields and to work together for the best interests of the young person. This study found an improved benefit of multi-agency working for families of disabled children but no effect on the quality of life on the young people. It is particularly important that multi-agency input adopts person centred approaches during the process of transition planning. This plan must reflect activities that the young person considers important in their lives. Effective consultation and consideration of the young persons views can significantly affect their mental well-being.