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

Technical Document -

Chapter 4.6 Literature Review – Learning Disability and Mental Health Services

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Introduction

The literature has well established that young people with learning disabilities are increasingly likely to develop mental health problems during adolescence, with anxiety, depression, phobias and behavioural difficulties being prominent at this stage of life (Emerson, 2002). However, what is not so well established is the assessment and management of mental health problems in an individual complicated by symptoms of severe learning disability.

Additional complications arise with respect to which service culture an individual belongs and ensuring transition between services is seamless in its execution. Many professionals, parents and service users have frequently reported instances of inadequate and inappropriate care leading to increasing levels of anxiety amongst all those involved.

The literature to date reflects changes in service provision and local area initiatives that are in their infancy, but nonetheless attempt to address the ways in which individuals gain access to the appropriate care and to ensure there are no gaps in service provision.

Meeting Mental Health Needs

Many mental health problems receive inadequate attention in those with learning disabilities and the literature highlights the importance of promoting and sustaining mental health in all contexts relevant to the young adult.

The Count Us In Inquiry (Foundation for People with Learning Disabilities, 2002) set to achieve ways of meeting the mental health needs of young people between the ages of 13 and 25 who have a learning disability. Based on oral and written evidence submitted by service users and a range of service providers, the report examines ways to foster positive mental health (within a family, educational and social context) as well as responding promptly to arising mental health problems. The committee highlights ways of promoting resilience and autonomy during adolescence through:

- Providing adequate accessible information to family carers and individuals with learning disabilities regarding promoting emotional resilience.
- Schools actively encouraging and providing meaningful opportunities and practical problem solving strategies (Carpenter and Morgan, 2003).

Additional key recommendations regarding prompter responses to emerging mental health problems include:

- Improved training of primary carers (particularly of GPs and school nurses) of mental health and learning disability
- Established links between schools, GPs and specialist mental health and learning disability services

- Clear protocols for accessible referral to services.

Finally, recommendations regarding learning disability mental health services include:

- 'Mainstream services should develop the resources and expertise necessary to respond to the needs of young people with learning disabilities'
- 'Specialist learning disability services should be developed as a resource for mainstream services and to support those young people with the most complex needs'.

The Count Us In inquiry is of particular importance for this guide as its recommendations for early associations between schools and specialist learning disability mental health services and for greater awareness of mental health problems between school teachers, family carers and individuals, can facilitate a smoother transition process.

The extent of the problem is highlighted in McCarthy and Boyd (2002) and more recently in Chan et al (2004) who present studies highlighting the experiences of adults with learning disability and childhood established psychiatric disorder, challenging behaviour or aggression. McCarthy and Boyd (2002) found that although most individuals had regular contact with primary care (i.e. GP, school nurse or hospital paediatrician) they were not in receipt of specialist mental health services, and were equally as likely to access mental health services and social care services such as day centres, residential respite services and voluntary clubs, as their 'non-mental health' piers. Similarly, Chan et al (2004) presented 2 case studies of adults' experience of barriers to obtaining specialist psychiatric input due to a continued tendency for practitioners to see the presenting behaviours as resulting from a lack of adaptive skills and the intellectual disability rather than as emerging symptoms of a mental health problem. Final psychiatric input resulted in response to a police intervention. Together these studies highlight the lack of awareness of the presentation of mental health disorders in the intellectual disability population amongst professionals, with mechanisms needing to be in place in order to identify children in need of specialist services as early as possible The authors suggest that an early association between education and specialist mental health services is vital and training intervention amongst primary care teams and education professionals must commence immediately. A greater number of learning disability psychiatrists specialised to work with children and adolescents with severe and complex needs is additionally much desired.

Generic or Specialist Service Provision

Whether an individual with a learning disability should receive specialist psychiatric input or be admitted to a generic mental health unit has been much debated in the literature past and present. Advocates of normalisation argue that specialist services lead to stigmatisation and further exclusion of the individual from society. In contrast, generic services would allow greater integration of the individual with the learning disability allowing them to lead as normal a life as possible. Traditionally both generic child and adult mental health services have been reported as unable to meet the specific needs of adolescents with learning disabilities and mental health problems, particularly if they are on the severe/challenging end of the scale. Lack of

specialised training opportunities in identification and assessment of mental health problems, and inadequate resources have been cited as some of the many common problems.

Current government policies support the use of either service as long as integration and inclusion dominate the services ethos and working practice (Department of Health 2001). Though mainstream access is preferred, it is acknowledged that some individuals may require specialist intervention. Although specialist learning disability mental health services are not established in all health trusts, the majority of the literature (though limited) favours their specialist input in assessing, managing and treating patients.

Interestingly, Chaplin (2004) conducted an extensive review of the outcomes of adults with learning disabilities and mental health problems occupying either generic or specialist services, with 3 distinct aims:

- Examining the extent of general psychiatric service use by adults with learning disabilities.
- Examining the outcome of those in either generic or specialist services.
- Examining the outcome of people with learning disability in a generic setting compared to those without a learning disability.

Through a review of literature, Chaplin found that people with severe learning disabilities were less likely to be referred to generic services (Gustafsson 1997 in Chaplin 2004). These services were more likely to be used by those with borderline intellectual functioning. In terms of the second aim, it was identified that specialist services admitted those with severe learning disabilities and autism and that although individuals occupied in-patient facilities for longer, they were less likely to be discharged to an out of area placement (Alexander, 2001 & Xenitidis 2004). Finally, Addington et al 1993, Burge et al 2002 and Lohrer et al 2002 (in Chaplin 2004), all reported inconsistencies in the length of stay or accessibility of a generic psychiatric unit between those with and without learning disabilities. However, it is worthwhile noting that the only outcome measure analysed in these studies was length of stay, which alone is a poor measure of the quality of a service and appropriateness of care provided. Chaplin (2004) notes that more robust outcome measure needs to be adopted to evaluate the efficacy of a service.

The only other study examining a multitude of outcome measures on the effectiveness of generic or specialist units for people with learning disabilities and mental health problems is that of Xenitidis et al (2004). In their study, patients had occupied either a specialised unit (n=33) or a generic unit (n=33). Length of stay was assessed for patients in both generic and specialist units. Psychiatric outcome was also assessed using the TAG, GAF, DAS, and PASS-ADD instruments that measure psychiatric symptoms, overall level of functioning, severity of mental health problems and behavioural disturbance. It was only patients in the specialist unit that received a psychiatric assessment before and after inpatient stay. Statistically significant differences were obtained in terms of length of stay between the generic and specialist groups. The specialist unit group remained inpatients for longer than the generic unit group. Statistically significant improvements were also found on all psychiatric measures for those patients occupying a specialist unit.

However, the patients were not randomly assigned to specialist or generic unit group and psychiatric outcomes were not obtained from the generic unit groups. This does not allow for valid comparisons between generic and specialist services in terms of psychiatric outcome and therefore limits the generalisability of the findings.

The study by Chaplin implies that services continue to operate on an IQ basis with those presenting with severe and challenging behaviour rarely being accepted to generic services. Whilst these individuals present with highly specialised needs requiring specialist assistance, it is important that these individuals are also given fair access to mainstream services with intensive support, which is in line with Valuing people. From the Xenetidis et al (2004) study it appears that adults benefit from specialist input as psychiatric outcome had improved after specialist inpatient intervention. However, their study only measures short-term outcome, with the long-term benefits of specialist provision being largely unknown.

Service users and Carer Perspective

Opinions regarding the ability of a service to meet the needs of individuals with learning disabilities and additional mental health needs, must be sought after by those primarily involved at the providing and receiving end.

Longo and Scior (2004) sought the opinion of 14 individuals with mild to moderate learning disabilities and additional mental health needs who had been admitted to a generic psychiatric unit and 15 individuals who had admittance to a specialist psychiatric unit. Twenty primary carers also agreed to take part in an interview, with 10 carers of individuals from the generic ward and 10 carers of individuals from a specialist ward. Carers and service users were asked to give an account of their experiences of psychiatric admission and treatment. The difference between the carers and service users accounts was also explored.

It was identified that service users' experience of generic psychiatric settings was positive in that they experienced rewarding relationships with their non learning disability peers. This was most frequently reported in their accounts. In addition service users felt disempowered as their opinions were rarely sought after during admission and treatment. Staff were perceived as unfriendly and uncaring often using harmful restraints. This compounded feelings of vulnerability and disempowerment. In contrast users of specialist services praised staff as caring, friendly and offering ample practical advice during treatment. These users were also more likely to report feelings of isolation and loneliness due to a lack of communication with other users. Carer's also reflected upon staff in generic services as under involved, neglectful of the service user and poor at discharge planning. Staff in specialist services were, in contrast, praised by parents for being informative and caring and good at discharge planning.

These accounts provide a range of positives and negatives for both types of services from a service users and carers perspective; highlighting that whilst users of generic services benefited from peer supportive relationships they equally required supportive relationships from staff. Primary carers needed to be kept informed during the process of admission and discharge. Whilst service users and parents were not questioned as

to their overall satisfaction of each service it appears maximum satisfaction may result from an integration of both services where service users benefit from supportive relationships with peers as well as the caring attitude of staff. Carers may also benefit from the knowledge of specialist staff in addition to being more involved in admission and treatment.

This study sought the perspective of individuals with mild to moderate learning disabilities with additional mental health needs (mainly schizophrenia), therefore the findings are limited to these individuals' own perspectives. Opinions of those with severe learning disabilities and mental health and/or challenging behaviour, have notoriously been less well-documented in the literature. It is important that augmented communication techniques are adopted appropriately for those individuals who have communication difficulties. Gathering users' views, particularly at, transition and in terms of service provision improves quality of care through achieving more responsive services and better outcomes of interventions.

Consultants in the psychiatry of learning disability also appear to favour management from integrated mental health-learning disability trusts (61%), allowing them to maintain their identity as psychiatrists (Alexander et al 2002).

Service Providers Perspective

Scior and Grierson, 2004, explored service providers' perspective on their service's ability to meet the needs of individuals with learning disabilities and mental health problems. A total of 11 consultant psychiatrists, social workers, managers of post 16 school and college special needs programmes and personnel from various voluntary sector organisations were interviewed. Participants were all asked to give an account of their views on current service provision. Analysis of interview transcripts revealed six distinct themes among service providers accounts:

- A difficulty in identifying what constitutes a mental health problem in these young adults.
- Breakdowns in communication, ('you don't know who is working with someone. You don't know who to contact') thus placing the young person at a greater risk of developing mental health problems.
- A lack of effective joint working between services ('She's in a sea of professionals where nobody is completely responsible for her.').
- Limited/non-existent specialist inpatient resources, respite facilities, safe leisure opportunities and skilled staff.
- A need to understand the family perspective and develop partnership working between families and services.
- Lack of genuine inclusive practice in mainstream education leading to increased risks of mental health problems.

This study expressed concerns regarding learning disability and mental health service provision and has many implications for future service provision from the perspective of service providers. Above all service providers indicated that getting together across all services involved with these individuals, as well as with family carers were integral to good practice. As it is recognised that many mental health problems arise during adolescence, service providers indicated that it is around this time where joint

working is essential and will lead to a more thorough understanding of the young person's needs.

Although this study is limited in that a small sample size was used, the key themes that were identified have been previously highlighted through other sources, as pitfalls in service provision. Individuals with learning disabilities and mental health or challenging behaviour may access a greater number of services owing to their specific needs, and may be more vulnerable to the consequences of disjointed information sharing. It is therefore important for service providers to access examples of good practice for joint working and information sharing to minimise vulnerability of these individuals to mental health problems that can be attributed to external factors.

Proposals for service delivery of a mental health service to those with learning disabilities

Many models have been proposed for delivering adequate mental health services for people with learning disabilities. (Moss et al 2000; O'Dwyer, 2000), that have been based on literature reviews and local area service models. O'Dwyer (2000), concluded, after having reviewed the literature and exploring local service provision, that a service for psychiatric disorders amongst people with learning disability must include:

- A multi-disciplinary community learning disability team that has been adequately trained in psychiatric disorders amongst this population
- In-patient facilities for the assessment and treatment of psychiatric illness
- Day care provision provided by both health care and social services
- Services for children and adolescents with psychiatric and/or behavioural difficulties
- Respite care
- General medical care.

The author highlights the importance of the input of a psychiatrist in planning services for those with learning disabilities, and emphasises the need for collaboration amongst psychiatrists and managers of learning disability services.

More recent developments in the delivery of psychiatric services for people with learning disabilities (RCP, 2004), aim at overlapping psychiatric services for adults with and without learning disabilities and those for other young people. Staff and personnel will be multidisciplinary and all trained in working with young people whose mental health problems are complicated by learning disabilities. In cases where inpatient admission is required, it is suggested that an outreach team be established in the inpatient unit to assist in cases of lengthy admission and prevent disruption of family and peer relationships.

In Ireland it is also acknowledged that mental health/psychiatric services for people with learning disabilities remain under resourced and underdeveloped across many health boards (Irish College of psychiatrists, Occasional paper, 2004),
It is recommended that funding for a redeveloped service is provided from the same source as generic mental health funding and that the Mental Health Commission and the National Disability Authority oversee its implementation and quality of service.

An adult mental health multidisciplinary team for people with intellectual disabilities should be established around two consultant psychiatrists - one in adult psychiatry and the other in child and adolescent psychiatry. Other members of the team would include psychologists, nurses, social workers, medical doctors, speech and language therapists and physiotherapists. This team would work at a primary care level for those with all levels of intellectual disability and would have a defined catchment area. The core advantage of the service is that it is offered by a multidisciplinary service in a range of settings and also with a range of treatment options (out-patient/in-patient service, day hospitals etc.). A close interface of the proposed service between Health boards, voluntary agencies, the learning disability team, administrative managers and clinical directors, generic mental health services and academic departments is recommended to promote close working relationships with a variety of service providers and to inform the service of training and development opportunities. Also recommended are separate adolescent/forensic mental health services for people with intellectual disabilities as well as for those with autistic spectrum disorder and learning disabilities.

Currently within the literature, two studies provides results from an audit of the development of a service that integrates childhood learning disability mental health service within an established Child and Adolescent mental health (CAMHS) generic service (Green et al 2001 & Gangadharan et al 2001).

Green et al (2001) present a model of their service in York. Developed in 1999 the service aims at providing an effective and efficient multi-disciplinary service for families and their children with learning disabilities and additional mental health problems. In addition, the service aims were to reduce waiting times and decrease the number of out of county referrals. The team consisting of multidisciplinary members and accepts referrals from a range of professionals including health visitors, school doctors and social workers. The authors stipulate the success of this service as due to placing it within an existing multidisciplinary CAMHS network, allowing for children and families to access other tier 3 teams such as family therapy. Audit of the CAMHS learning disabilities service after 8 months showed that waiting times were reduced from 1 year to 29 days, as well as the number of out of county placements (only 1 in 8 months).

Gangadharan et al (2001) also describes a similar service integrated within CAMHS Directorate in Leicestershire Partnership NHS trust. An audit over an 8 month period revealed a broad patient population attending the service, with 2/3 of children being referred having multiple disabilities (autism, speech and language difficulties and epilepsy). The authors highlight the usefulness of such specialist services in assessing and managing patients with these severe and complex learning disabilities as well as other additional disabilities, which would not be achieved by their neighbours in general CAMHS services.

Within both these services, those with mild learning disability and mental health problems access general mental health services with support from learning disability professionals. Learning disability psychiatrists and other members of the specialised team were in greater consultation with the individuals with moderate and severe learning disability and additional mental health needs. Alexander et al (2002) argue that this approach allows fair access to community teams (such as assertive outreach,

and crisis resolution) and the more specialist input when it is required, and is in line with the national strategy on learning disability. However, extensive reorganisation of management structures and a clear definition of roles of general adult psychiatrists and other professionals involved must be established to allow patients access to the appropriate support without individuals falling through gaps in service provision. The studies by Green et al (2001) and Gangadharan et al (2001) provide initial evidence of the successes of the type of service model that may best serve this population of individuals.

Conclusions

Generic or specialist service provision for adults with learning disabilities and additional mental health needs is dependent on the available resources of an individual's local area.

Many individuals with established LD and MH disorders fail to access the appropriate psychiatric care. (Chan, 2004)

Psychiatric outcome has been shown to improve after specialist intervention (Xenitidis et al).

Chaplin (2004) found inconsistent outcomes of adults occupying generic mental health services with/without a LD.

Service users and carers reported a mixture of opinions regarding whether they preferred a generic or specialist service. Benefits were reported for both. Longo and Scior (2004).

Service providers emphasised the importance of multidisciplinary teams and joint working strategies for people with LD and MH (Scior and Grierson, 2004). Service providers felt confused when attempting to identify what constitutes a MH problem in those with LD. More training.

Service models emphasise the importance of specialist provision set up within an established CAMHS service allowing families and individuals access to tier 3 services.

There is paucity in the literature surrounding outcomes of patients occupying either a generic or specialist mental health service for people with learning disabilities, with the literature available supporting specialist input. As the gold standard in research is considered to be a randomised controlled trial (RCT), ideally further RCT's comparing specialist and generic care should be carried out on the basis of a multitude of variables including psychiatric symptoms, length of stay, opinions of parents and service users, opinions of service providers and reported behavioural events. This may give an indication of where clinical need lies and how these needs may be fulfilled to improve the quality of services.

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