Mental health services for children and young people with learning disabilities

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Key messages

- There is little robust research evaluating the effectiveness of different treatments and forms of support for children and young people with learning disabilities and mental health problems.
- The available evidence indicates that standard mental health programmes and interventions in use with children and young people can be applicable with some adaptations and modifications to those with learning disabilities.
- Extra time and resources may be needed to enable CAMHS staff to undertake assessments and interventions. Training may also be required in both verbal and non-verbal methods of communicating with children and young people with learning disabilities.
- There is as yet insufficient evidence to recommend a particular organizational model for providing mental health services to children and young people with learning disabilities, but good inter-agency collaboration and joint working appears to be a key factor.

Introduction

Children and adolescents with learning disabilities have a much greater prevalence of mental health problems than their non-disabled peers. Rates are three to four times higher in those with a significant learning disability [1]. Yet there is significant variation in the level and type of mental health services provided across England [2], and concerns have been expressed about the accessibility and quality of provision for this group [3] [4] [5]. Children and young people with learning disabilities access support (if at all) through paediatric and child health services, through child and adolescent mental health services (CAMHS) or through learning disability teams. Standard 9 of the children's National Service Framework [6] expects CAMH

services to be available to all children and young people who need them, and a Public Service Agreement target has been set for commissioners of CAMH services to offer the full range of services to children and young people with learning disabilities by December 2006. A National Care Pathway for mental health services for children with learning disabilities was published in June 2006 [7]. This briefing paper draws on a review of the literature on prevention and treatment interventions for children and young people with learning disabilities and mental health support needs.

Promoting good mental health

There is a substantial literature describing the additional stresses on children and young

people with learning disabilities and their families [8] [9] [10]. Programmes and interventions that aim to address these sources of stress could be expected to promote positive mental health, either through working directly with children or through providing support to their parents/carers. Services at this level might be provided by a range of agencies including health, social services, education and the voluntary sector, with support and training provided by CAMHS. Three broad groups of actions and intervention can be identified:

- Early behavioural interventions, especially for children with autistic spectrum disorders (ASD)
- Training and support for parents/carers
- Support for the development of social skills

Early interventions
There is consensus in the literature that behavioural programmes developed to improve the skills and behaviour of children with ASD are likely to be beneficial, although more robust evidence is needed [11]. Such interventions include the Lovass ABA (Applied Behavioural Analysis) programme [12], the TEACCH approach (Treatment and Education of Autistic and related Communication Handicapped Children [13] and the Autism Pre-school programme. However, these are highly structured and intensive programmes (up to 40 hours a week in the case of Lovass ABA), that have mostly been offered in clinical settings in the USA. These have been difficult to replicate to the same degree of success in community based programmes, for example in parent-run programmes in the UK [14] [15].

Parent training and support
Programmes that support parents and carers and teach effective parenting skills appear promising, especially when they enable parents to feel more competent and less stressed [16]. Parents find the role of therapist, such as in ABA programmes, to be extremely demanding, and high stress levels and lack

of support for parents can impact on the success of this form of provision [17]. The addition to the Stepping Stones Triple P parent training programme (a version of the Positive Parenting Programme for parents of children with learning disabilities) of sessions aimed at reducing parental stress has been shown to result in longer-lasting improvements in children's behaviour [18]. In the UK, evaluations of the Earlybird programme, developed by the National Autistic Society for parents of children recently diagnosed with ASD, have also suggested that a key factor in the programme's success lies in reducing parental stress and helping them to view their child more positively [19] [20]. Parents of children with disabilities often become stressed by the difficulties they experience in accessing services. The allocation of a key worker or liaison worker to act as a single point of contact with professionals in different agencies, including mental health can facilitate easier access [21].

Social skills development
Social support is recognized as an important mediator of positive mental health, and friends are very important to children and young people with learning disabilities [22], yet many are isolated and lack the opportunity or skills to develop friendships [23]. Peer support or 'befriending' projects may be helpful [24] [25], although the evidence is limited. Care also needs to be taken that social skills training does not have the unintended effect of making young people more aware of their difficulties in this area [26].

Diagnosing mental health problems
The identification of mental health problems in children and young people with learning disabilities can be complex. Poor self-care, anxiety or obsessive behaviours may be attributed to the learning disability rather than as indicative of a possible mental health problem [27] [28]. Accurate diagnosis may often depend on an assessment of mental state, which can be difficult to ascertain when there is a significant learning disability. However, it has been shown that adults with mild

learning disabilities can effectively describe their symptoms of mental illness, given the right support and using appropriate interviewing techniques[29]. A number of scales and checklists have been successfully used to screen children with less severe learning disabilities for emotional and behavioural disturbances. These include the Strengths and Difficulties Questionnaire [30] and the Developmental Behaviour Checklist [31] [32]. However, such tests may be less suitable for diagnostic purposes. Assessment tools completed by a carer or professional who knows the person well can be of special value in assessing mood and diagnosing depression in those with more serious learning disabilities. These include the Reiss scale [33]; the Anxiety, Depression and Mood Scale [34] and the Mood Interest and Pleasure Questionnaire [35], which have generally been tested with carers of adults rather than of children. Including carers in assessment is key to ensuring that diagnoses take account of current behaviour in relation to what is 'normal' for that child.

Adapting standard interventions

A review in 2004 by the Royal College of Psychiatrists [36] of services for children and young people with learning disabilities states that the evidence base for mental health work with young people of normal ability can be assumed to be applicable to young people with learning disabilities, unless there is specific evidence to the contrary. Gale [37] has argued that children with learning disabilities should be able to benefit from the full range of services offered by CAMHS, since these cover children from the age of five to sixteen or eighteen. The majority of children and young people with learning disabilities will fall within that developmental span unless they have severe or profound learning disabilities. Interventions would need to be adapted in one of two ways. Either an intervention appropriate to the child's chronological age could be modified by the use of appropriate language or additional visual and communication aids; or a developmentally appropriate intervention might be modified to make it age appropriate

in its use of materials, content or language. There is little research evidence to show how this might work in practice. However, the principle of adapting well-established techniques for use with a different population is already established, for example in the modification of adult Cognitive Behavioural Therapy techniques for use with children by employing a higher proportion of behavioural rather than cognitive techniques. In general, there is a lack of rigorous research that evaluates the effectiveness of different types of treatment for children with learning disabilities and mental health support needs.

Delivering mental health services

Many staff working in CAMHS believe that they lack the competence or experience to offer assessments and interventions for children and young people with learning disabilities. However, the available evidence suggests that the core competences to identify mental health problems or carry out therapeutic interventions appear to be similar whether or not a child has learning disabilities [38]. Several UK studies have described how CAMHS staff working in partnership with other agencies can deliver mental health services to children and young people with learning disabilities in a range of settings, including in-patient units [39] [40] and psychotherapy clinics [41]. Sufficient time needs to be allowed for both assessments and interventions, which are likely to take longer to complete than for children and young people in general. CAMHS staff need to develop expertise in a range of verbal and non-verbal communication methods as well as having access to support from learning disability specialists. There is no clear evidence in the literature to support any one particular model for delivering mental health services to children and young people with learning disabilities (for example through CAMHS or through Learning Disability teams) [42]. Instead, the recurrent theme is the need to establish strong inter-agency working arrangements and joint planning between all the agencies that support children and young people with learning disabilities.

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