NICE Health Technology Appraisal: Parent training/education programmes for children with conduct disorders

Introduction

This paper has been prepared jointly by the Challenging Behaviour Foundation and the Tizard Centre at Kent University.

The Challenging Behaviour Foundation (CBF) is a charity that was founded in 1997 in direct response to the lack of an easily accessible first point of reference for families, carers and professionals who support people with severe learning disabilities and challenging behaviour. The CBF provides information and support about all aspects of severe learning disability and challenging behaviour.

The Tizard Centre is a unit of the University of Kent whose teaching, research and service development work on severe learning disability and challenging behaviour is nationally and internationally recognised.

This paper will consider the support needs of children with severe learning disability and challenging behaviour, using the following definitions:

Severe learning disability (SLD):
Children with SLD typically have a severe global intellectual impairment (IQ below 55), combined with deficits in social functioning and/or adaptive behaviour. (Emerson et al, 2001a)

Challenging behaviour (CB):
The definition of challenging behaviour used by the CBF and the Tizard Centre is that developed by the Mental Health Foundation, and is as follows:

“behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to and use of ordinary community facilities; or behaviour that is likely to impair a child’s personal, development and family life and which represents a challenge to services, to families and to the children themselves, however caused.” Mental Health Foundation (1997).

In practice, challenging behaviour can be divided into the following categories, and an individual may display one or more of:
- Aggression
- Self-injury
- Disruption (of others)
- Destruction (of the environment)
- Stereotyped behaviour
- Other (idiosyncratic) behaviour

The Government White Paper, Valuing People, (Department of Health 2001) advocated the inclusion of people with learning disabilities within mainstream healthcare. It should be noted that the definition of conduct disorder (Appendix 1) of the protocol for this NICE consultation would exclude most individuals with severe
learning disability because of the inherent element of intent within the criteria. The early draft of this consultation appeared to exclude children with severe learning disabilities altogether, despite the fact that defining the disorder in this way excludes a part of the population that has an increased prevalence of challenging behaviour. We are pleased to note that this group has subsequently been included. It should, however, be noted that learning disability is not the same as dyslexia, which is specifically mentioned in the NICE consultation papers.

Children with severe learning disabilities are more likely to display challenging behaviour (Mental Health Foundation 1997, Kiernan & Kiernan 1994, Emerson et al 2001a) which is likely to have a negative impact on their quality of life, and that of their families. Services and families often struggle to meet their needs, and the cost of appropriate support and placement is commonly high.

The wider impact of a having a child with challenging behaviour is considerable. Families are under increased stress, face financial disadvantages, increased rates of depression and anxiety (Quine & Pahl 1985). Many studies have confirmed that family life for those with a disabled child is subject to increased pressures that are detrimental (Lamb & Layzell 1995). Lack of support and early intervention is more likely to lead to requests for residential provision, with high costs for local authorities and increased costs for families (Values into Action 2002).

**Prevalence**

Studies of the prevalence of challenging behaviour in children with severe learning disabilities suggest that 8% of pupils in special schools present behaviour that is extremely or very difficult to manage (Kiernan & Kiernan, 1994) with a further 14% presenting challenges of a lesser nature. These figures are broadly consistent with studies of challenging behaviour in adults with learning disabilities which suggest that between 5 and 15% of the population of people with learning disabilities display challenging behaviour. Many of these behaviours emerge in childhood and persist into adulthood (Emerson, 2001; Emerson et al, 2001b, 2001c). Children with the most severe challenging behaviour are likely to be placed in independent specialised 52 week residential schools. These have developed as a result of the failure of local authorities to provide support and services that can meet the needs of children with SLD and CB, and not as part of a coherent strategy. There are less than 20 such schools nationally, providing a total of around 500 places. Costs for such places are high, and usually involve the child being placed outside of their home area. This suggests that there are a considerable number of children with challenging behaviour who are not in specialist provision, and there is little information about this population. Equally, little is known of the characteristics of those within 52 week schools.

It is clear therefore that a significant number of children with severe learning disabilities develop behaviour that presents a significant challenge to services and their families. This behaviour impacts on their quality of life and has long-term implications. A great deal of research has been carried out into the factors that are likely to influence the development of challenging behaviour, but there has been no co-ordinated strategic approach to address the situation.
History of CBF
The CBF was founded by a parent as a direct result of the lack of effective support to families and the lack of local service provision. The CBF aims to be an easily accessible source of information and current developments within the field. The four main aims of the charity are:

- To provide and access support, advice and information
- To raise public awareness and understanding of learning disability compounded by challenging behaviour
- To promote and develop high quality services for people with learning disabilities and challenging behaviour
- To promote and actively engage in research

The CBF has been staffed by volunteers for 6 years (and recently appointed its first employee) and despite a lack of direct publicity, receives approximately 800 requests for information and support each year. The approach of the CBF has been to utilise existing knowledge and expertise to enable children and adults with learning disabilities and challenging behaviour to receive greater and more effective support.

If we know who is most likely to develop challenging behaviour, what factors influence it and what helps to reduce it, it makes sense to utilise that knowledge. This will result in an improved quality of life for the individual, their families and carers, and will enhance the quality and effectiveness of service provision. The CBF has therefore taken the initiative to work in partnership with the Tizard Centre to conduct research in this under researched area.

Research
Three specific research projects have been carried out jointly between the CBF and the Tizard Centre. These surveyed the views of family carers of children who had been placed at 52 week schools, gathered specific information about the children at 52 week schools, and surveyed the views of parents of children with SLD and CB known to the CBF with regard to their support needs.

One study surveyed the views of parents of children who had been placed at 52 week schools (Tennyson et al, 2003). Parents were asked to rate advice and support they had received from professionals prior to the 52 week placement, and this was not rated highly. In view of the fact that these children had SLD and challenging behaviour, a key professional to provide support would be a psychologist, but over 30% of parents had no contact with a psychologist, and of those who did, 25% rated their support as “very poor”. When parents were asked for their reasons for requesting a 52 week placement, failure to cope, challenging behaviour and exclusion from local services were cited.

The experience of the CBF is that current attempts to support families of children with SLD and challenging behaviour are insufficient and ineffective. In a second study (Papachristoforou, 2003), 87 parents completed questionnaires about their support needs and experiences. Of these families, 26 children no longer lived at home with their parents, and 70% of these parents gave lack of support with their child’s behaviour as the reason for this. Levels of satisfaction with the range of support received were low. This study supported previous research that there is room for a great deal of improvement in the support provided to parents, and concluded that
"parents of children with both learning disabilities and challenging behaviour do not receive adequate or helpful support to help them cope..”. Parental quotes from this research include:

“ I have had to search and search for help by myself... I have had to change my parenting skills to cope with son with no outside support.”

“ My main concern is that I don’t get any help with my daughter’s behaviour.”

“ families are left to cope as best they can. The result is depression, anxiety, suicide, loss of hope... it is only at this crisis point, when it might be too late anyway, that social services may step in.”

In a third study (Pilling, 2003) 156 children attending 52-week residential schools were surveyed. Three quarters were diagnosed with an autistic spectrum disorder, over 90% displayed aggressive behaviour and/or social disruption and/or non-compliance. Over 60% were restrained physically on a regular (at least monthly) basis and over a quarter were receiving medication for behaviour management purposes.

Taken together, these three studies document the substantial problems of conduct displayed by a proportion of the population of children and young people with severe learning disabilities and the general failure, to date, to adequately support family carers to manage their child’s behaviour. Consequently, a proportion of the children end up receiving high-cost residential schooling of uncertain benefit and opportunities to prevent the persistence of their conduct problems into adult conduct disorders are lost.

**What needs to be done**

This review of conduct disorders in children encompasses children with learning disabilities and challenging behaviour – **but there is currently no nationally recognised parent-training programme for parents of children with LD.**

A key element to improving the situation for families of children with SLD and CB is to clarify who should be the lead agency. Currently this is informally shared between learning disability services and CAMHS (Child & Adolescent Mental Health Service). For children, the Children Act stated clearly that children with disabilities are “children first”, and should have access to mainstream children’s services. However, learning disability expertise has tended to reside within adult learning disability services. Additionally, parent trainers are unlikely to have significant learning disability expertise.

**Cost effectiveness**

Our knowledge from research suggests that CB develops in childhood, is likely to persist and that established CB in adults is difficult to overcome. It has been suggested therefore that research into early intervention techniques should be undertaken to determine whether early intervention could prevent the development of CB in children considered to be at risk. There is evidence to suggest that intensive
home and community based intervention for autistic children can significantly reduce the development of CB (Emerson, 1996)

Modern behavioural approaches to managing CB can lead to short and long term reduction in CB (Emerson et al, 2001a), whereas there is little or no evidence to suggest that the use of anti-psychotic medication is effective. Despite this evidence, people with LD and CB are more likely to receive anti-psychotic medication than positive behavioural support.

Research has clearly established that the physical and emotional costs to families with a child with severe learning disabilities and challenging behaviour are immense (Quine & Pahl 1985; Tennyson et al 2003; Values into Action 2002). In addition, the financial costs to statutory services of specialist placements for children and adults with challenging behaviour are extremely high. A child with challenging behaviour is likely to become an adult with challenging behaviour. Parents/family carers are those individuals who are most likely to have the longest term relationship with their child, and therefore be motivated and committed to achieving change in their behaviour.

Inadequate support is likely to increase the likelihood of parents seeking residential provision for the child. This has great long-term cost implications for statutory services, aside from the detrimental costs to the child and his/her family (Abbott et al, 2000)

Implications

It is clear that parents of children with learning disabilities and challenging behaviour have not had an opportunity to benefit from parent training in the management of their child’s challenging behaviour. There is also clear evidence to suggest that early intervention with positive behaviour support could reduce the onset of challenging behaviour.

The main recommendation of the CBF and the Tizard Centre for this consultation is to propose the development of a pilot training scheme for parents of children with learning disabilities and challenging behaviour. This would involve a comprehensive review of previous studies of parent training for this client group and a comparison with conduct disorder training for parents of children without disabilities.

In addition there is a need to:
- Clarify responsibility for addressing behavioural issues in children with learning disabilities (LD services or CAMHS)
- Re-state the need for effective and appropriate respite care services for this group
- Train trainers to support families with children who have learning disabilities and challenging behaviour.

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