Meeting the emotional needs of young people with learning disabilities from minority ethnic communities

English script to accompany CD

This CD has been made for parents and family members of young people with learning disabilities aged between 14 and 25. It is based on some research into the needs of families from Pakistani and Bangladeshi communities in Bradford that was carried out by the University of Bradford and the Foundation for People with Learning Disabilities. The research looked at the emotional difficulties young people with learning disabilities may experience during their adolescence and the kinds of support and services they and their families wanted.

This CD is made up of the following sections:
Growing up
The future
Emotional problems and adolescence
Mental health problems
Support for family carers

Growing up
Growing up can be both exciting and challenging. It is a time of change which brings gains and losses. Some of these changes are very obvious, for example, changes to your body, or the move from school into more adult settings. Others are harder to see, such as the changes in feelings which adolescents commonly experience at this time. Like all teenagers and young adults, young people with learning disabilities will go through the usual ups and downs of adolescence.

Emotional difficulties are not uncommon amongst adolescents and some young people with learning disabilities may go through mild and brief periods of being anxious or depressed. Occasionally, they may experience longer or more serious difficulties and will need specialist help.

The future
Many of the Bradford families were uncertain about what the future held for the young people. Transition from school into adult provision, for example, college, work or day services, can be a stressful and confusing time both for the young person and for family carers, particularly when they are unsure about the available options. Again, talking to the school can provide a starting point for transition planning which should begin well before school leaving. It needs to involve the young person, the family and relevant services
Families play a vital role in helping young people to grow up feeling self-confident and able to cope well with life, but as the young person approaches teenage years, friends and social networks at school, college and in leisure time become important too. Some of the young people in the Bradford study stayed at home for long periods during the week and did not have enough social and recreational opportunities. This meant that they became bored and isolated which added to their own and their family carers’ stress levels. Both young people and their family carers wanted more daytime activities, as well as things to do at weekends and in the holidays. Like all young people, teenagers with learning disabilities want to take more control of their lives, try out new things and make new friends. Again, making sure that the young person has a plan for transition from school can help in this process.

It is often difficult for a parent to ‘let go’ when their children reach their teens, particularly if the young person has a learning disability and lacks self-confidence. As a family carer, you can help to encourage and support the young person to make choices and decisions, try new activities and keep in touch with their friends. Local voluntary organisations and befriending schemes can provide a way for young people with learning disabilities to get involved in community-based groups, religious groups and social activities. Direct Payments can now be made to over 16s in place of social care services, so that the young person can employ someone to accompany them to activities of their choice. Direct Payments are also available to carers. Self-advocacy groups can help young people learn to speak up for themselves, share their experiences and support each other.

**Emotional problems and adolescence**

Young people with learning disabilities may be particularly vulnerable to emotional and mental health problems for a number of reasons. They may have physical ill health, for example, chronic pain or discomfort from physical disabilities, or sight and hearing problems which make communication difficult. They may have suffered some loss or bereavement, for example, a favourite teacher leaving the school, or a family member dying. They may have been bullied or experienced some form of abuse, including racist abuse. They may suffer loss of confidence and self-esteem as they become aware that the opportunities open to them are more restricted than those for other young people. They may also be vulnerable to mental health problems if they and their families are
not receiving the practical, financial and emotional support they need.

The Bradford study showed that many family carers had not been aware that their children were experiencing emotional or mental health problems. They also felt that their family reputation might suffer or that they might be blamed for failing to care properly for their child. Developing this awareness is the first step to ensuring that the young person is helped at an early stage, before difficulties get worse.

How can you recognise possible mental health difficulties? As a carer, because you know the young person well, you’ll often be the first to notice that something is wrong. They may tell you they feel unhappy, worried or strange, or that something ‘isn’t right’. In this case, it’s important to seek help straight away as it can stop problems becoming more serious.

If the young person can’t or isn’t saying how they feel, you may notice that their behaviour has changed. They may be quieter and more withdrawn, or restless and tense. Their normal patterns of eating or sleeping may change – for example, they may be refusing food or over-eating, staying in bed or sleeping badly.

If a young person finds it difficult to communicate, they may not be able to explain what is happening. If you notice their behaviour has changed quite markedly, this could be related to physical illness or pain, so it is worth arranging for them to have a full physical check-up with their GP to identify any health problems which need attention.

Sometimes young people are described as having challenging behaviour if they harm themselves, like head-banging, or are aggressive to others. This can sometimes be a sign of an underlying mental health problem but may also be linked to communication difficulties. If a young person can’t find other ways of letting people know what they are feeling or what they want, behaviour may be the only way they can express their frustration. They may then need help with communication.

**Mental health problems**

Some of the young people in the Bradford study had experienced more serious mental health problems. Early assessment and diagnosis is vital if the young person is to receive the treatment they need and if further problems are to be prevented. If you suspect that your son or daughter may be developing mental health difficulties, you should ask for a thorough assessment of their
physical and psychological health. Depending on your contacts and services which are already involved, you might want to contact your GP, school nurse, educational psychologist, community paediatrician, social worker, or member of the local learning disability team, for example, a community nurse or clinical psychologist to support your referral. Investigations should include finding out whether there is any physical problem, but if you are told that the problem is because the young person has a ‘learning disability’, don’t leave it at that, but persevere. Once the problem has begun to be understood, then help and treatment can be organised.

Many of the families in the Bradford study did not know what services were available following diagnosis. There are many different treatments and ways of helping people with mental health difficulties including medication and psychological therapies. The young person may be referred to specialist services such as a child and adolescent mental health service, an adult mental health services, or a psychologist or psychiatrist within a learning disability service. If this is the case, you might need to consider whether the staff treat the young person as a person, not just focusing on the learning disability or mental health problem, and whether the family is offered help in ways which respect your ethnic background.

When a young person is experiencing a mental health difficulty, you may also be able to help by making changes to the young person’s surroundings or routine, for example, making adaptations in the home, or altering routines at mealtimes or bedtimes. Young people with learning disabilities have also talked about what helps them handle their stresses and problems. These include sharing their feelings with their friends, a parent, or another person, being left alone, listening to music, going for a walk or doing some exercise.

**Support for families**

Most of the Bradford families were providing care and support for their young people with little help from elsewhere. While they valued this self-reliance, they could sometimes feel overwhelmed by the young person’s behavioural and emotional difficulties or additional health complications, and this placed them under high levels of stress. A main reason why they were not receiving the help or support they required was their lack of knowledge about what services were available and how to access them. Families who were unable to speak English faced additional problems in making contact with services and discussing their problems and needs with professionals. Sometimes families found it hard to make time to seek help and were put off by long waiting times at appointments.
The Bradford families wanted services which were sensitive to their cultural and religious needs. For example, many were not keen about their adolescent children staying away for short breaks, because the provision was not geared to these needs. Some wanted to see female-only day services for their daughters. Some needed the services of an interpreter who was not a member of their family.

The kind of support services available can vary according to where you live and can often seem complicated and confusing. A main point of contact and help for most of the Bradford families was their GP or the young person’s school. Either of these is a good place to start, as the GP and school will know about other services you may need, and can sometimes refer you directly to these. Alternatively, you could approach your social worker, if you have one, a member of your local learning disability team or is there a voluntary organisation you can turn to?

Finding your own emotional and practical supports can help to protect your health and well-being, especially when you have little time for yourself. Ideally you will want help which meets your particular needs as a family carer and is sensitive to your religion and culture. You might want to think about whether you would like one-to-one support or would prefer to join a carers’ group. Are there activities which help you to cope when you feel stressed, for example, going for a walk, taking a bath, or doing relaxation exercises? You may want to find out whether there are any short breaks or respite care schemes in your area so that everyone in the family can recharge their batteries.

You do not have to undertake the role of caring and supporting alone. If you do need help, ask for it, and prepare to be persistent. Helping the young person to make a successful transition into adulthood needs to be a partnership between the young person, the family, friends and professionals. Planning for the future is important, so find ways of supporting your son or daughter to express their wishes and explore possibilities. This way, they will grow in self-confidence, get through the difficult times and develop an enjoyable and satisfying life as they move towards adulthood.