Children and young people with intellectual disabilities are at greater risk of mental health problems, argue Barry Carpenter and Jo Egerton. Schools need to be alert to the signs and take steps to build their resilience.

By Barry Carpenter and Jo Egerton

From vulnerability to resilience

The United Nations Convention on the Rights of the Child, Article 24, states that mental health is of overriding importance in the quality of life for children and young people. Among all children, 20 per cent may have a mental health problem in any given year, and about 10 per cent at any one time (The Fundamental Facts). For children with intellectual disabilities, the figures are even greater and the consequences more bleak.

This group of children and young people can experience the full range of mental health problems. However, educators often confuse the signs with diagnoses, eg attributing acute anxiety to autistic spectrum disorder (ASD), communication difficulties, challenging behaviour or lifestyle (eg an unsettled home life) [Meeting the health needs of people with learning disabilities].

Yet it is estimated that over one-third (36 per cent) of children with intellectual disabilities have diagnosable mental health problems [The Mental Health of Children and Adolescents with Learning Disabilities In Britain].

Seven in 10 children with an ASD and nine in 10 children with fetal alcohol spectrum disorders will experience at least one mental health issue [Mental Health of Children and Adolescents with Intellectual and Developmental Disabilities A Framework for Professional Practice] [Take Another Look: A Guide on Fetal Alcohol Spectrum Disorders for School Psychologists and Counselors].
Schools and educators are part of the first level response to mental health issues. While educators now recognise that, ‘underpinning success and achievement for any student of any ability is the quality of their mental health’ [Mental Health: The new dimension in the curriculum for children and young people with special educational needs], they need targeted training [What About Us?]. Schools need to develop whole-school and individualised early identification and intervention strategies as well as clear support and referral procedures. Coughlan et al’s [Module 3.4 Emotional well-being and mental health] online training module provides excellent guidance.

Signs of mental health problems
All children and young people with mental health problems experience significant changes in thinking, emotions and behaviour (eg eating, sleeping, personal care, level of interest, etc.) which impact on their everyday behaviours and ability to function. For those with moderate to profound intellectual disabilities, signs of mental problems may be different including:

- Loss of skills (eg communication)
- Increased obsessive activity (eg requesting reassurance)
- Hyper-arousal (eg tremors, fast pulse, sweating)
- Outbursts of aggression, destructiveness or self-harm
- Disruptiveness, non-compliance, anti-social behaviours
- Loss of bowel or bladder control
- Sexualised behaviour
- Persistent aches and pains without physical cause
- Restlessness, wandering or searching
- Unusually fearful behaviour without cause
- Return to persistent developmentally young behaviours (eg bed-wetting)

[Clear Thoughts] [Developing Mental Health Services for Children and Adolescents with Learning Disabilities: A Toolkit for Clinicians] [Candle (CAMHS And New Directions in Learning Disability and Ethnicity) Project].

While some mental health problems pass quickly and can be addressed by schools, others become long term and serious. Concerns should be raised if these signs do not respond to well-designed, consistent, school-based interventions, if they occur for longer than two weeks and if they are seen across different environments (eg school, home, etc.). Extreme behaviours (eg self-harm, running away, or not wanting to go on living) need urgent professional help.

School-based interventions
The challenge for educators is to lift children from vulnerability to positions of resilience. It is important to identify and put in place school-based interventions that can alleviate the impact of mental health problems.

When children are feeling emotionally vulnerable, their emotional turmoil may affect their ability to focus on, understand and begin a task. Coughlan et al. [Module 3.4 Emotional well-being and mental health] and Carpenter [‘Navigators of learning’, Special! March 2010, 22-23] suggest that educators can support children by helping them to acknowledge their feelings about their class work, structure it by breaking it down into a sequence of small steps and, building in strategies for asking for help.

Case study – Stephen

[Engaging Learners with Complex Learning Difficulties and Disabilities A resource book for teachers and teaching assistants]

Stephen is 11 years old and currently attends a mainstream secondary school. He transitioned from primary school with a statement to support his learning needs due to complications with speech and language communication and behavioural, emotional social development needs. His parents are currently investigating the possibility that he falls within the Autistic Spectrum.

Mental health concerns were raised due to his behavioural outbursts and difficulties in engaging within the curriculum. The support he is provided with now allows for appropriate educational strategies to be put into place.

However, there is a growing concern for Stephen’s emotional wellbeing as he is becoming less motivated by learning and interacting within his environment. These concerns are heightened by verbal outbursts from Stephen, including suicide threats, comments about his own mental state and self-injury.

The school is implementing strategies which have been shown to benefit children’s mental health – increasing the amount of exercise he can access, involving him in peer mentoring, and giving him time with trained staff to allow him to discuss his difficulties. They are also working with Child and Adolescent Mental Health Services (CAMHS) and the speech and language service to investigate Stephen’s issues and appropriately support him, enabling him to focus on learning once again.
Pre-empting mental health problems
It is important that the people who work and live with the child or young person with intellectual disabilities are aware of any signs, symptoms and changes in how the child behaves, feels, communicates and goes about their daily life. They can maintain awareness of the at-risk child’s mental health through systematic observations in collaboration with colleagues and family. They can build a picture of what ‘normal’ functioning is for them (including any idiosyncratic behaviours). They can personalise approaches and strategies to enable the child to understand and express what they are feeling (eg through mind maps, flow charts, feelings thermometers; personal tutorials, etc.). They can recognise and respond to their learning and communication needs (eg providing visual structure and communication systems). They can create an exercise programme, and ensure they have a Health Action Plan to promote and monitor health, diet and medication. They can pre-empt anxiety by preparing the child in advance for difficult situations and developing with them personalised coping strategies (eg social stories). They can reduce stresses on young people and their families through early intervention and support programmes. They can arrange access to therapeutic approaches if necessary where there appear to be limitations in the curriculum-based approaches.

Developing protective factors
From early years, and throughout school life, it is important to work with all children and young people with intellectual disabilities to increase their resilience against mental health problems by specific teaching in [Mental Health of Children and Adolescents with Intellectual and Developmental Disabilities A Framework for Professional Practice].

Adults with Intellectual and Developmental Disabilities A Framework for Professional Practice:
• Using an effective, personalised communication system
• Understanding communication from others
• Knowing and applying the rules of social interaction flexibly
• Expressing and recognising their own emotions and those of others
• Self-regulating emotions, behaviours, etc.
• Understanding and sharing their experiences
• Developing a sense of self and building relationships with others
• Goal setting and problem-solving
• Coping strategies (eg for stressful situations, bullying, etc.)
• Developmental/age appropriate life skills.

Conclusion
Although school-based interventions do not substitute for trained clinicians or specialists, they are an effective first step intervention in increasing children’s resilience. In responding to possible signs of mental ill health in a child or young person, it is important to:
• Acknowledge the issue, and don’t ignore or dismiss it; other colleagues might not have noticed.
• Early intervention increases chances of full recovery
• Keep a written record of the signs, your concerns and the time/context/date.
• Assess the risk of harm for the young person or others
• Consider other possible causes of the behaviours than a mental health problem
• Talk to line managers, colleagues, the young person and their family about your concerns and keep them appropriately informed
• Support the young person to keep mentally well, and provide self-help strategies.

To address mental health risks for children and young people with intellectual disabilities, schools must put themselves in the front line and address their needs through a responsive and personalised ‘emotional wellbeing’ curriculum, with a paramount goal of strengthening emotional resilience.