Child and adolescent psychotherapy with children and young people with disabilities and their families

"36% of children and adolescents with learning disabilities, age 5-16, have a diagnosable psychiatric disorder. This is about six times more likely than peers."
Emerson, E. and Hatton, C. (2007)

Working with children, families and professionals

Having a disability as a child or young person increases the likelihood of emotional problems and can compound them. Difficulties can include bullying, abuse, family distress, loss through separation or death, sibling rivalry, inappropriate expectations and demands, depression, sleeping problems, eating problems, low self-esteem and loneliness as well as a range of challenging and difficult behaviour.

Case example: A child with cerebral palsy is placed with peers in a mainstream school. She is refusing to eat. She has been provided with support and a mentor but her inability to control her involuntary movement and the resulting mess at the table is unbearable and humiliating to her. She responds aggressively out of frustration, even towards her mentor. Parents become desperate and the school starts to feel powerless and unable to manage.

Feelings of intense sorrow and anger are commonly experienced by parents. This can result in ongoing depression. The mourning process of the "ideal" or longed-for child can be lifelong, often being reactivated at critical points in the child's life, for example when the child reaches puberty. Having a child with a disability in the family puts an emotional strain on parents individually and on their relationship as a couple.

Siblings of children with a disability have an increased vulnerability to psychological problems. Siblings may feel less loved than their disabled sibling because their parents spend much more time looking after the disabled child. They can feel pressed into growing up prematurely.

Most families with a disabled child who seek support for their emotional and mental health have experienced trauma, for example, at the point of birth, the moment of diagnosis or in the face of ongoing social exclusion and discrimination. If left untreated, the impact of trauma compounds difficulties.

Case example: Mr and Mrs E were considering separating. They slept separately, taking turns to sleep with their epileptic learning disabled child, and had no sexual relationship. After working with the child psychotherapist for several months, they made new sleeping arrangements. They are currently expecting their second child and looking forward to the pleasures of a 'normal' family.

How the child and adolescent psychotherapist can help

The child psychotherapist plays a unique part in any service involved in the treatment of such children and their families. Their approach is primarily based on observation, listening, and interpretative skills. Their in-depth training gives them a capacity to respond flexibly when faced with these complex problems. The child and adolescent psychotherapist is well equipped to work with disabled children and their families. Their method:

- places emphasis on play, non-verbal communication and developmental processes. This approach is particularly suited to children with delayed and uneven development and those with significant difficulties with speech and language.

- aims to help people adjust to the reality of their lot in life. This often involves 'working through' the loss and trauma associated with disability.

- can be used with individuals, couples, families and groups.

- provides mental health assessments, including assessing:
  - state of mind
  - capacity to use child psychotherapy as a treatment modality
  - family functioning
  - relationship between disability, developmental stage and environmental factors

- provides a unique approach to children and adolescents especially at points of transition. For example, the issue of 'being different' is most acute during the adolescent period of the disabled child's life. Depression and low self-esteem can be helped by psychotherapy.

- emphasises the importance of working closely with others in the multi-professional network, collaborating to provide packages of care which are multi-layered.

- works flexibly in a variety of settings e.g. education, health and the voluntary sector.

The child psychotherapist also works with staff in organisations to:

- deliver consultation and support, helping staff to observe and report their experiences as well as to focus on the emotional impact of their work on them. By this means staff are helped to better manage the children in their care.

- deliver training, covering a wide range of issues, for example attachment and separation issues, and developmental processes across the life cycle.

"A child psychotherapist is an invaluable member of the team especially where there are mother/partner/infant/child relationship difficulties that impair health and development in disabled children. The psychotherapist input means that doctors and speech and language therapists or occupational therapists can work more easily with the child… They also understand the dynamics within the team so difficulties in the team do not stop the optimum treatment for the child."

Community paediatrician

What does the literature tell us?

Child and adolescent psychotherapists are mental health professionals equipped to deliver clinical services which comply with recommendations from national drivers and the relevant NICE guidelines on treating and caring for the health needs of children and young people with disabilities. Many of the children and young people have more than one condition, with emotional, behavioural and mental health difficulties co-morbid with the primary disability. Child and adolescent psychotherapists are trained to work with the complexity of psychological health, which rarely depends on single-issue resolution.

The input of child and adolescent psychotherapy as part of a multidisciplinary team can help improve outcomes for children and young people with disabilities, and their families.

NICE Clinical Guidance: Diagnosis and Management of Attention Deficit and Hyperactivity Disorder in Children and Young People and Adults (2008): "Healthcare professionals should offer parents or carers of preschool children with ADHD a referral to a parent-training/guidance programme as the first line of treatment."
CAPT: Child and adolescent psychotherapists are skilled in working with groups and with parents. These skills alongside their understanding of emotional and developmental processes in pre-school age children, equip them to offer such provision.

Aiming High for Disabled Children programme, Department for Education and Skills/Department of Health (2007): "Underpinning better support and improved provision of specific services for disabled children and families is the need for: …focused, effective support early in life and at key transition points, with early support for disabled children and their families, which promotes emotional and social development for disabled children and their siblings, to help to improve outcomes for all.
CAPT: The orientation of the child psychotherapist towards family functioning, their understanding and training to contain psychological pain and their understanding of early attachment and developmental processes, equips them to promote emotional and social development in line with AHDC goals.

NICE Clinical Guidance: Depression in children and young people (2005): "Psychological therapies used in the treatment of children and young people should be provided by therapists who are also trained child and adolescent mental healthcare professionals"; "Attention should be paid to the possible need for parents' own psychiatric problems (particularly depression) to be treated in parallel"; "Health care professionals in primary care, schools and other relevant community settings should be trained to detect symptoms of depression and to assess children and young people who may be at risk of depression"; "Children and young people with moderate to severe depression should be offered, as a first line of treatment, a specific psychological therapy."

CAPT: The child and adolescent psychotherapist is a specialist mental health worker, alert to the mental health of parents and to signs of depression in children and young people.

Case Example: Emma is a little girl with a learning disability. At the age of seven she displayed challenging behaviour, hurting other children and staff at her special school by scratching, hitting, kicking, biting and pulling hair. At home, similar behaviour was causing distress. Following a multi-disciplinary assessment she began weekly psychotherapy at her school. Emma initially displayed the same aggressive behaviour with her psychotherapist and she had a very limited capacity to identify and express her feelings. Over time the therapist helped Emma to understand and express her feelings, including the pain of her difference from others, in words rather than through actions. The aggressive behaviour diminished after less than a year of psychotherapy and at the same time Emma showed a surge in her development and capacity to learn. Parallel work with Emma's parents helped them to understand her better and help her with her day-to-day feelings and worries.

National Service Framework for Children, Young People and Maternity Services, Department of Health (2004): Children and young people who are disabled or who have complex health needs, receive co-ordinated, high quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, enable them and their families to live ordinary lives.

CAPT: The child and adolescent psychotherapist works in multi-disciplinary/multi-agency settings, their assessment and treatment interventions complimenting those of colleagues in other roles. Their focus is not on the disability, but is child or family centred, promoting psychological health and well-being.

Autism Exemplar: Autistic Spectrum Disorders, National Service Framework for Children, Young People and Maternity Services (2004): recommends the following interventions: "Mental health and behaviour assessment…consider the family's needs and strengths which affect care for the child and his difficulties (e.g. sleep and behaviour problems) and maximise his inclusion in family life…supporting parents and keeping them informed…It also includes assessment of the needs of the other child in the family and the parents as carers. This includes an assessment of the parents' needs under Carers and Disabled Children's Act 2000."

CAPT: The child psychotherapist is trained to provide all the interventions recommended in the exemplar.

Every Child Matters, Department for Education and Skills (2003): "We need to pay more attention to the critical relationships between children and their families and provide them with better support"….a comprehensive CAMHS service "should cover a diverse range of services appropriate to the age and circumstances of children and young people, and to their

different levels of need…people working in universal services should be able to identify children who may need help. Trained mental health workers need to be able to support workers in other agencies. Specialist multi-disciplinary teams should…provide assessment and treatment, and short and long-term interventions and care services may need to be located in a range of settings, as near as possible to home in environments which are perceived as less stigmatising than traditional clinic settings, such as schools, homes and family centres."

CAPT: The child and adolescent psychotherapist functions as an integral part of comprehensive CAMHS, providing generic interventions *and* unique interventions, adapted to meet the individual circumstances and levels of need of children and young people. The child psychotherapist also contributes to the understanding and practice of professionals in other agencies including universal services.

What does the research show?

As part of their everyday clinical practice, most child psychotherapists rely on evidence generated from regular clinical evaluation as well as outcome monitoring to support their clinical practice. This evidence is brought about through work with families, particularly parents, and also with professionals from other agencies. Feedback from parents is one of the most valuable sources of evidence for the outcomes of the work and in most NHS settings outcome measures, including goal-based measures, are utilised. They provide a focus for the therapy and this process is integrated into the clinical practice and regularly reviewed.

Case example: "As a result of the stress, anxiety and chaos that living with an autistic child…I was put in touch with the school child psychotherapist who helped me to look at ways which I could handle my son's behaviour and see him in a more positive light. It was almost like my "counselling session" because we started off by working on me. I always used the term that my son was "marking time". Unfortunately what I did not notice was that "so was I". Listening to another individual describe my situation in exactly the way I had described helped me step back…which left me less agitated and I could deal with "A" without being so frustrated. The support we received from the child psychotherapist has been very helpful to my son, his brother and myself. It has showed us…ways of dealing with an otherwise negative situation. It was helpful for me to have someone who saw my situation from my point of view."

Extract from letter sent to school by the mother of a son with autism and severe learning disability. She wrote it following eight sessions of parent work with a child psychotherapist.

In terms of more formal research, providing evidence to support psychotherapy with children and young people with disabilities is complex, but not impossible. This is primarily due to the difficulty in choosing methods and measures that reflect the true nature and outcomes of the psychotherapeutic process. In the area of disability this task is further complicated by the nature of the difficulties of the children and young people who use our service. These can range from profound physical disabilities to social communication problems. Our work is therefore often focused on other forms of communication, some of which are not straightforward to record and present as data. These kinds of complexities underpin some of the difficulties we have undertaking research but do not undermine the value of the work we do with this particular group.

Generally, research in child psychotherapy is an area of rapid growth. There is a growing body of literature and outcome studies that can now be relied upon to support our input in the

field of child and adolescent mental health. This field of study has produced some significant results from larger scale studies, the results of which have contributed to NICE guidance, including **Childhood depression: A place for psychotherapy**. **An outcome study comparing individual psychodynamic psychotherapy and family therapy** (Trowell et al, 2007). This found significant reductions in disorder rates in both groups. At follow up six months after treatment, 100% of cases in the individual therapy group, and 81% of cases in the family therapy group, were no longer clinically depressed.

In addition there has been a steady growth in smaller practice-based studies. Many are discussed in the recent publication **Child Psychotherapy and Research** (Midgley et al, 2009), which refers to 'a significant number of studies showing that therapy improves various aspects of mental health problems associated with specific diagnostic conditions'. Clinical problems or diagnostic categories given particular attention, and with examples of illustrative studies include:

- specific learning difficulties
- pervasive developmental disorders
- the effects of trauma

Another recent publication, **Assessing Change in Psychoanalytic Psychotherapy** (Tsiantis and Trowell, 2010) discusses a range of evidence to support the use of psychoanalytic psychotherapy with families and children with a variety of difficulties.

In addition to the large-scale and smaller scale formal studies, child psychotherapy has produced a wide range of practice-based studies that reflect the kinds of outcomes one would expect from psychotherapy with children with developmental problems and disabilities. In **Live Company** (1992), for example, Anne Alvarez reflects on thirty years' experience of treating autistic, psychotic and borderline children and adolescents through psychoanalytic psychotherapy. In **Autism and Personality: Findings from the Tavistock Autism Workshop** (Alvarez and Reid, 1999), the authors outline new developments in therapeutic techniques to treat autistic children. They underline the importance of support for parents and siblings, who are too often ignored as a factor in the child's progress.

Another practice-based study is the groundbreaking work described in **Mental Handicap and the Human Condition: New Approaches from the Tavistock** (Sinason, 1992), based on the author's in-depth clinical work at the Tavistock Clinic where she was a consultant child psychotherapist until 1998. The book became a catalyst for change in the treatment and perception of disability in the UK, Europe and South Africa. Verbatim accounts of therapy show how even the most profoundly multiply physically and intellectually disabled have an emotional intelligence that can be reached through talking treatment.

Commissioning child and adolescent psychotherapy

If you are interested in commissioning a child psychotherapy input in your locality, either via your local NHS CAMHS or via a private provider, please call the ACP office on 020 8458 1609 or email contactus@childpsychotherapy.org.uk. You can access more information on our website, including further briefing papers on the work of child and adolescent psychotherapists in schools, in hospitals, with fostered and adopted children, with parents, in the court system and through long-term and intensive work.

www.childpsychotherapy.org.uk